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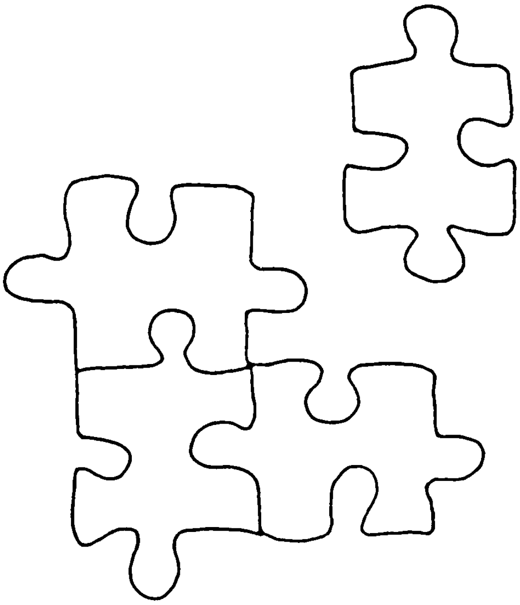

BETTER SERVICES FOR THE MENTALLY HANDICAPPED ?

LESSONS FROM THE SHEFFIELD EVALUATION STUDIES

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One important focus for the Centre's work in recent years has been the practical steps necessary to develop comprehensive community-based services for people with mental handicaps and their families. In parallel with the present paper, the Centre has already published two project papers:
An Ordinary Life (Project Paper No 24, reprinted July 1982, price £1.50) describing the philosophy and planning of local residential services; and
Bringing Mentally Handicapped Children out of Hospital (Project Paper No 30, November 1981, price £1.25) describing the alternative services in the community required to relocate the remaining children and young people in hospitals.
A series of complementary shorter papers is also being produced, including to date:
Short Term Care for Mentally Handicapped Children (King's Fund Centre Discussion Paper, February 1981, 75p)
The Portage Model of Home Learning Services (King's Fund Centre Discussion Paper, April 1982, 75p)
Mentally Handicapped People with Special Needs (King's Fund Centre Discussion Paper, July 1982, 75p)

All these papers are available from the Centre. Prices include postage and packing.

BETTER SERVICES FOR THE MENTALLY HANDICAPPED?
Lessons from the Sheffield Evaluation Studies

by Alastair Heron

August 1982

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FOREWORD

The initials SDP have recently acquired new meaning as the symbol of a movement to 'break the mould' – either fundamentally or superficially according to one's viewpoint – of institutionalised politics in Britain. For policy makers and practitioners in the field of mental handicap, however, these are also the initials for an earlier, more specialised mould-breaking exercise. Informed by much of the same thinking which led to the 1971 White Paper *Better Services for the Mentally Handicapped,* The 'Sheffield Development Project' has been a major attempt to implement, test and demonstrate a new pattern of community-based services for people with mental handicaps and their families. As such, the results of this work deserve detailed scrutiny by everyone still involved a decade later in the continuing struggle to achieve decent mental handicap services.

In relation to the pragmatic and incremental tradition of British public administration, the Sheffield Development Project seemed at first a radical departure in three key respects. The 'Better Services' White Paper itself was an overdue effort by government to provide clear leadership and a long-term strategy for the development of mental handicap services still dominated by large institutions inherited from a previous era. With hindsight it may be argued that this new policy was ambiguous in important respects and like other 'top down' initiatives government may have given inadequate attention to the detailed arrangements for its successful local implementation. Partly to learn about and counter these possible weaknesses, the Sheffield Development Project was novel in bringing together government, NHS and the local authority in a large scale demonstration project which in capital costs alone involved extra investment of over seven million pounds (in 1976 prices). Even more distinctively, the Department of Health and Social Security subsequently supported what by British standards has been an extensive and detailed programme of studies designed to evaluate these new services.

Over five years the Evaluation Research Group based at the University of Sheffield and under the direction of Professor-Emeritus Alastair Heron has produced no less than thirteen weighty reports on key aspects of NHS and social services contributions to a comprehensive mental handicap service in Sheffield. Unfortunately it is probably not too pessimistic to assume that copies of these reports have mostly found their way onto the shelves of other researchers or into the cupboards of central policy-makers, with correspondingly limited impact on the local planners and providers of services elsewhere who also have much to learn from the Sheffield experiences. Accordingly, the King's Fund Centre is pleased to publish this paper by Alastair Heron, providing a succinct overview and summary of all the Evaluation Research Group's studies together with the director's own reflections on the most important wider lessons arising from the project.

While describing both the achievements and limitations of the Sheffield Development Project, Professor Heron does not disguise his view that despite all the effort and expenditure, the opportunity to implement a comprehensive and genuinely community-based pattern of services in Sheffield has so far been missed. However, his commentary on the events of the last decade is constructive and it is encouraging to note that within a year of receiving the final report on these studies, the Health and Local Authority Joint

Consultative Committee in Sheffield has agreed a new strategic plan for developing integrated services, starting from a philosophy which regards mentally handicapped people of all ages as ‘members of the public, usually living at home or in ordinary accommodation in the community, and as entitled to both general and specialised medical, paramedical, educational and social services as are their fellow citizens’. This new strategic plan clearly seeks to address the main issues raised by the evaluation studies.

If past investment in the Sheffield Development Project and the evaluation studies is to be worthwhile, it is equally vital that these lessons should be widely applied. There seems to be mounting evidence from a review of current strategic plans and from reports on local developments that many authorities are still repeating past mistakes, despite the even greater premium on using resources wisely in the present climate of restraint on public expenditure.

Professor Heron shows that both government and field authorities need to think through the philosophy which should guide service provision and the steps needed to ensure that this philosophy is implemented and sustained in practice. Staff working in these services need to consider carefully how their contributions can be coordinated around the changing needs of people with mental handicaps throughout the life-cycle. Further attention is required to developing appropriate relationships between statutory, voluntary and informal components of the support which people with mental handicaps and their families should receive.

