



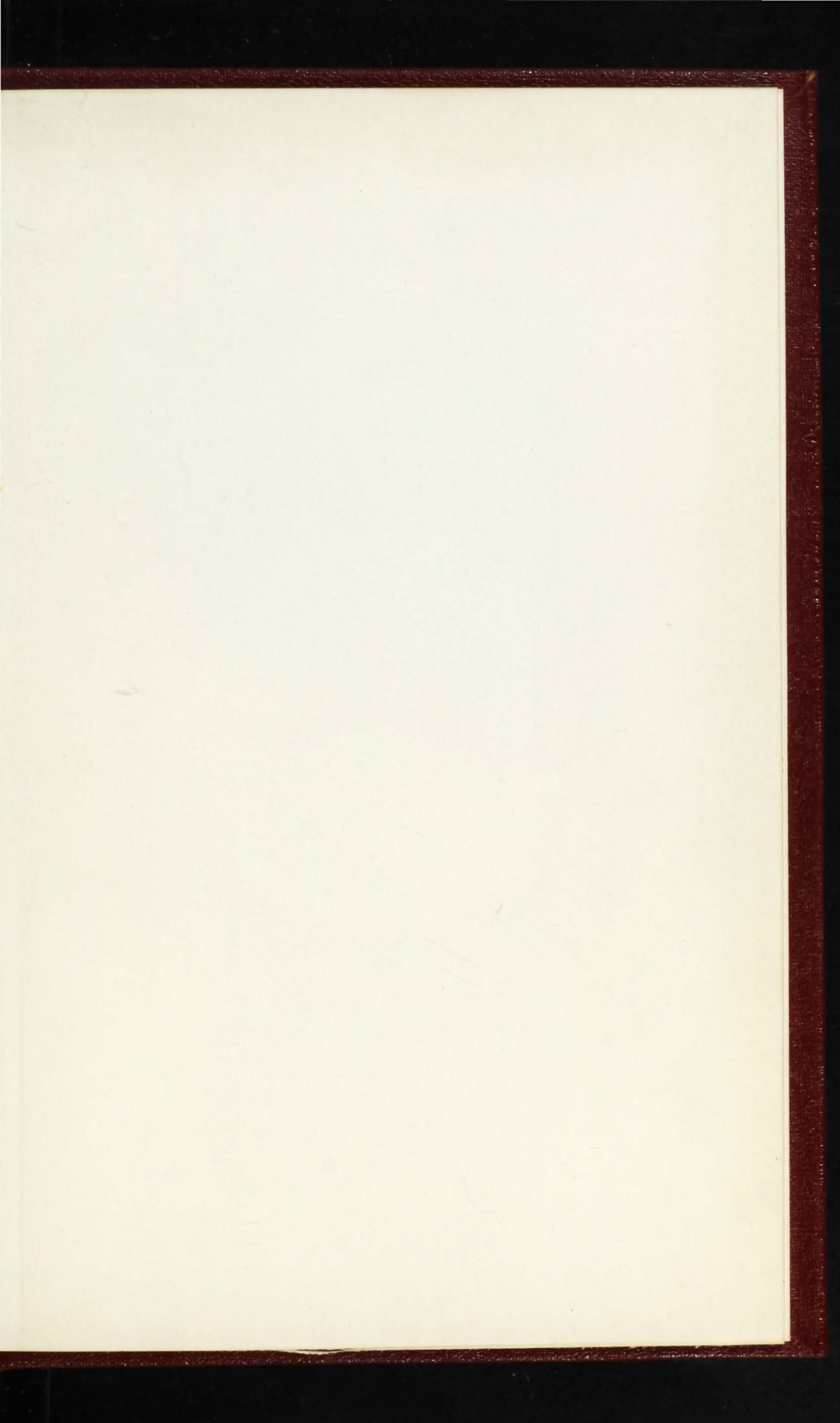
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# FAMILY SERVICE for the mentally handicapped

Research in  
Education 2:50





# a family service for the mentally handicapped

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Walter Jaehnig  
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## a family service for the mentally handicapped

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# 1. myth and community care

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More than a decade has passed since newspaper allegations of mistreatment of mentally handicapped patients at Ely Hospital, Cardiff, broke upon the unsuspecting public. The report of the official enquiry, published in 1969 by Richard Crossman, Secretary of State for Social Services (*Report of the Commission of Enquiry into Allegations of Ill-Treatment of Patients and other Irregularities at the Ely Hospital, Cardiff*, Cmnd 3975, HMSO), described disturbing conditions in the hospital and provided a lengthy catalogue of nursing and management malpractices. While many professed surprise that such conditions existed within the National Health Service, a spokesman for the National Association for Mental Health was quoted in the press as saying, "If you investigate any major mental hospital you are likely to find that it is in the same boat with overcrowding, staff shortages and old buildings".

Time made him a prophet. Highly publicised reports of official investigations into several other mental hospitals in the early 1970s—the Normansfield inquiry being only the most recent—reiterated many of the Ely Committee's findings. But in addition, publication of other studies, such as Dr. Pauline Morris's national survey of hospitals for the mentally handicapped (*Put Away*, Routledge & Kegan Paul, 1969) and later the Hospital Advisory Service's annual report on NHS long-stay institutions, raised fundamental questions about the appropriateness of custodial forms of care. The official response came in 1971 when the Conservative Government published its policy statement, *Better Services for the Mentally Handicapped* (Cmnd 4683) HMSO. This White Paper, repeatedly and consistently re-affirmed by Labour ministers, promised an improved balance between hospitals and community services for some 120,000 severely mentally handicapped (formerly designated "severely subnormal" or "mentally deficient") people and an unestimated number of mildly handicapped people in England and Wales.

But has this prolonged period of public anxiety and ministerial concern

actually resulted in a more effective and compassionate service for mentally handicapped people? Spokesmen for successive Governments and providers of services have taken an optimistic, if somewhat narrow, view of recent developments. Conceding that much remains to be done for the mentally handicapped the magnitude of change thus far has not been impressive, they attributed the failure to exact more comprehensive improvements to the country's general economic situation. They have argued that within these financial constraints, nonetheless, it is possible to improve conditions in the hospitals while simultaneously encouraging greater community provision. Thus in 1975 Barbara Castle, then Secretary of State for Social Services, noted that increased expenditure on the mental hospitals had practically eliminated overcrowding (by the Department of Health and Social Security's 1969 standards) and improved nurse/patient ratios. Local authority requests for loan approval for capital projects (residential and training facilities) reportedly were running well ahead of White Paper targets before the December 1973 cuts in public expenditure (speech to National Society for Mentally Handicapped Children conference). A joint financing arrangement was developed to encourage collaboration between health and local authorities. The Government's consultative document (*Priorities for Health and Personal Social Services in England*, DHSS, 1976) reported that local authorities added 3,500 residential places and 9,000 adult training centre places between 1969 and 1974, while hospital beds for the mentally handicapped were reduced by 5,000 during this period. More important, the document proposed that services for mentally handicapped people should receive above average expenditure during the lean 1975/6 to 1979/80 years—a policy that was reaffirmed in late 1977 (*The Way Forward*, DHSS). As Professor Peter Mittler, chairman of the National Development Group for the Mentally Handicapped, wrote in *New Society* of 1 July 1976 "After decades of neglect, mentally handicapped people are now beginning to get nearer to the priorities they deserve". David Ennals, Secretary

of State for Social Services, repeated the Government's commitment: "I shall give my full backing to the development of services for these groups (the mentally ill and handicapped, arthritis sufferers, and those needing speech therapy). We really must promote a more effective balance between the hospital and community services and improve the quality and atmosphere of some of the hospitals which serve the mentally ill or handicapped. In general terms, *the right direction of advance . . . is now clearly mapped out*, but the task now will be to make the plans a reality" (speech to Medical Journalists' Association, 4 June 1976, emphasis added).