If local efforts to develop comprehensive community-based services are really to ‘break the mould’ imposed by their inheritance from the past, it is clear from this paper that these efforts will require not only sustained commitment and political backing, but also the willingness to examine critically existing provision and learn from experiences elsewhere. The way forward identified here by Professor Heron provides a valuable starting point.

King's Fund Centre
August 1982

David Towell

1 THE SHEFFIELD DEVELOPMENT PROJECT

In October 1968 the then Ministry of Health approached the Sheffield Regional Hospital Board (RHB) and the Sheffield County Borough Council (CBC) 'to discuss a development project which we hope to mount in the field of services for the mentally handicapped'. This approach was certainly not unrelated to the RHB's earlier request for ministry approval of a scheme to build accommodation for an additional 300 patients at an existing mental handicap hospital outside the city. But more positively it arose from the 'new thinking' that produced the White Paper *Better Services for the Mentally Handicapped* in 1971.

Before the year was out, the RHB had abandoned the hospital extension scheme and joined with Sheffield CBC in agreeing to a six months on-the-spot study by a feasibility team from the ministry. This was carried out during 1969; discussions on its draft report occupied most of 1970; negotiations based on its final version (February 1971) led to formal acceptance by the RHB and the Sheffield CBC; and the first meeting of a joint coordinating committee took place in early December 1971. The project effectively started two months later when the executive working group (of senior officers) met for the first time.

This historical summary makes it clear that from the very outset the ministry was committed to the concept of a major *joint* initiative at *local* level, based on a programme worked out and largely funded at *national* level. In fact, the greater part of this central funding was for capital schemes (both NHS and local authority) costing over seven million pounds at 1976 prices.

Better Services for the Mentally Handicapped?

What were the essential features of the Sheffield Development Project? They were summarised in the Feasibility Study Report as follows:

> 'Basically the plan is that, apart from a special unit for emotionally disturbed mentally handicapped adolescents and adults which will be at a mental illness hospital just outside the Borough boundary, there should be within Sheffield County Borough:
>
> - a comprehensive assessment and advisory service and a system of referral to it for all mentally handicapped children and their families
> - hospital residential units with associated day care units for children and adults requiring a hospital service
> - hospital service "hostels" outside hospital precincts for those requiring limited medical and nursing supervision
> - local authority residential accommodation (hostels, boarding out, etc.) for those who could be cared for within a normal home if such a home were available to them
> - facilities for education, social and work training or some form of occupation or employment to meet the estimated needs of the mentally handicapped.
>
> 'It is envisaged that the existing services provided by general practitioners, health visitors and social workers will continue but with the latter reorganised to provide an expanded joint hospital and local authority service giving substantial support to the mentally handicapped and their families. It is recommended that the appointment of a whole-time organiser of voluntary services be shared between the hospital and local authorities.

> 'The additional local authority facilities proposed conform generally to existing patterns but include an adolescent work assessment unit which is new and also group homes and an advanced industrial type of adult training centre which are experimental. The hospital units and "hostels" follow new ideas. The hospital provision for children is based on a 24-bed unit providing for "family" groups of 8 children. The hospital units for adults are also based on separately identifiable 24-bed units but grouped together to form units of 96 beds. The 24-bed hospital "hostels" for adults will be separately sited although it is suggested two could be on the same or adjacent sites. The number of hospital beds proposed represents about two-thirds that of the current national average provision. It is proposed that the caring staff of the hospital "hostels" for children be chosen for personal attributes and need not necessarily be nurses. But the hospital "hostels" for adults will be staffed by nurses. Experience will show whether this should continue. All the caring staff will have had or be given the opportunity to obtain training in residential care.'

Those responsible for the report were clearly and consciously endeavouring to be as innovatory as possible within the constraints of a particular situation as it then existed in the Sheffield area. This they did largely within the prevailing philosophy enshrined in the 1971 White Paper. The explicit purpose of the development project was to enable:

> '. . . the mentally handicapped person *to live as much a part of the community* as his/her disability will allow, and to confine entry to hospital as an inpatient to those individuals who require specific medical treatment, continuous care by nursing staff, or a degree of supervision and observation which is not practicable elsewhere'.

To render more likely the achievement of this purpose, the Feasibility Study team explicitly looked to the provision of

> '. . . *an integrated service* [as] a primary objective of the project [through] suitable coordinating arrangements . . . both at policy and officer level'.

They placed considerable emphasis on the importance of *staff training* (in both the health and local authority contributions to 'the new service') and made it clear that:

> 'There is an important role in the service for the *voluntary organisations,* who should be invited to work closely with the hospital and local authorities, so that a coordinated and purposeful programme of assistance should be planned'.

Considerable emphasis was also placed on the provision of *comprehensive assessment and re-assessment services* and of new facilities designed to increase the number of mentally handicapped adults who could *enter open employment.*

The Feasibility Study Report provided explicitly for *evaluation* of the project to be carried out by 'an independent group, not involved with local services', given the task of 'assessing the effects of the changed pattern of care on the burden which is placed on the relatives of the mentally handicapped people concerned'. Despite the specific comment in August 1971 by a member of the feasibility study team that this evaluation was 'a continuing need, not something to be done after the event', the director of the Evaluation Research Group was not appointed until October 1975. This delay obviously precluded the use of 'before and after' studies in several projects. The use of 'time series' designs was effectively ruled out by the fact that implementation of the Sheffield Development Project coincided with the progressive local impact of national legislation, in particular the Education (Handicapped Children) Act 1970; the Local Authority (Social Services) Act of the same year; the National Health Service Reorganisation Act 1973; and the Local Government Act 1974.

Nevertheless, despite its methodological frailties what seems to be the first major evaluative study has been made of most services for the mentally handicapped of all ages in a large urban area (population 574 000). What follows is based upon the thirteen project reports of the Evaluation Research Group (ERG) (listed in the appendix) and the final report (April 1981) of the director. In the interests of brevity and clarity, emphasis will be placed on the findings rather than on the various methods employed in each project to obtain them.

2 THE SERVICES THAT RESULTED BY 1980

The findings of the evaluation can of course be organised in a variety of ways. Given a primary emphasis on meeting the needs of the individual, the method of choice becomes 'developmental' – that is, start at birth and move up to adulthood. The Sheffield studies can then conveniently be divided as follows.

a From birth to school age: the under fives.
b During childhood: from five to 16.
c The transition period: 16 to 19.
d Adult services, day and residential.

As one moves up this age-ladder, the responsibilities of the service agencies change in nature and amount. In (a) the dominant role is held by the health service, in (b) by the education department of the local authority. How far this extends into (c) is determined by the age at which the adolescent finally leaves the school system, but in health service terms the shift from 'paediatric' to 'adult' comes at 16 years. From the school leaving point in (c) and up into (d), the main role is held by the social services unless the young adult is in health service residential care. But at each stage, one or more of the other services can and does share the overall responsibility. This makes necessary a theory and practice of inter-service coordination: and therein lies the major problem, as we shall see.

The under fives

Our information here is drawn from two studies.* Of these, one compared the perceptions of parents in Sheffield with those in

* *ERG Reports* Nos 8 and 11 (see appendix)

Leeds, a nearby larger city which had not received any special additional health or social services funding for mental handicap. The other study was wholly concerned with the early development – under the Sheffield Development Project – of the greatly expanded Ryegate Centre (an annexe of the children's hospital) as the focal point of a comprehensive assessment and therapeutic service for mentally and multiply handicapped children.

Let it be said right away that the overall picture is favourable, and that this should not be forgotten as attention is of necessity drawn to weaknesses or imperfections in the service. It is obvious, for example, that Sheffield has well planned arrangements in its maternity units and through the health visitor service. There is not much likelihood of a potentially serious developmental disability being missed, and the system of reporting to the Sheffield Mental Handicap Case Register (another input of the Development Project) is well established. But it has taken a long time to convince some paediatricians that referral to the Ryegate Centre for comprehensive assessment may be better (for both child and parents) than 'hanging on to the case' and referring to selected paediatric specialist colleagues as seems to be necessary. Only recently has there been welcome evidence of a belated upturn in *early* referral to the Ryegate Centre of infants with Down's Syndrome. Despite this, however, the number of under fives with this condition 'known to the services' in Sheffield was very much closer to expectation than was the case in Leeds. The clear intention that the new Ryegate Centre would provide an integrated service for *all* mentally handicapped children in the Sheffield area was frustrated by the administrative arrangements. When plans were being made for the reduction of the Sheffield AHA from three districts to two, the opportunity was taken to create an area mental handicap sector and to locate it administratively in the Northern District. Because the new Ryegate complex – consisting of the comprehensive multidisciplinary assessment unit, therapeutic services, a day care centre and a 20-bed residential unit – had been developed from an annexe of the children's hospital, pressure from that source resulted in Ryegate remaining in the new Southern District. In the long term, that could well be the right solution if two complementary conditions were eventually to be met. One is that the Ryegate Centre be designated as the key integrating element in a service for mentally and multiply handicapped children – as originally intended – and therefore having a primary responsibility for them, whatever other specialist paediatric services it rendered. The other is that all services for *children* – including residential – provided administratively by the mental handicap sector should be organised on the explicit basis that the Ryegate Centre is the recognised integrating element.

But in the short term, no agreed clear policy was laid down for the provision of paediatric services in the hospital and hostel accommodation under the administrative control of the mental handicap sector. Consultant medical services for all such children have been entirely in the hands of the two consultant psychiatrists in mental handicap, and the many and varied resources of the Ryegate Centre were made use of on a discretionary basis, rather than as a regular element in the total provisions available. The exercise of that discretion was found to have been very limited during the period of the evaluation studies (1978-1980).

How satisfactorily were the needs of the under fives and their parents being met? Parents in both Leeds and Sheffield frequently referred to the apparent lack of knowledge about mental handicap among local doctors, midwives and health visitors – though there was general appreciation for the other qualities of these professionals, and few specific complaints. This problem made itself felt most acutely during the first six weeks of life. Only one third of the children had been seen by a psychologist during the first five years of life, and the majority of these were in connection with school entry assessment. Some parents expressly asked for more professional help and advice at home in the earlier years. Only *very few parents had been in receipt of the home-help service* (and these all valued it very much), and there was *a massive dissatisfaction with the information brought to parents about aids and allowances.*

On the whole, the families of Sheffield under fives, as compared with Leeds, received more support from social workers; were more able to use toy libraries, not only to obtain the toys but as a valued meeting place with other mothers; and had more children attending some form of pre-school day placement. More Sheffield than Leeds parents expressed 'overall satisfaction' (90 *versus* 68 per cent). The main benefits obtained from attendance at the Ryegate Centre (43 mothers) were listed in the evaluation report as:

> frank and detailed information on the handicap and its implications;
> the opportunity to observe their child's performance and reactions to activities provided by the staff;
> the availability of all the professionals and services at one place;
> the opportunity to take another professional along (for example, health visitor, nursery nurse) to support the parents and to give information to the team.

During childhood

An intensive study was carried out by two members of the evaluation team of ten children who passed through the full two day initial assessment procedure at the Ryegate Centre. Six children were under five, one over five, one over six, and two over seven. Parents were – with prior consent – interviewed at home four weeks and approximately six months later. General satisfaction was expressed about the Ryegate service as a whole, including the assessment; home visits by the medical social worker; and the follow-up action on recommendations. Many parents did find the two-day assessment tiring and often confusing, but nevertheless felt it had been worth it in terms of better understanding of the problems faced by their child and themselves. The procedure was compared favourably with previous experience at hospitals. The parents (at the six months interview) reported that the great majority of the case-conference recommendations requiring action had been implemented, and they were very appreciative of the home and school visits by the various therapists. Many recognised that their journeys had been minimised by the way staff arranged among themselves for several to see a child coming in for a particular purpose, such as physiotherapy.

To evaluate the day care unit of the Ryegate Centre, two Evaluation Research Group members spent 20 half day sessions there during the spring of 1980, carrying out a systematic time-sampling observation study. The staff were seen to work very well together with a wide variety of children, most of whom were severely handicapped and needing individual attention. Every child had an individual programme devised by the day care staff, usually in conjunction with other Ryegate colleagues. All members of the unit's staff were familiar with the programmes of all the children.