### the limitations of current policy

These improvements, however modest, can seem satisfying in view of past failures. But when present policies are examined more broadly, lingering questions remain without answers. These are concerned with the strength of the Government's long term commitment to community care and discomfiting elements of the White Paper's pattern of services. "Community care", quite simply, suggests a social, rather than medical, pattern of care, with an emphasis on the maintenance of the handicapped person's relationships and, where necessary, assistance from the non-institutional resources of the community. What place therefore do long stay hospitals—of any size or location—have in this pattern, particularly when the DHSS's own statistical studies demonstrate that the majority of mentally handicapped people are not in need of medical supervision or treatment? "Community care" is meant to be integrative, enhancing the individual's links with his home, neighbourhood and community. What benefits therefore do institutions such as hostels, whether located in the community or in hospital grounds, bestow upon handicapped people: to what extent do they sustain these important linkages? Finally, "community care" is meant to be preventive, aiming to aid and support the family of the handicapped person so that his admission to a segregative institution may be

prevented or deferred. Considering that about half of the severely handicapped people in England and Wales live with their families or elsewhere in the community, what levels of support does the White Paper provide for them? Is it possible to see the White Paper, as it applies to the handicapped and their families, as any more than an attempt to reformulate a "minimum" level of services? And can we be optimistic about the possibility of a comprehensive development of long neglected services, financed by a growth in spending of less than 3 per cent annually?

The concept of community care that emerged 20 years ago from the report of the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency 1954-57 (Cmnd 169) was both comprehensive in recommending the establishment of a wide range of preventive services and family based: "The whole approach should be a positive one offering help and obtaining the co-operation of the patient and his family . . .". The Royal Commission recognised society's responsibility to share the burden of families with mentally disordered members, and to provide care for those without families: "It should also be remembered that the sense of belonging to a family may be of great importance to the patient. It is not always in his best interests to remove him from a not entirely satisfactory home to even the best run foster home or public institution."

The theme of this pamphlet is that when present services for mentally handicapped people are measured against this standard, it will be recognised that "community care" is nearly as much a myth as it was in 1961 when Richard Titmuss questioned the country's commitment and preparation to carry it out (reprinted in *Commitment to Welfare*, 1967). In spite of the seemingly irresistible case for fundamental reform made in recent years, the policies that have emerged are narrow in their conception of the problem, timid in their prescriptions and ambiguous in their execution.

## 2. the dilution of community care

To propose a community care service is one matter, to make it a practical reality is quite another. The translation of the Royal Commission's broad ideals into a new pattern of care over the past 20 years has been shaped by determinations of other issues—issues peripheral to the problem of mental handicap itself. Foremost was the traditional division of political responsibility between central government and local authorities. A change in policy from a hospital based service to one founded upon community provision implied not only a substantial redistribution of financial resources from central government (and the NHS) to local authorities, but also raised questions about whether local communities possessed the political will to reassume the responsibility for the mentally handicapped and the other groups in need of community provision (local authorities had operated the hospitals for the mentally handicapped before the establishment of the NHS). In addition, the 1960s and 1970s witnessed the emergence of several helping professions with respective claims over services for mentally handicapped people. But each also had its own conception of the problem of mental handicap and special skills to apply to it, and the articulation of their interests further complicated the political process, making it more difficult to allocate scarce funds straightforwardly without offending competing groups.

Moreover, neither the new community services nor the emerging professionalism of these groups reversed the trend toward the provision of services (and ultimately, institutionalisation) as substitutes for the resources of the handicapped person's family. Relatively little attention was paid to the potential of different types of family structure to cope with the problems of the handicapped person or how ancillary services might be offered to complement the family's own efforts. The political leadership continually failed to outline the specifications for a comprehensive, family based service, or provide the resources to fund and develop efforts along these lines. If anything, the period since the acceptance of the Royal Commission's report—supposedly marking the

elaboration of a "community care" policy—has been a growing confusion over the nature of the needs of handicapped people and their families and, paradoxically, a subtle extension of the categories of handicapped people seen to be in need of institutional care, whether in the community or in hospital.

Members of the Royal Commission thought it should be a duty of local authorities to provide integrative and preventive services; this general approach was adopted in the Mental Health Act of 1959. One of the Act's objectives was to establish a comprehensive community service to meet the needs of all types of mentally disordered patients not requiring hospital (medical) treatment. Circulars issued by the Ministry of Health made many services, including residential accommodation, obligatory on local authorities. But in an important circular, the ministry sharply restricted the categories of persons likely to need residential care in community accommodation to: *firstly* the "educational subnormal or maladjusted young people who are in employment but need . . . some care and guidance which cannot be sufficiently provided in their own homes; *secondly* patients discharged from hospital needing some support on re-entering community life and *thirdly* elderly infirm persons who do not need the service and resources of a hospital" (Ministry of Health Circular 9/59). Sections 12 and 13 of the Mental Health Act added a fourth category: children unable to attend junior training centre daily because of distance or lack of transportation.

The Younghusband Working Party reported while the Mental Health Act was moving through Parliament (*Report of the Working Party on Social Workers in the Local Authority Health and Welfare Services*, Ministry of Health, Department of Health for Scotland, 1959). Commenting on impending changes in the mental health services, the working party wrote: "Perhaps most important of all are efforts to make it possible for the family to care for its physically or mentally handicapped members . . . The tendency is now to provide for them in the

community and accordingly there will be increasing demands on the social services to enable all but the lowest grades to lead satisfactory lives in the community and to make full use of their abilities, limited though these may be”.

Perhaps not surprisingly, considering the subject of the Younghusband Working Party's deliberations, the social worker's role was claimed to be pivotal. In fact, the working party described the needs of various segments of the population in terms of the level of training and skill required from social workers to help them. This shifted the attention from the family's instrumental needs to the social worker's recognition of the family's problems. Practical difficulties involved in caring for a mentally handicapped child for example could be explained away as psychological problems with the family itself. The working party described an instance in which a simple request for material help called attention to a complicated and troubled situation: “Caring for a mentally defective child may often place heavy emotional and physical strain on the family. The social worker must be able to give steady and continuous support, eventually perhaps help the parents to evaluate the respective claims of their normal children and the defective child. In one instance the mother of a seriously defective child saw the problem only as one of obtaining help to enable her to carry on somehow. But the observer could see other problems”. The working party described the mother as “over-protective” and said that “she may have felt responsible for his defect.”

Quite likely if her child had not been handicapped and the mother was “over-protective”, the social worker never would have come in contact with her. In this sense, a mother's request for assistance became an invitation for an exercise in family pathology; the family's practical needs were superseded by the professional arrogance of case-work. This confusion between need for assistance and the family's vulnerability to professional analysis was a theme running throughout the Younghusband report. Too little attention was paid to the pro-

fessed or felt needs of families, and the nature of the relationship between the social worker and the users of the general social services (for a further discussion, see Adrian Sinfield's *Which way for social work?* Fabian Society, 1970).

The working party also noted that: “It is salutary to reflect that the demands made on the health and welfare services . . . are rapidly increasing. The services for the general classes of handicapped persons have touched only the fringe of need; an expansion of all forms of community care for the mentally disordered has been recommended and the importance of more effective preventive work with families is generally accepted.”

However it made no real attempt to define these needs, the nature and scope of service required, or the form “effective preventive work” might take. Although the report was a long time in the making, the working party did not itself investigate consumer needs, nor did it exhibit its awareness of social needs that had been established in social research since the war.

In 1963 the Government issued *Health and Welfare: The Development of Community Care* (Cmnd 1973) in which local authority health and welfare plans for the next decade were published. The intentions were laudable; the document described “community care” in this way: “. . . to help them live as nearly normal lives as the nature and extent of their disabilities allow . . . the object is always to give the utmost opportunity to develop his potentialities. Accordingly the mental health services provide help in all the main aspects of ordinary life, in the home and at work”. Services should be family oriented and based upon the home: “It is usually best for the mentally disordered person in the community, whether adult or child, to live at home when this is possible. The willingness and ability of relatives to provide a home depend on the severity of the disability, the size of the family, and the effect of the mentally disordered member and the rest of the family on one another. *But the services provided inside and out-*

side the home can improve an unfavourable situation and make it unnecessary to seek an alternative. Advice and support from a social worker or health visitor or the services of a home help can make a significant difference. Access to training, occupation and social facilities in centres and clubs, and the availability of short periods of residential care, can make all the difference in keeping the family 'together' (emphasis added).

But *The Development of Community Care* (op cit) also described the likelihood that more mentally disordered persons would need residential care. The Government for example broadened its heretofore restricted categories of persons needing institutional accommodation to include children attending junior training centres because "of the situation at home". No description was provided of the sort of home environment the document's authors had in mind, nor did the plan specify who would make the decision to institutionalise the child. Perhaps in justification, the report recommended that residential provision should resemble "a real home": "Nevertheless, there will always be many cases in which an alternative home is needed. A foster home or suitable lodgings may be the best arrangement. The right background can, however, be established in premises built or specially adapted as residential accommodation for the mentally disordered".

This minor shift in policy would have been inconsequential had the remainder of the document, which signalled local authority community care intentions, been more promising. It has been described elsewhere as "one of the most disappointing publications in the mental health field for many years" (Peter Mittler, *The Mental Health Services*, Fabian Research Series 252, 1966). The published figures demonstrated how unprepared local authorities were to accept their new responsibilities, and exposed great geographical disparities in the quantity of services planned for the future. And although the plan was intended as a companion for the 1962 hospital plan (*A Hospital Plan for England and Wales*,

Cmnd 1604), the Government declined to provide guidance or suggest standards for local authority services. Indicators concerned with services for the mentally handicapped were restricted to the number of adult and junior training centre places available and planned. Support services were defined only in terms of staffing ratios for health visitors, home helps, home nurses, midwives and social workers—not all of whom, obviously, would be concerned directly with families of mentally handicapped people. It would not seem possible to measure the effectiveness of community services solely in terms of residential and training places available or staffing ratios (though this numbers game is still standard practice at the DHSS). But nowhere did the Government in *The Development of Community Care* (ibid) provide the level of concern and leadership that was evident in the hospital plan.

### the Seebohm report

By 1968 when the Seebohm report (*Report of the Committee on Local Authority and Allied Personal Social Services*, Cmnd 3703, HMSO) was published, the consequences of this leadership vacuum were apparent. The Committee wrote: "The widespread belief that we have 'community care' of the mentally disordered is, for many parts of the country, still a sad illusion and judging by published plans will remain so for years ahead". The Seebohm Committee, with its emphasis on administrative efficiency and professionalism, did little to remedy this. Writing often and somewhat ambiguously of "an effective family service" the Committee made little attempt to describe this service or how it would aid families of the mentally handicapped. Constituent elements of what the Royal Commission considered to be a family service were virtually ignored in Seebohm; home helps for example were recommended for families of the physically handicapped but never mentioned with reference to the mentally handicapped. At times Seebohm appeared to suggest what would have been obstructions to an effective family service: the Committee

recognised a chronic problem in co-ordinating efforts of health and welfare workers and recommended that responsibility for the mentally handicapped should be held by social services departments. But it also invested great responsibility for the mentally disordered in the public health doctor (in what remained of the old local health departments): "In the task of co-ordination, the contribution of the public health doctor, the community physician of the future . . . will, we believe, be crucial . . . For its part, a social services department of the kind we have proposed should be well placed to collaborate with other social agencies as well as with the local medical services".

Why this collaboration should take place in the future when it had not in the past was not explained by the Seebohm Committee. A number of surveys had found that such co-ordination was one of the unresolved difficulties of the pre-Seebohm health and welfare services. A comparative study, for example, of services for the mentally handicapped in seven local authorities discovered that professional providing services—general practitioners, health visitors, social workers, clinic doctors and others—tended to view their own role as predominant and assumed that others were doing the co-ordinating. As the authors of the project report wrote: "The lesson to be drawn is not that the multitude of services now available should be reduced, or even that fewer people should be involved, but rather that more effective means of co-ordinating their activities have to be devised" (see *I Thought They Were Supposed to be Doing That*, The Hospital Centre, 1972).

Events would seem to have reduced further the possibility of co-ordination of services from the social services department. In 1971 responsibility for the junior training centres (now special schools) passed, logically, to education authorities, general practitioners, health visitors and school health officials are now associated with area health authorities established by the 1974 re-organisation of the National Health Service. In terms of early contacts with the mentally handicapped child, the social services department

would seem to play a secondary role—perhaps reducing the possibility of developing an effective family-support service. It is now quite possible, if not likely, that the department will not know of the child's existence, much less of his family's need for assistance, until he is of school leaving age. The DHSS's Harvie Committee on residential care noted this problem: "In our view these haphazard arrangements are undesirable and should not continue. The social services department should be routinely notified whenever it is established that a family has a mentally handicapped child. We believe that the family . . . should have a social worker nominated, who would have the special duty of keeping regular contact with the family and of ensuring that it receives all the appropriate support and material help" (*Mentally Handicapped Children in Residential Care*, 1974).

The Conservative reorganisation of the National Health Service exacerbated this problem of health and social services co-ordination. The medical profession fought Labour's earlier attempts to tie health services more closely to local government, preferring instead to deal directly with central government (see Barbara Castle's discussion of this point in *NHS Revisited*, Fabian Tract 440, 1976). The continuing division therefore between social services departments, financed through local councils and the Treasury financed health service has acted as a potent disincentive to the development of support services. As long as local authorities could shift responsibility for supporting a handicapped person off the rates by admitting him to hospital, it had no compelling incentive to develop its local services. Similarly, while the hospital service was bolstered by apparent local authority demands for accommodation, it could continue to make powerful claims for funds from the Government. It is against this standard that the present Government's joint financing arrangement must be measured.

# 3. failures of policy: the white paper reconsidered

The long awaited White Paper on mental handicap appeared in June 1971, between the prospective re-organisation of the local social services and the NHS. Though its rhetoric suggested a renewed commitment to the Royal Commission's principles, its practical proposals conveyed hesitancy, caution and compromise. It called for a continued extension of the community care concept, but estimated that after 20 years a hospital population of 34,000 (about 56 per cent of 1969 levels) would be retained. It emphasised the importance of supportive services for mentally handicapped people and their families, but predicted that more handicapped people would go into residential care in the future. It exhorted local authorities to make greater efforts on behalf of the mentally handicapped, and called for greater collaboration between health and social services departments in planning services—but presented a spending programme heavily weighted in favour of modernising the hospital service.