A high staff ratio, both overall and in terms of trained to untrained was clearly essential for this work. Most of the children did not interact with each other, and if left alone tended to 'do nothing', to 'rock', or to seek attention disruptively. Considerable educational skill was seen to be essential and – over a period – to be effective. The unit had succeeded in placing some children into school who had previously been regarded as incapable of such placement.

The overall conclusion from the under fives and Ryegate evaluation studies is that the new centre has made a significant and valued impact on the Sheffield services for mentally and multiply handicapped children. This is *not* to say that either the centre in particular or the services as a whole are beyond legitimate criticism, and some of those made during the evaluation studies have led to a constructive response and various changes in procedure.

There are two points in this review which need special emphasis. The first is that the 'success' with which services for these children are provided and delivered, and the needs of the child and of the parent met, cannot be wholly evaluated in a necessarily short-term study.

Such evaluation ought to be sustained over a period of years through childhood, if possible by an independent team but if not by a carefully planned programme of monitoring. This leads naturally to the second point: the Sheffield evaluation did not, because it could not, extend into the services rendered by the special schools and the psychological service of the local education authority. It could not, simply because no steps were taken at national level in 1971 by the Department of Health and Social Security to enlist the interest and active cooperation of the Department of Education and Science. This is unfortunately no novelty: the joint report *Under-fives* issued in 1977 by the Association of Metropolitan Authorities and the Association of

County Councils concluded that '. . . the fact that the DES and the DHSS seem so far unable to work in concert in the interest of young children constitutes a serious obstacle to the development of the structure of services. There are hardly any signs of real coordination'.

It can however be noted that the input to the total services for the 5-16 age group from the School Psychological Service of the Sheffield Education Department was generally recognised to be small. This is by no means peculiar to Sheffield in the UK, since it arises largely from the general neglect of mental handicap in the postgraduate training of educational psychologists. When this is taken in conjunction with a policy of professional resource allocation that is heavily biased in favour of influencing teacher activity and school management in the ordinary schools, the observed outcome is unsurprising. But unfortunately it has been complemented in the Sheffield area by the similar lack of input from the clinical psychologists in the health service. They too have mostly received an unbalanced training, and operate within a policy which gives priority in resource allocation to the mentally ill, at the expense of the mentally handicapped, whether child or adult. Taking the two psychological services together, so far as mental handicap is concerned, Sheffield has with little or no exaggeration been described as 'a psychological desert'.

On the other hand, there can be no doubt that the overall response of the Sheffield Education Department to the Education (Handicapped Children) Act 1970, has been energetic and effective.

The transition period

The development project provided for 'an adolescent work assessment unit [to be] operated in association with the Youth Employment Service, [where] the work potential of the young special school leavers will be assessed over a period of about six months'.

This was intended to form the base of a post-school system, the apex of which was to be an industrial training workshop: the adult training centres (augmented by one) would form the central core. The focus of the evaluation studies was initially placed upon the impact made by the innovatory 'adolescent work assessment centre', to become known as the Woodside Assessment Unit, and this also occasioned a replicated study (with a two years interval) of all the adult training centres (ATCs). No formal study was made of the industrial training workshops, known as Crown Hill Industries, simply for lack of time and staff resources. It will however become evident that what was learned from the four evaluation studies* was particularly valuable for the light thrown by them on the 'system' as a whole, and on questions of policy and management.

Woodside Assessment Unit When the time came for the Sheffield Social Services Department to plan the design, objectives and staffing of this new unit, key policy decisions were taken, some of which ignored the recommendations of the feasibility study, while others went beyond them in a positive way. No specific arrangements were made for close cooperation with the Youth Employment Service (or the disablement resettlement officers), nor was a proposal accepted that the assessment unit should 'place

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* *ERG Reports* nos 2, 6, 7 and 13. Reports 2 and 7 cover the ATC replicated study; no 6 deals with Woodside Assessment Unit operations; and no 13 with a follow up, three years later, of four consecutive annual cohorts of mentally handicapped school leavers.

small groups in open industry with their own instructors'. It must be noted this 'enclave' formation was not undertaken either by the Crown Hill Industries at the 'top end' of the system where it would seem most appropriate.

It was decided that:

> The Woodside Assessment Unit should have *two* equally important tasks: assessment and re-assessment of school leavers and adult mentally handicapped people, with a view to appropriate placement and training; and inservice training of the instructor staff, existing and when newly-recruited, of the ATCs.
>
> The principal of the unit should be an educational psychologist, who would have as deputy principal a person with experience in the field of adult training of the mentally handicapped. The latter would be responsible for the day-to-day running of the unit, including the domestic side.
>
> 'Assessment' and 'training' should be combined in a positive way over the whole period of placement at the unit (envisaged as likely to range from a few weeks to several months, on an individual basis), so that capacity to benefit from one-to-one supervised training became an integral part of the assessment process.

It seems reasonably clear that the Woodside Assessment Unit succeeded in making training the main vehicle for the assessment of latent potentialities, both social and intellectual, in relation to an ultimate target of maximum independence in adult life. But as to the longer term 'success' of that approach it is harder to be definite. That emphatically does not imply doubt: it is simply a problem of obtaining wholly satisfactory evidence. The search for that evidence must take into account the findings of the two ATC studies and of the four-cohort follow up study of school leavers. These in turn lay emphasis on the interaction between the two unit objectives – assessment, and inservice training of ATC staff – because there is a very large common element, which is of course the 'training' method of assessment referred to above.

The reports provide evidence of the unit's impact on ATC staff, notably in the use of written individual training plans, greater specificity in their aims, a more optimistic outlook about possibilities in trainees, and an enlarged perception of their own role. But many admitted difficulty in putting their newly acquired methods and insights into action 'back at the ranch'. While recognising that the unit and ATC situations differ both in scale and in organisational complexity, *it seems clear that for inservice training to have its full effect all levels of staff need to be exposed to – and to have largely accepted – whatever is novel about the philosophy and methods with which that training is concerned.*

One consequence of passing through the original assessment period should have been a series of review assessments for each individual, at intervals determined during the previous 'case conference'. These intervals were usually six or twelve months, and the review could take place at the unit or at the ATC, as seemed appropriate in each case.