## the case against hospital care

Nevertheless, the Government presented in the White Paper a strong case against the long-stay hospitals and their segregative pattern of care, noting that many institutions were too old, too large and too remote from their patients' communities. "Isolation also affects professional work, cutting off staff and patients from the rest of medicine, nursing and social work, and tending to inhibit the dissemination and application of ideas and methods, including methods of management, which have proved beneficial in other hospitals". Hospitals were overcrowded and under staffed, providing patients with little activity, privacy or amenity. More important, under such conditions "hospital 'treatment' is restricted to meeting the patients' most basic physical needs". The White Paper quoted extensively from the first report of the NHS's Hospital Advisory Service, which had attributed many problems in the hospitals to bad management: "These conditions are the fault of management at all levels, not of ward staff, and the latter are understandably resentful of

criticism they have sometimes received". The White Paper concluded: "Fundamentally, what has happened is that outdated views have continued to influence the allocation of financial and other resources to many hospitals for the mentally handicapped. In some places attitudes have not kept pace with new knowledge about the latent capacities of the mentally handicapped, public expectations of better services and the general rise in the standard of living. Too little account has been taken of the increasing burden placed on the hospital staff by changes in the make-up of the patient populations".

The significance of this explanation was its perception of the hospitals' problems in terms of a lack of resources. It followed that their solution must lie in the allocation of greater resources to the hospital service. The Government accordingly announced it was stepping up the interim programme to upgrade the existing hospitals begun in 1969 by Richard Crossman following publication of the Ely report. The White Paper also called for the construction over a period of years of new hospitals containing a maximum of 200 beds (based on local population bases of 250,000). Meanwhile hospital populations would be reduced by some 26,000 patients by the expansion of community residential provision.

It is difficult to argue with the decision to upgrade existing facilities, improving the conditions of life for people who have spent long periods in hospital and staff as well. But this would seem to be a programme that needs to be monitored closely, for the greater the investment that is made in the existing institutions, the more difficult it will be one day to abandon the large hospitals entirely in favour of a more integrative pattern of care.

Other elements of the White Paper might be questioned more basically. Nowhere, in the White Paper or elsewhere, did the Government present evidence supporting the decision to construct the new, 200-bed subnormally hospitals or, for that matter, the future hospital population of 34,000

people. The DHSS's own statistical studies seemed to show that the great majority of present hospital patients were not in need of medical treatment and possessed substantial capacities for self care. Of 64,000 patients in 1970, 78 per cent were ambulant, 70 per cent continent, 68 per cent had no behaviour disorders, and 58 per cent needed no assistance in feeding washing and dressing themselves. This is in spite of the fact that 59 per cent of all patients over age 5 received no education or training at all in hospital (see the *Census of Mentally Handicapped Patients in Hospital in England and Wales at the end of 1970*, DHSS, 1972). Even among the most severely handicapped patients, 54 per cent could care for themselves and were neither non-ambulant, incontinent or behaviour-disordered (the figure rises to 82 per cent when mildly handicapped patients are considered). These figures, quite obviously, are not in accord with public perceptions of mentally handicapped people in hospital. Periodically however an outsider penetrates hospital boundaries and reports on the inaccuracy of the public's stereotype. Thus, a sub-editor of a national Sunday newspaper expressed his surprise in the headline of a story about a number of elderly women who were confined in a northern hospital because they once had had illegitimate children: "Thousands of 'mental patients' are sane"!

In short, the White Paper represented a political compromise designed to protect the hospital service while encouraging community services to develop at their own pace over the longer term. Both Richard Crossman and Sir Keith Joseph, successively Secretaries of State responsible for the mentally handicapped, pursued seemingly contradictory policies during this period. They increased expenditures upon the hospitals while simultaneously promising that the hospitals' role in the total range of services would be diminished. These strategies were in part a response to political pressure; Peter Townsend has shown how in the period between the publication of the Ely report and the White Paper the medical and hospital lobbies closed ranks in response to external criticism (see "The

political sociology of mental handicap," in *The Social Minority*, Allen Lane, 1973). It also was symbolic of the political division between central and local government; a Secretary of State could not simply pronounce a renewed emphasis upon community care without greater implementation of this policy by local authorities. But it is also true that local authorities could not enlarge community provision without a redistribution of resources from the hospital service.

Absent from the White Paper was a recognition that the problems of the subnormality hospitals were more than financial: they are political and sociological expressions as well. They are political at the level of representing the division of relatively scarce health and welfare resources between competing groups, such as local authority social services department and the NHS. They are also political in representing the authority of some people over others. The segregative nature of the isolated mental hospital is a form of public expression regarding mentally handicapped people (see for example David J. Rothman's *The Discovery of the Asylum*, Little Brown, 1971). The physical separation of the hospitals' patients and medical and nursing staff from members of the general community contributed to conditions in the subnormality hospitals in the 1960s—conditions which undoubtedly would not have been tolerated in sectors of the health and welfare establishment that receive more public exposure. One of the poignant aspects of the Normansfield affair was the difficulty persons close to the hospital experienced in attempting to call attention to conditions there; it took an unpopular strike by members of the hospital's nursing staff to gain the attention of the general public and health administration. In addition the custodial pattern of hospital care traditionally has accorded substantial authority to professional staff members over mentally handicapped people and their families. The medical concept of "clinical autonomy" for example came under strong criticism from members of the Committee of Inquiry into conditions at South Ockendon Hospital: "The



history of one of the villas which was intended for medium security revealed a decline to a wholly unacceptable and completely unjustifiable way of life. The intentions of the consultant were good; he made no secret of what he was doing; but he lacked the experience to carry out the very difficult job required of him. He needed clear guidance from the Regional Hospital Board, but did not receive it; he required close questioning about his actions and intentions when the early fruits of the unjustifiable regime began to appear, but he seems to have proceeded on his way without challenge. We have seen in the history of this villa all the stultifying effects that can flow from an unimaginative subservice to the doctrine of the clinical autonomy of the consultant. The patients undoubtedly suffered because of it" (*Report of the Committee of Inquiry into South Ockendon Hospital*, HMSO, 1974).

The South Ockendon Committee concluded that "multi-disciplinary control" of treatment standards by professional teams would prevent reoccurrences. Similarly, after the recent report by the Committee of Inquiry at Normansfield hospital, improved monitoring procedures by health authorities were offered as preventatives. But these prescriptions seem to miss the point. Public scrutiny and demands for accountability seem at least as important in ensuring that handicapped people are able to enjoy similar living standards as those enjoyed by non-handicapped members of the community and the question becomes one of whether this can be accomplished in an isolated institutional setting.

The nature of the hospital organisation and its administrative chain of command presents formidable social barriers to meaningful reform of services. The White Paper encouraged hospital authorities to work toward the development of a community based service, with the smaller, 200-bed institutions as the focal points. However an assessment of health authorities' progress five years later concluded: ". . . the great majority of the new developments . . . either built, building or being planned are quite conventional

mental handicap hospitals, many of them in existing hospitals, some of them 'tacked on' to other hospital premises." Even where the new, smaller hospitals were being built, they hardly represented community care: "The new 'small' units of 180 beds or so . . . are likewise essentially hospitals and are situated on segregated 'mental handicap' campuses. It would be quite wrong to see them as developments of 'community care' in domestic-type accommodation . . . the overall conception of these developments has more in common with the 'colonies' of the past than it has with the communities and neighbourhoods in which non-handicapped people live" (*Plans and Provisions for Mentally Handicapped People*, Campaign for the Mentally Handicapped, July 1976).

The White Paper also strongly encouraged health and social services departments to collaborate in planning future services, and asked local and hospital authorities in each area to "fix a date after which the hospitals will not be expected to admit from that local authority's area, any more people who need residential rather than hospital care". The inquiry found after five years however that: "The failure of central government policy to be interpreted into action is nowhere more clearly seen than in relation to the 'local dates' to be determined for the cessation of 'inappropriate' hospital admissions on purely 'social' grounds. Only one Authority had set such a date, and even that Authority admitted that inappropriate admissions had nevertheless been made, where no alternatives were available" (*ibid*).

The case against institutional care has an economic aspect as well. There can be little question that an effective community care system, providing a complete range of service, can be developed only at great expense. But this understanding raises further questions with regard to the White Paper's emphasis on hospital expenditure. A study published by the Office of Health Economics argued that continued investment in the subnormality hospitals was draining off funds that might be spent more economically on community pro-

vision—thereby postponing the time in which community care might be considered a practical reality rather than a pious hope (*Mental Handicap*, 1973). And evidence from the United States, generated in a rigorous cost-benefit analysis by a federal government economist of American services for mentally retarded people, suggests that in the long term community based services may be less expensive than they appear: “a full-scale programme to deal with mental retardation is, however, an expensive undertaking that must be compared with other worthwhile uses of resources. Thus, we are confronted with a problem that involves a large use of resources and one cannot await a scientific determination of the optimal use of these resources. However poor the data may be, we must make the best use of it. The mentally retarded are human beings, with as much capacity for love, hate, hope, fear, contentment, frustration, and anger as any of us. Most of the retarded can live reasonably useful and happy lives if provision is made for their special needs” (Ronald Conleg, *The Economics of Mental Retardation*, Johns Hopkins University Press, 1973). Sheltered living arrangements, his study found, could be provided less expensively than large scale institutional care. Expenditures on employment programmes and rehabilitation services in the long terms generated greater incomes and less dependency. Comprehensive prevention programmes would reduce the incidence of mental retardation eventually as well as the need for other types of services. Investment in services aiding families of handicapped people could be considered a form of economic redistribution and in economists’ terms, be figured as transfer payments rather than social costs. “Altruism need not always be the motivating factor in providing developmental and supportive services to the retarded,” Conley concluded (*op cit*).

### financing the future pattern of care

Notwithstanding the White Paper’s continuing support for the hospital service, it also called upon local authorities to provide a social support service based

upon the families of handicapped persons. It admitted for example that “only a small start” had been made in providing these services: “Most parents are devoted to their handicapped children and wish to care for them and help them to develop to their full potential. About 80 per cent of the severely handicapped children and 40 per cent of the severely handicapped adults live at home. Their families need advice and many forms of help, most of which at present are rarely available . . . a handicapped child needs the affection and stimulating company which a family normally provides for its children.” Also, “Children living with their own families have been shown to be much less backward in social development than children of similar intelligence in institutional care.”

But when it came to concrete plans, the White Paper failed to support this rhetoric; its projections for the future described a service strongly resembling traditional patterns of care. Over a 20 year period, the number of children in hospital was expected to decrease by only 13 per cent, from 7,400 to 6,400 (assuming a stable birth rate see table on page 11). Considering all forms of residential care, the White Paper actually forecast a 15 per cent increase in the number of handicapped persons expected to need all forms of residential care including lodgings and foster care. In 1969, 134 mentally handicapped people were in residential care per 100,000 population; the White Paper’s projections boosted this to 155 per 100,000 population by 1991. (It should be noted that the White Paper’s figures on the numbers of handicapped people in residential care were in substantial disagreement between its table 1, “Incapacity associated with mental handicap” and the planning projections in table 5).

Examination of the White Paper’s pattern of expenditure demonstrates the ambiguity in the Government’s policy. While committed to a greater shift toward community care, the spending proposals were weighted towards propping up a hospital service that even the White Paper’s authors found “intolerable”. And

while local authorities were called upon to improve "domiciliary and other services to make it reasonably possible for families to keep mentally handicapped children and adults in their homes", funds under central government control were planned to be expended largely upon forms of residential care.

The White Paper's financial estimates were presented obliquely and were incomplete in many respects, largely because ministers could not predict local authority response to the policy statement or the pattern of local expenditure. The estimates seemed to indicate that the hospital service, beginning of course with a much larger base, would receive up to £130 million in capital funds over the 20 year period, at a rate of about £7.5 million per year. Local authorities were expected to make capital expenditures totalling £154 million on mental handicap projects during this period.

Revenue expenditure on the hospitals was expected to grow from £48 million in 1969-70 to £65 million five years later, and remain stable at this level over the long term. However, revenue expenditure on community services would increase at a rate of only £2 million annually from a base of £14 million, to an estimated peak of only £54 million after 20 years.

While the White Paper did not provide complete revenue figures for all types of services for comparable periods, the fol-

lowing statistics seem to best convey the Government's intentions (in 1971 prices): (i) In the five year period 1969-70 to 1974-75, revenue expenditure on the sub-normality hospitals was to increase at a rate of £3.4 million each year (ii) in the decade 1971-81, revenue expenditure split evenly between local authority homes and adult training centres was to increase at a rate of only £2 million annually from the same ten year period mental handicap's share of revenue expenditure on other local authority services, including domiciliary, was to increase at a rate of £0.5 million each year.

This third category included the recruitment of social workers, home helps, other staff for domiciliary services, increased use of foster homes, lodgings and sheltered housing, and day care for children under five years of age. In other words, the Government was forecasting increased expenditure on hospitals and community residential accommodation at a rate more than three times larger than combined spending on all other community services for mentally handicapped people—including adult training centres, relatively costly projects to build and operate.

The rationale for the low planned investment in domiciliary and other community services was uncertainty over their availability and use by the mentally handicapped and their families. Ministers did not feel it was realistic to establish goals that local authorities would not—or could

RESIDENTIAL CARE: NUMBER OF PLACES PROVIDED (1969) AND NUMBER REQUIRED (1991) IN ENGLAND AND WALES

type of residential care	children (ages 0-15)		adults (ages 16+)		total	
	provided	required	provided	required	provided	required
local authority, voluntary and privately owned accommodation	1,800	4,900	4,300	29,400	6,100	34,300
foster homes, lodgings, other hospital	100	1,000	550	7,400	650	8,400
in-patients	7,400	6,400	52,000	27,000	59,000	33,000
totals	9,300	12,300	56,850	63,800	66,150	76,100
shortfall	3,000		6,950		9,950	

source: *Better Services for the Mentally Handicapped*, Cmnd 4683, HMSO.

not—meet. But the White Paper's chief failure was that it failed to propose a method of assisting local authorities in developing these services; the broad separation between central government and local authority responsibilities remained unbridged.