Evidence was found that this system had not been operating dependably, and that the causes lay more in the staffing problems faced by upper management than at the level of the assessment unit and the training centres. The effects were of course felt most by the young handicapped adults who became 'stuck' in the system, instead of being enabled to develop the competences they needed in order to move through it towards independent living.

Overloading of the unit principal and the absence of supporting professional staff also led to another example of sound planning which could not be fully realised in practice. The principal of the unit had from the outset intended to involve parents actively in ways other than the purely 'social' through the medium of 'parents workshops', and to extend this programme into the ATCs. *In the event, there was – four years later – clear evidence of a need for a well planned programme to convince parents that they are welcome and needed in the whole ATC based operation, not just as fund raisers and at purely social events.* The follow-up study* emphasised 'the importance of those at home and those at the day placements working closely together as a team, each partner understanding the problem of the other, both sides reinforcing one another's methods and efforts. The ATC is not a "school", but neither is it a "place of employment" '.

Services for adults

The planning, commissioning and building to full operation of the Woodside Assessment Unit in Sheffield was such a genuine innovation that it became both possible and essential to have a section of this account entitled 'The transition period'. We have therefore already begun to describe part of the day services for adults, most of whom in Sheffield are found places in an ATC. It seems logical to continue with the day services, before turning to residential provision for adults.

Day services Sheffield has five ATCs which between them provide places for about 530 adults; to this total can be added the 40 'transitional' places in the Woodside Assessment Unit and the 120 places (which are intended – over much longer periods – also to

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* *ERG Report* no 13.

be 'transitional') in the industrial training centre (Crown Hill Industries), making a grand total just short of 700. *No unit in this system makes any planned provision for very profoundly handicapped or severely emotionally disturbed or hyperactive adults who are living in their family home.* Provision for these adults was intended by the planners of the Sheffield Development Project to be made in the two new-type 96 bed hospitals, as part of their own day activities programme. The unfortunate combination of staffing difficulties with unsuitable building design resulted by late 1980 in an effective absence of provision for most of these adults needing special day facilities, with obvious consequences for their parents and relatives at home.

Even the one large new ATC provided in late 1975 under the development project was so ill-designed that it experiences great difficulty in accommodating trainees with physical handicaps. There is, for example, only one small lift to the upper floor: it can take only one wheelchair, and the controls are above the reach of a seated adult. Not surprisingly, safety regulations permit only two adults in wheelchairs to be on the upper floor at one time.

The Evaluation Research Group carried out a replicated study, with a two year interval, of the attitudes and activities of the staff in the ATCs. The same two ERG members carried out the time-sampling observations and individual interviews on the two occasions.* Evidence of change, in both the pattern of activities and in some attitudes of staff, over the two year period was obtained. More staff time as observed in 1979 was spent in activity which involves a direct relationship with individual trainees than was the case in 1977. This was consistent with staff responses to an

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* Full details of the methods and results can be found in *ERG Reports* nos 2 and 7

open ended question about the 'aims of ATCs'. By 1979 there was evidence of more concentration on actual social skills needed to achieve some measure of independence, and on the importance of work skills, coupled with a very marked reduction in the number of staff who perceived the ATC as a place where mentally handicapped adults should be 'kept occupied'. This whole process was almost certainly facilitated by an increased emphasis on outdoor pursuits of various kinds, and by the fact that most staff had begun to help on a routine basis in sections other than their own.

In 1979, the 44 staff interviewed were unanimous that *their centres did not get enough support from outside professional people.* Among the 58 specific suggestions made there was a clear emphasis on 'doctors' (used generically), speech therapists and social workers. It seemed reasonable to infer that most of these ATC staff had come to see their centre as part of what *should* be a wider multidisciplinary service to the mentally handicapped adult: in organisational terms as much more analogous to a school, and quite different from a factory or other employment setting.

Some changes in practice and in attitudes must have resulted from decisions by ATC managers and by middle and upper management in the social services department, taken during the two year interval between the ERG studies. Decisions at these various management levels were probably affected, consciously or otherwise, both by the findings of the first ERG report and by the working out of the Woodside Assessment Unit philosophy and methods. Other changes – and the extent to which changes due to management policy were implemented – can reasonably be attributed more directly to the general work of the Woodside Assessment Unit within the system as a whole, and not solely to the effect on 22 (of the 24) instructors of their participation in the unit's inservice training programme.

Residential services The Feasibility Study Report for the Sheffield Development Project recommended the provision of 312 places for adults in hospital and NHS hostel units, and 350 places in local authority hostels and group homes. The 312 NHS places were to be divided between two 96 bed units, to be sited on the north and south sides of the city, four hostels with 24 places each and a 24 bed unit for emotionally disturbed adolescents and adults. In practice, the 24 bed unit was replaced by an additional hostel following a DHSS decision to meet this need through regional centres which would not be solely or even mainly for mentally handicapped people. Of the 350 local authority places proposed, 143 had been provided in hostels and 29 in group homes by the end of 1980. The feasibility study proposals made no new provision for the long-stay residents in the old hospitals who had originated from outside the Sheffield area.

As a result, by 1980 this group – numbering about 270, many of them elderly – posed an additional problem over and above the shortfall in local authority places indicated above. Since local authorities are not bound to accept from the NHS persons originating elsewhere, the situation has clear implications for the rate of closure of old hospitals.

The authors of the Feasibility Study Report identified three categories of adult resident, and assigned them to three types of provision, as follows.

1 In the *new 96 bed hospitals,* 'those who, because of additional heavy physical handicap, or severe behaviour problems, require the support of a full hospital service fairly close at hand'.

2 In the *new 24 bed NHS hostels,* 'those who, because of less obvious physical handicaps, possibly some degree of incontinence and behaviour problems, require limited medical and nursing supervision'.

3 *In local authority hostels and group homes,* 'those who could be cared for within a normal home if such a home were available to them'.

The evaluation studies made it clear that residents in different types of provision did *not* conform to the intended pattern.* While the new 96 bed hospital units had generally 'worse' residents than either NHS or LA hostels, there were similar people still to be found in the old hospitals. More importantly, there were also similar people to those found in both sorts of hostels resident in the old hospital units, and *there was certainly no clear distinction to be found between the NHS and LA hostels themselves.* So far as these were concerned, the major deciding factor for their admissions did not seem to have been related to the ability levels of individuals or to any degree or type of behaviour disorder, but rather to *the sources from which the individual referrals had come.* The ERG team observed that 'it is scarcely surprising that a LA hostel is not viewed as "progress" by NHS hostel staff, when both types of unit have in many respects comparable sets of residents'.

Turning to the outcome of a very detailed study of the local authority's five *unstaffed group homes,* which accommodated 29 men and women, it was found that:

- previous residential placement did not influence the success of subsequent group home living

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* The evidence on residential services comes from four *ERG Reports:* nos 4 and 12, dealing with all NHS and local authority provision, no 9 with local authority unstaffed group homes, and no 10 with short-term relief and emergency residential care for both children and adults usually living at home.

- criteria for the selection of residents had been implicit rather than explicit, and were generally unclear
- residents received their main outside support from official rather than informal sources
- the social services department had no clear policy for the organisation and administration of its group homes.

It is fairly evident that although a useful start had been made to provide the group homes recommended by the Feasibility Study Report, the enterprise had been haphazard and ill-coordinated – a classical example of 'Topsy-like' growth.

Short-term and emergency care

When it was found that the relevant senior officers of the health, education and social services all believed that the 'supply' (except in peak holiday periods) of *short-term relief and emergency* residential care exceeded the 'demand', the ERG designed and carried out a special study.* On the 'supply' side it was established that:

- *NHS mental handicap units* (other than the Ryegate Centre) did not have any positive policy for short-term care (STC)
- availability of places was largely determined by the chance occurrence of empty beds in the long-stay hospitals and hostels
- despite the fact that all are medical units, the available STC places for multiply-handicapped adults were few
- *on the local authority side,* five adult hostels could provide between them a minimum of *eight* designated beds, which might be increased by the temporary availability of long-term beds

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* *ERG Report* no 10.

- four LA units could between them cater for a *maximum* of about 28 children and adolescents in STC
- *there was no evidence at the time of any effort to achieve inter-service coordination of STC provision.*

With the notable exception of the Ryegate Centre, in *none* of the three services (health, education, social) was it perceived as important to *make known to parents* the STC available, or to *develop it as a significant supportive service* to the families of mentally or multiply handicapped people.

Evidence on the 'demand' side was obtained through home interviews with one or both parents in a stratified random sample (103 households in all), drawn from the Sheffield Mental Handicap Case Register. It was found that the main factors *promoting* uptake of available STC were:

- ease of arranging
- becoming a 'regular' at a particular unit
- the quantity and quality of information provided about available STC.

The main factors *militating against* use were:

- lack of appropriate initiating action by the potential STC-providing service or units
- inability or unwillingness of many adult units to accept non-ambulant or 'difficult' cases
- on the adult side, dependence on 'casual vacancies' in a long-stay system, resulting in some 'unacceptable places' as perceived by parents, and (especially in NHS units) reduced probability of STC being available later in a familiar unit
- inadequate and sporadic contact between parents and

relevant professional people, notably general practitioners and health visitors

- and, as noted above, the absence of coordinating mechanisms on the supply side, both between health and local authority provision and within the health service.

The authors of the *ERG Report* concluded that

> 'Our investigation has made it quite clear that the time has come – that it is in fact overdue – for a distinction to be made by the three providing services, acting in concert, between the apparent "demand" for short-term care and the latent "need" for it. Need is greater than demand mainly because the parents and relatives of mentally handicapped children and adults *feel* guilty about seeking or using STC in order to give themselves a "break" from the constant strain of caring and coping . . . we have shown that even those who *have* used what STC was brought to their notice, frequently did so only reluctantly and at the last moment before breaking point'.

The social services

In what has gone before, reference has been made where appropriate to the part played by the local authority, and in particular to that of the social services department. When planning a major study* of the role and function of the social services, the ERG team concerned noted that the Sheffield social services department, known as the Family and Community Services Department, 'had a number of elements not found in other local authority SSDs', and also its specially funded innovatory nature in relation to mental handicap under the Sheffield Development Project. These factors made a comparison with another city

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* *ERG Report* no 5.

desirable, and the cooperation was obtained of the health and local authority services in Leeds. This city was large enough (population about 750 000), near enough (40 miles) for practical travel arrangements, and yet sufficiently far away to avoid any direct impact from the development project. It must be stressed that this was *not* regarded as a 'control' area in the classical sense.

Differences in organisation between the two social services departments were found mainly at headquarters level, a number of posts being unique in each city. For example, Leeds had a centralised day care section which included control of ATCs, but tended to devolve responsibility for its residential units to the field work divisions. Sheffield, on the other hand, whilst having some central control over ATCs, did so separately from day care services to all other clients, but had a central control over all types of residential provision. One of the common characteristics of the health, education and social services in both cities, despite organisational differences, was *the lack of precise definition as to who was actually dealing with mental handicap.* Apart from the relevant proposals in the feasibility study report, no objective policy statements were in existence for the Sheffield Family and Community Services Department contribution to the mental handicap services at the time of the study (1978). As a result, no measurement of performance against objectives could be attempted.