It was also thought that because the services provided by social workers, home helps, play group organisers and similar staff benefit other groups as well, it was not possible to estimate how many of these workers would be needed by the mentally handicapped alone. Yet the lack of equivalent information about other services did not inhibit the Government's planners from making projections. Little consideration for example has been paid to the needs of mentally handicapped adults, either in applied or academic research. Parents of mentally handicapped children feel a growing insecurity as they witness the gradual development of services for children, but the lack of corresponding development for adults.

Even in communities with adult training centres there is a certain ambiguity regarding their role in the overall pattern of employment and education services, and their objectives for the handicapped individual. Are they truly training centres, attempting to advance the individual's social and occupational skills, preparing him for greater participation in community life? Are they sheltered workshops, with the emphasis upon obtaining and fulfilling manufacturing contracts with local industries? What are their links with community education, rehabilitation and employment services? Or are they merely centres for occupying handicapped people all day, providing them with a change of scene and rudimentary employment while offering relief to their families? Though the answers to these and other questions are still to be determined, the Government planned a threefold increase in adult centre places (to 73,500 places in the community). Later the DHSS contracted with an outside investigator to study the role of the adult training centre. Only recently with the publication of the National Development Group's pamphlet on day services for the mentally handi-

capped has the DHSS encouraged a discussion of the objectives of adult centres and moved towards issuing a revised model of good practice for local authorities to consider.

The White Paper not only forecast a greater number of people in some form of residential care; it also provided the impetus for the development of the 25 bed hostel for mentally handicapped people as the standard for measuring a local authority's progressiveness.

### homes, hostels and community care

The Seeborn Committee first saw the hostel as the preferred form of community residential care for the mentally handicapped. The Government in the 1960s was recommending foster homes or lodgings as the alternative to hospital (or hostel) care. But the comprehensive experiments with hostel care in the Wessex region, and the apparent intermediate quality of the community hostel between the custodial regime of the subnormality hospital and non-institutional care in the community seemed to appeal to the Committee as an appropriate compromise.

The White Paper in fact recommended "residential accommodation according to individual need" and listed many possible forms of accommodation for handicapped people: foster homes, lodgings, ordinary housing or group homes with social work support, in children's homes, in local authority homes for the elderly mentally infirm, or in hostels. But it also stated that hostels with a maximum of 25 beds (20 for children) "will supply much of the residential care needed" and further called for the substitution of the word "home" for "hostel" because of hostel's "ring of impermanence and . . . certain austerity."

Such pronouncements from the DHSS undoubtedly have a direct impact on local authority behaviour and thinking (see Nicholas Basanquet, *New Deal for the Elderly*, Fabian Tract 435, July 1975): White Paper recommendations acquire greater strength when a local authority

must approach the DHSS for loan approval of capital projects. The hostel recommendation also possessed a power of its own, due to the fact that of more than 92,500 people already in some form of local authority residential accommodation in 1972, more than 88 per cent were in institutions containing more than 31 beds (*Health and Personal Social Services Statistics for England*, DHSS, 1973). And a local authority building note (No. 8, *Residential Accommodation for Mentally Handicapped Adults*, published in 1973, encouraged local authorities to experiment with hostels with from 16 to 24 places. However, the cost allowance table showed that largest is cheapest, and this might account for the popularity of the 24 bed hostel as the primary form of community residential provision; of 32 approvals granted by the Government in 1974-75 for residential accommodation for mentally handicapped adults, 24 were for projects containing 24 or 25 beds. As one observer commented: "Experience of a wide variety of homes and hostels up and down the country suggests that the large hostel is becoming standard local authority provision for mentally handicapped people" (Alan Tyne, "Residential provision for mentally handicapped adults," *Social Work Today*, 10 June 1976).

Yet many questions must be asked about the suitability of the standard hostel. As Professor Kathleen Jones has noted, "Somehow the magic figure of 25 places has been arrived at as a suitable size. Yet very little research has been undertaken into the realities of hostel care, and I know of no study, empirical or theoretical, which suggests that homes for 25 people have an automatic social viability" (*Annual Conference Report*, National Association for Mental Health, 1973). The social relationships of hostels of different size and social organisation must be examined very carefully. To what extent do they resemble the family homes or other living arrangements of non handicapped people? How flexible and meaningful are staff/resident relationships and how much of an improvement are they over those found in traditional hospitals? (See Ann Shearer's *No place like*

*home*, Campaign for the Mentally Handicapped, undated, for an apt discussion of staff/resident relationship in different forms of accommodation for mentally handicapped people.) What kind of personal relationships are hostel residents able to maintain with their friends and relatives? Equally important are questions concerned with the integration of hostel residents with their community: are their links with the neighbourhood, local services, recreational facilities, employment services and the social life of the community improved over other forms of institutional and residential accommodation? Before the hostel can be advanced as the all purpose solution to the residential care problem of mentally handicapped people, these and similar questions must be answered carefully and positively. But if hostels are found to be no more than mini institutions in the community, it already might be too late to change course. Clearly the momentum is running in favour of the yet unproven hostel arrangement: "There is still too the element of civic pride in buildings. A hostel can be named after a local personage and provides scope for the borough's architect, and the parks and gardens department. It can also be built on land already owned by the corporation, and it's surprising how often this leads to a site next to the sewage works or the hospital, or in a complex of other 'deviant' institutions—reception centres or homes for the mentally ill. Hostels reflect our passion for investment of capital into property, rather than the less tangible revenue into people" (Tyne, *ibid*).

### views on handicap and the family

Domiciliary and other family support services are investments in people. But in spite of the White Paper's frequent admonishments that these services are crucial components of a community care system, the Government declined to set planning targets for local authorities. With regard to financial projections for domiciliary services, which involve little or no capital expenditure, the White Paper said: "... it has been assumed that as these other services develop up to £1 million

additional expenditure may need to be incurred in any one year, and on average expenditure will rise over the whole period by at least £0.5 million a year. The rate of development will depend on the possibility of recruiting certain types of staff such as home helps, or of finding suitable lodgings, the output of training programmes, and other factors some of which will be outside individual authorities' control."

This hardly was an inspiring charge to local authorities. But it was consistent with previous practice. Since the Royal Commission proposed a preventive community care system, no systematic evaluation has been made of the effects of different combinations of domiciliary services on families' capacities to cope with the problems of mental handicap.

No government paper or circular has outlined the content or appearance of a domiciliary service. Even the DHSS's elaborate project on the "development and evaluation of modern community-based services" in Sheffield ignored this important variable: the effect of domiciliary and other services on the "need" for residential care. The Department of Health has steadfastly refused to assume leadership on this issue; even its request for the submission of ten year development plans from the new social services departments in 1972—seemingly an excellent opportunity to establish standards of care—neglected to outline the practical form of a domiciliary service (DHSS Circular 35/72).

### **the lack of information**

In a sense the DHSS misses this opportunity every year. Statistics collected by local authorities on their operation are determined largely by the information requested by the DHSS (M. Bone, B. Spain and F. M. Martin, *Plans and Provisions for the Mentally Handicapped*, George Allen & Unwin, 1972). Central departments therefore might construct more useful indices of the quantity and quality of local provision through the annual mental health returns—equivalent to the

revealing data on the subnormality hospitals, their patients and services published by the DHSS in recent years.