The outstanding finding from this two city study, which involved interviews with about 400 staff and over 200 parents, was that *'far fewer differences exist between the two cities than had been expected'.* No significant differences were found in relation to parents' perceptions of services related to social, educational or vocational training – or, for that matter, in relation to hospital, medical, nursing and other associated services, when considered overall. The major difference in favour of Sheffield concerned the advice, support and practical help given by the social workers to the families of mentally handicapped people living at home. This was largely attributable to the fact that Sheffield had been enabled under the development project (on a 50 per cent subsidy basis) to provide each of its seven social services divisions with a social worker to specialise in work with the mentally handicapped. It would be easy to miss the wider implication of this positive finding. The immediate reaction is that the addition of one full-time social worker (trained and/or experienced in mental handicap or not) would of course 'improve the service'. Yes, but it is the 'other side of the coin' that is more important: without the presence of those specialists in the several areas of a large city, the amount of time and knowledgeable input available to the mentally handicapped and their relatives will be wholly at the mercy of over extended field social workers, *guided by a mixture of personal and administrative priorities.* The numerically small size of the mental handicap group paradoxically tells against them in the pecking order.

Finally, it has to be recorded as symptomatic of the 'non effect' of the development project that only half of the 174 members of the health, education and social services staff interviewed in Sheffield had reasonably full knowledge of facilities supposedly covering the entire mentally handicapped population of the city, while one in six had no knowledge at all of the development project. This was six years after implementation of the project commenced and at a time when some of its most substantial new inputs were becoming operational.

3 THE KEY ISSUES: A WAY FORWARD

It was the task of the Evaluation Research Group to enable as many insights as possible to be gained from the input of substantial special funds through the Sheffield Development Project on Services for the Mentally Handicapped. What has been summarised above identifies both strengths and weaknesses in the services that have resulted. It now remains to focus attention on the underlying questions which seem to have a general significance far beyond the special circumstances prevailing in one city at a particular time.

At this point it seems more profitable and constructive to use these insights in a forward-looking analysis. So far as services for intellectually handicapped persons are concerned, the decade of the 1970s provided a period in which change in philosophy was not only rapid but accelerating. At the beginning of 1982 it has become *realistic* to put forward, as a practical basis for policy and action, what even five to seven years ago was still generally regarded as idealistic.

If the needs of intellectually disabled persons are to be met in such a variety of appropriate ways as to reduce to an absolute minimum the extent to which they are handicapped, an effective partnership must be forged between three independent sources of support and service. These are:

the family
the neighbourhood community
the public and voluntary service agencies

For that partnership to become and to stay effective there must be:

an accepted basic 'philosophy'
explicit objectives
a workable delivery structure
adequate resources
sustained commitment

A tall order? Asking for the moon? Let's have a look.

Philosophy

The stated purpose of the Sheffield Development Project was 'to enable the mentally handicapped person to live as much a part of the community as his/her disability will allow'. In 1970 that was no mean attempt, but unfortunately it did not seem to have inspired and unified the implementation of the project during the ensuing decade. Right from the start, there was a marked preoccupation with buildings, no doubt reinforced by the high proportion devoted to capital expenditure of the several million pounds injected by the development project. As that preoccupation is still to be observed elsewhere in the United Kingdom, despite the relative shortage of large-scale funding, it is an opportune time to spell out a 'philosophy' which directs attention to the intellectually disabled child or adult as a member of the public, instead of to the provision of purpose built miniature institutions, however 'home-like' it may be hoped these can be.

While recognising that something thus explicitly spelled out is *a necessary but not sufficient basis* for future progress, what about something like this:

> Intellectually disabled people of all ages should be regarded as members of the public, usually living at home or in ordinary accommodation in the community, and as entitled to both general and specialised medical, paramedical, educational and

> social services as are their fellow citizens. These services should be closely integrated and designed to respond flexibly to gradually changing needs.

Such a statement of 'philosophy' provides the basis for explicit objectives, both long term and short term. It must stand or fall on its own intrinsic merits, not on whether it can be realised universally and equally quickly. It starts with the individual and makes explicit the meaning of 'community'. For example, this term was used consistently for ten years in Sheffield to mean 'out of hospital', so that it became necessary to state publicly in 1981 that people who live permanently in hostels are *not* 'living in the community'. The statement rejects the status of 'chronically sick' and emphasises instead the individual's right to services which are geared to the individual's gradual development through the life span.

Explicit objectives

The best known example in the field of intellectual handicap of an objective which is *not* explicit must surely be 'to realise his/her maximum potential'. *An objective is not explicit enough unless and until it permits the formulation of relatively simple criteria by which to measure progress towards that objective.*

One important lesson from the Sheffield Development Project, and the attempt to evaluate it, is that agreement on objectives and criteria, as defined above, should always form part of the planning for a new service, or for a different way of providing it.

A workable delivery structure

The development project gave Sheffield a unique opportunity to provide itself seven to ten years later with one of the most integrated and operationally effective mental handicap services in the United Kingdom. What did Sheffield do with that unique opportunity? The short answer is that it 'muffed it'. It entered the 1980s without even a reasonably well coordinated service, let alone an integrated one. As will be evident from the findings set out earlier, some parts of the overall service are operationally highly effective, but many are not. There are features of the Sheffield scene which are unique or nearly so, and these continue to attract the attention and interest of other cities in Britain and abroad. But there are also increasingly frequent examples of successful innovations elsewhere which involve the close and enthusiastic cooperation of more than one service agency. Even taking note of such examples, the growing recognition that intellectually impaired people should not be regarded as chronically ill and that they should be supported and served in the ordinary community, suggests that the long-term solution must, of course, be administration of a *single* service by the local authority, with appropriate inputs from the health authority. That is not possible in the short term: what is needed quickly is a new type of structure which provides for *joint* action, at both policy and management levels, by the health and the local government authorities, explicitly designed to produce what in actual effect will be a *single service* for intellectually handicapped persons. This is not an original idea: similar attempts to devise such a unified delivery structure have been made in several places in the United Kingdom. What the results of the Sheffield evaluation studies make clear is that something of this kind is an absolute prerequisite for any significant improvement in services. Even the necessity for both a special coordinating committee (at 'member' level) and a special executive working group (at senior officer level), to ensure that development project funds were spent responsibly, did not lead in Sheffield to a satisfactory delivery system, as we have seen. This was not a truly *joint* structure and the two separate systems were left almost completely free to go their separate ways.