The present mental health returns are more remarkable for what they fail to tell us: they say how many social workers or home helps are employed by local authorities, but not how many lend assistance to mentally handicapped people and their families. They tell us how many handicapped people attend adult training facilities or live in community hostels, but not the number benefiting from the provision of housing aids or adaptations, incontinence services or going on holidays paid for by authorities. They provide crude estimates of the numbers of handicapped people using various services, but not the extent of overlapping between services, the severity of handicap of the people served or, most important, the numbers not receiving these forms of help. The conclusion seems inescapable that present returns are highly insensitive indicators of the quality of local authority services for mentally handicapped people.

Evidence from other sources however suggests that community services have helped relatively few families since the Royal Commission's report. Only the provision of special school places has approached demand for them, and the White Paper conceded that about 1,800 children were still on waiting lists in 1969 and that provision varied widely from one authority to another. In a sense, this policy of developing special school provision for mentally handicapped children is reaching fruition just as current thinking is abandoning it. The trend is toward providing education for handicapped children within conventional schools; in April 1977 for example the American Department of Health, Education and Welfare issued regulations stipulating that all handicapped children, regardless of the nature or severity of handicap, are entitled to a free public education appropriate to their needs, and these children "must be educated with the non-handicapped in regular classrooms to the maximum extent possible". In 1969, only half of the adult centre places required were provided (White Paper). A report in 1970

said that less than one half of one per cent of cases served by the home help service were families of the mentally ill as well; see *The Home Help Service in England and Wales*, Government Social Survey, HMSO). The shortage of trained social workers, particularly those with knowledge of mental handicap, has been well documented. Studies of families with handicapped members repeat this picture: the mentally handicapped apparently have been a low-priority group in the expansion of community health and welfare services (see for example M. J. Bayley, *Mental Handicap and Community Care*, Routledge & Kegan Paul, 1973, or Olive Silver and Peter Moss, *Mentally Handicapped School Children and Their Families*, Liverpool Education Department Child Guidance Clinic, 1972).

One consequence of this lack of domiciliary provision is that gross disparities exist across the country in terms of the number of people from different local authorities who are resident in sub-normality hospitals. The national average in 1970 was 131 patients in hospital per 100,000 population, but English boroughs had an average of 153 patients, with a range of 24 to 294. Lincoln had about ten times as many handicapped patients in hospital as Tynemouth. The average for London boroughs was 129, with a range of 67 to 240; Tower Hamlets had four times as many patients as Bromley. English counties averaged 103, with a range of 36 (East Riding of Yorkshire) to 159 (Devon) (*Census, op cit*). Many explanations could be offered for these disparities—changes in local authority boundaries or hospital catchment areas, the play of historical factors such as the evacuation of handicapped children during the war years, or varying incidence of mental handicap itself. But there also is a suggestion here that these figures are representations of the quantity and quality of community services provided by the local authorities of these hospital patients. As recently as 1976-77, 33 local authorities and 19 London boroughs still had no residential places of their own for mentally handicapped children and nine authorities had no place for handicapped adults

(Nicholas Bosanquet, "Services for the mentally handicapped," *Nursing Times*, 27 October 1977).

The implication is that as long as mentally handicapped people are living with their families—or elsewhere in the community—they are a low priority group in the distribution of services. Considering that 80 per cent of handicapped children and 40 per cent of adults live in their family homes, the Government's balance of expenditure seems ill judged indeed. The White Paper's pattern of future services was based upon a number of DHSS-sponsored epidemiological studies of mental handicap, including the numbers of handicapped people in institutional care. But these figures must be considered only as very provisional estimates. Changes in the birth rate and the rendering of effective support to families will affect the number of residential places needed in the future.

Implicit in the White Paper's pattern of services—in spite of rhetoric to the contrary—was a familiar administrative attitude expressing a lack of confidence in the family as an institution and its ability to withstand the pressures wrought by mental handicap. This attitude is represented by the development of a "minimum" level of service, one which emphasises residential accommodation as a substitute for the family and its own resources. It also is evident in the reliance placed upon casework that features interpretations of behaviour rather than the co-ordination of supplementary services by social services departments. This is due largely to the scarcity of resources available to provide direct assistance (see for example Michael Brill's account of the difficulties of the Seebohm worker in supplying maintenance services following re-organisation of the social services departments in the *Year Book of Social Policy in Britain*, 1971). Where goods are in short supply, members of the family seeking assistance too often find that they are subjected to an exercise in family pathology which is concerned not with how the family might be helped, but the essentially negative issue of the morbid effects of mental handicap on family or-

ganisation. As Eugene Heimler described these effects: "... there is a grave risk that the parents' relationship with the child will be disturbed. If they become aware of their feeling of guilt, they very often over-protect the child. On the one hand this often hinders his development by cultivating an unnecessary degree of dependency; on the other hand they may make quite exorbitant sacrifices, often at the expense of their own mental health and sometimes that of the other children. If they are unable to face their guilt they may simply reject the child, withdrawing their affection from him. They feel guilty at having produced a subnormal child, and this sense of guilt is often the driving force behind their behaviour. It makes them over-critical and over-sensitive, sometimes to a pathological degree. These mothers are desperately in need of help, attention and care. It is society's responsibility to help them by relieving them of the burden of their guilt, so that they do not destroy either themselves or their marital relationships" (*Mental Illness and Social Work*, Penguin, 1967). This passage is quoted at length because it illustrates the ease with which nearly any behaviour exhibited by the parents of handicapped children can be explained solely by the fact that they have a handicapped child. If parents sacrifice to keep their child at home, they are endangering their mental stability of their non handicapped children. If they seek residential care, they are rejecting the child. If they try to stimulate him, they are not accepting reality; if they cater to his whims, they are contributing to his dependency.

The emphasis upon family pathology is symptomatic of contradictory attitudes toward mentally handicapped people and their families that find expression in professional ideologies in social work, medicine and nursing, psychiatry, and also in official policy. Traditional values uphold the sanctity of the family unit, perhaps unfairly, and parents who seek residential care are chastised for "rejecting" their child. Yet we are aware also of the potential borne by the presence of handicap for disrupting what are considered to be "normal" family relations: the popular and professional literatures are littered

with references to broken marriages, guilty or inadequate parents, neglected siblings, overprotective families, and other stressful phenomena that are said to occur when families attempt to accommodate their handicapped member. Many professionals advise parents to admit their child to institutional care with the hope of maintaining the integrity of the family unit; many parents refuse their offer for similar reasons. Yet the family is not a perfect institution, nor is it exempt from the pressures of change and modernization. What is needed is closer examination of the forms of family unit that can offer the affection, protection and linkage to the surrounding community that are needed by handicapped people, and official recognition of the role of those families in provision of services.



## 4. labour and mental handicap

When Labour returned in 1974 it had little room for manoeuvre: realignments of local government and welfare services had already taken place, the National Health Service reorganisation was only a month away and familiar pressures on public expenditure inhibited discussion of ambitious reforms. With regard to mental handicap, ministers recognised that these reorganisations had not dealt with the clash between medical and social philosophies and were unlikely to engender the collaboration between health and social services authorities necessary to make even the White Paper's modest proposals workable. As Barbara Castle noted: "But whilst there is rationality about the division of responsibilities generally between say the National Health Service and local authority social services, I think we should be frank and admit that the boundaries appear the least rational, the most arbitrary where the mentally handicapped are concerned" (NSMHC conference speech, *op cit*). Mrs Castle and Dr David Owen, then her Minister of State, apparently gave consideration to radical recastings of services, such as by creating a national, centrally financed mental handicap service with a "social service and not a sickness service" orientation (by combining the hospitals with local authority services, as proposed by the Labour Party's 1973 Green Paper, *Health Care*) or by transferring the subnormality hospitals to local authority social services departments. However, fearing the upheavals that might be caused by another juggling of services and responsibilities and probably inhibited by its costs as well, their eventual decision was to "reaffirm the philosophy and general approach of the White Paper" (*ibid*).