Adequate resources

Under any system of responsibility and of operational management, services for the intellectually disabled person are inevitably in competition for usually scarce resources with other – and much larger – groups of citizens. This is not the place to argue their case in a league table of priorities. It can however be noted that in the United Kingdom the group with which we are here concerned remains in the 'top three', along with the very elderly and the mentally ill, despite changes in governments and in ministerial appointments. This high priority at the level of central government does not, of course, ensure similar priority at local level where spending decisions are actually made.

Costs

It is however essential to make it clear, beyond any possibility of misunderstanding, that meeting the needs of the intellectually handicapped genuinely 'in the community' is *not* a cheaper option. From the limited costing experience available, a community-based service is likely to be more expensive in the short term, and at best to break even in the long term. It is more expensive in the short term because existing institutions, including many relatively new small ones, cannot be closed and savings effected immediately; and some of essential elements of an *acceptable* community-based service will involve substantial inservice training of present staff, and an increase in the strength of several relevant professional groups, notably psychologists, physiotherapists and speech therapists. Here it should be noted that, costs apart, there are national shortages in the supply of suitably trained professionals interested in working with intellectually disabled people.

Training

Even within the framework of the Sheffield Development Project, neither of the two separate authorities – health and local government – where able to cope at all successfully with the problems of staff training created by the expansion. An acceptable community-based service will demand skills and attributes not necessarily possessed by staff now in post, but there is already adequate evidence that such new skills and attitudes *can* be acquired through specially designed reorientation courses, which should be interdisciplinary – and by seeing for themselves that the new approach can and does 'work'. It is therefore a management responsibility to ensure that such personal progress is made possible. All existing resources of experienced staff can and must be redeployed with increased job satisfaction to those concerned: but leadership must be from the front. Managers are in as much need of reorientation as are those who care and teach.

The voluntary sector

The Sheffield Feasibility Study Report stated explicitly that:

> 'There is an important role in the service for the voluntary organisations, who should be invited to work closely with the hospital and local authorities, so that a coordinated and purposeful programme of assistance should be planned'.

It was thought that voluntary help would 'play a large part in the overall services', and the appointment of a coordinator of voluntary services was recommended. That appointment was never made, not by oversight, but because the senior officers representing the separate services did not pursue it, ostensibly on financial grounds despite the availability of a development project subsidy.

Better Services for the Mentally Handicapped?

Today, the 'voluntary sector' can no longer be thought of solely in terms of one or more voluntary organisations, concerned at local and national level with the needs and interests of intellectually handicapped persons and their supporting families. The accelerating movement towards life in ordinary accommodation in the real community, as distinct from semi-institutional living in hostels which do not form part of the community in which they are located, means that intellectually disabled adults will have *neighbours,* just like the rest of us. So 'the rôle of the voluntary sector' must now include *the mobilisation of active interest and involvement on the part of the general public.*

This daunting but vital task can only be carried to a successful level in any given community by means of that partnership, already described in the Feasibility Study Report more than a decade ago, between the public and the voluntary sectors. Where it does not exist, it must be forged. Another decade cannot be allowed to pass: as someone wrote in a different connection three hundred years ago: 'There is no time but this present'.

A sustained commitment

Over a period of more than four years, the members of the Evaluation Research Group met and talked with hundreds of parents of intellectually disabled children and adults, and with hundreds of staff in the various parts of the local services. *They found a sustained commitment.* In terms of a changing philosophy that sustained commitment may need some fresh targets, for parents as well as for service staff. But its very existence in the forms determined by the realities of the existing philosophy – or the lack of one – commanded admiration and respect.

The failure of Sheffield to make the most of the opportunity provided by the development project cannot be wholly attributed to deficiencies in the management structures and systems of the principal service agencies. One of the most important lessons to be learned is surely that money is by no means the only constraint in the attainment of goals. Wherever the representatives of the people – of *all* the people, including the intellectually disabled – and the senior public servants in the relevant service agencies, are faced with something like a 'quantum jump' in innovation, their wholly understandable reaction is likely to be cautious, conscientious and conservative.

Despite the harsh realities of the worst economic recession for half a century, *everyone* concerned with the future of this neglected minority of our fellow citizens is challenged to be adventurous, cooperative, flexible and decisive. Then the 'sustained commitment' goes beyond the immediate carers to those who make policy and those whose responsibility it becomes to bring it to reality.

Appendix : Evaluation Research Group Reports

1 The Sheffield Development Project on Services for the Mentally Handicapped: Implementation of the Feasibility Study Recommendations

2 Staff Attitudes and Activities in Adult Training Centres

3 Voluntary Services for the Mentally Handicapped

4 Residential Services for Mentally Handicapped Adults: Interim Report on Stage One

5 The Role and Function of the Social Services Department in the Total System of Provision for the Mentally Handicapped

6 The Woodside Assessment Unit (for school-leavers and adults)

7 A Study of Change in Adult Training Centres 1977-79

8 Mentally Handicapped Under-fives: Leeds and Sheffield Services as seen by Parents

9 Group Homes for Mentally Handicapped Adults

10 Short-term Care for the Mentally Handicapped: a Study of Availability and Use

11 The Ryegate Centre (for children: assessment, therapies, review)

12 Residential Services for Mentally Handicapped Adults: Stage Two

13 Mentally Handicapped School Leavers: a Follow-up Study

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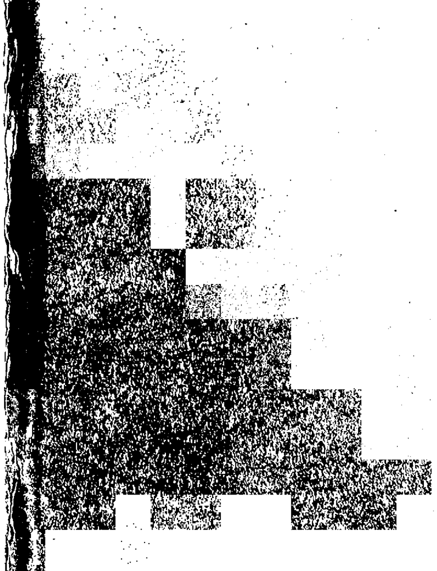

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