Since then the Government's policy on mental handicap has had two limited elements: first, attempts to maintain mental handicap's share of reduced levels of public expenditure, and second, efforts to encourage greater efficiency and co-ordination in the development and delivery of services. In spite of the tepid nature of the Conservative Government's White Paper, there is no indication that fundamental reforms of the mental handicap

services have been given further consideration. Moreover official statements have warned that reforms will be contingent upon brightening of the economic picture: "There is increasing public and professional recognition that the scale and quality of the health and personal social services depends on our national economic performance, along with all the other main public services and so many other aspects of our national life. We cannot insulate the financing of health care or the personal social services from the economic facts of life" (David Ennals, Medical Journalists' Association speech, *op cit*).

But the economic facts of life have not been much kinder to the mental handicap service under the Labour Government than under previous administrations. Originally, the Government suggested in the 1976 DHSS Consultative Document (*Priorities for Health and Personal Social Services*) that a number of services, including mental handicap, needed special protection from the slowdown in public expenditure. Average growth rates in current expenditure for these priority or 'cinderella' services were: services used mainly by the elderly and younger physically handicapped people 3.2 per cent, services for mentally handicapped 2.8 per cent, services for children and families with children 2.2 per cent and services for the mentally ill 1.8 per cent.

Gains in these services were to be financed by cuts in the growth rates of others—in particular, the acute, general and maternity hospital services—and by reduced dispensation of drugs. In the words of the Consultative Document: "Such a pattern of distribution would broadly maintain the rate of progress towards the targets set out in the White Paper of 1971 on the Mentally Handicapped and the recent White Paper on Mental Illness." However it should be pointed out that these services for mentally handicapped people grew by 8 per cent per annum between 1970/1 and 1973/4. That their growth rate could be cut by nearly two thirds yet maintain the White Paper's timetable further emphasizes the White Paper's timidity. Ministers responsible for mental handicap ser-

vices in Wales took a more pessimistic view in their corresponding document: "... in view of the difficulties which social services departments will be facing in the next few years, Ministers have reluctantly concluded that growth in these services will be considerably reduced, *although progress towards the realisation of the aims of the 1971 White Paper will be resumed in full as soon as resources become available*" (emphasis added).

Amid indications that the development of new facilities was falling behind the White Paper's targets, the Government issued another statement on health and social services priorities late in 1977 (*The Way Forward*, DHSS, HMSO). In spite of further cuts in public expenditure, the Government's aims, the document said, remain broadly the same: "... to remedy past neglect of services, particularly those for the mentally ill and the mentally handicapped." But it was apparent that this strategy was running into difficulty; the expected transfers from the acute and general hospitals were not occurring and in some circumstances, expenditure on these services might need to be increased.

The best indication however that the White Paper strategy was being compromised by the needs of the hospital service was provided in an appendix in which regional health authority strategic plans were reviewed: "All regions foresaw slow progress in providing district based services for the mentally ill and handicapped and in closing large psychiatric hospitals. There were widespread doubts about the ability of local authorities, despite joint financing, to provide residential and day care services for those groups. Most regions still had large institutionalised populations. Several commented on the increased revenue cost of providing treatment in smaller centres. But the main problem appeared to be a conflict, at least in the shorter term, between the priority for services for the mentally ill and mentally handicapped proposed in the consultative document, and the pressures on regions to invest in acute services" (Appendix II).

Within local authorities as well there

are conflicts between social services expenditures on domiciliary and community-care services, on capital investments on residential facilities for the mentally handicapped and mentally ill, the elderly and physically handicapped people. Rather than promoting an expansion of community care services, the term of the current Labour Government has seen the balance shift somewhat toward spending on residential accommodation; between 1974-5 and 1976-7, the net share of personal social services expenditures devoted to residential care by local authorities has grown from 44.8 to 46.2 per cent, while community care spending has dropped from 24.6 to 22.9 per cent (*The Government's Expenditure Plans, 1978-79 to 1981-82*, Cmnd 7049-11, HMSO, 1975).

### the joint financing scheme

In this context, the Government's joint financing scheme, announced in 1976 and revised the following year, must be watched carefully. Joint financing is meant to provide a financial incentive for health and social services authorities to collaborate in planning and delivering assistance to groups such as the mentally ill and mentally handicapped, the physically handicapped and the elderly. There already is a statutory obligation upon these authorities to co-operate in this manner under the NHS Re-organisation Act 1973, but this linkage has failed to develop. As Mrs Castle said in her NSMHC speech in 1975, "... we must be disappointed that there has not been that dramatic change in attitudes nor, as a consequence, that improvement in collaboration and joint planning between health and local authorities which was, and is, central to the full success of the White Paper's strategy".

The Government's strategy has been to foster the creation of a bewildering array of consultative and planning teams to develop these improved attitudes and better co-ordination: the National Development Group for the mentally handicapped (NDG) and Development Team (DT) at the DHSS level, joint care planning teams

(JCPTS) and sub-groups in appropriate specialities—such as mental handicap—on the Area Health Authority (AHA) level, and district planning teams (DPTS) to assist the district management (DMTS) in health authorities. These are in addition to the joint consultative committees (JCCS) established in 1974 to advise Area Health Authorities and local authorities on their performance. To give all this collaboration an edge, the Government has announced that funds would be available—up to £43 million in 1980/81 in capital and current financing for joint planned projects.

Under this plan, health authorities are permitted to provide, from their own resources, capital funding for selected social services projects, funds to underwrite the operating costs of these or other social services projects, or special arrangements giving local authorities the use of National Health Service land or property. The criterion to be used by health authorities in making the decision to provide this assistance is that the authority is satisfied that the "spending is in the interests of the NHS as well as the local authority, and can be expected to make a better contribution in terms of total care than if directly applied to health services" (DHSS).

The joint financing plan provides a method of transferring central government funds to local authority social services departments. It also places the onus upon local authorities to develop services and assume the future costs of their operation. The joint financing circular recognised that in the current economic situation many local authorities would be reluctant to make heavy capital investments without assurance that they could bear the operating costs in the future. Therefore, "... it will be appropriate for a significant proportion of these funds to be directed to support of revenue activities not requiring capital investment. In these circumstances, joint financing assistance may be used to maintain existing personal social services which might otherwise be at risk, or to support capital projects already begun by LAS". So if used imaginatively, the joint financing scheme could be used to

develop non capital domiciliary services to prevent or postpone the need for institutional admissions.

It remains to be seen how the joint-financing plan will work in practice. An early assessment of the scheme published by the Disability Alliance, found that while some health authorities and social services departments were taking advantage of it in developing innovative domiciliary and non-institutional services, in other areas, "the joint financing scheme seems to be adding to the pressures to institutionalise larger sections of the population, or, at least, provide an alternative form of institution for those who would previously have been cared for within the hospital system" (*The Choice Between Family Support in the Community and Segregation of Client Groups in Residential Institutions*, 1978). It might be questioned whether local authorities possess the imagination or means to take full advantage of the plan, or whether the health authorities will concede that it is in the public interest to develop non-medical, non traditional services in the community as a matter of high priority.

Finally one of the reasons why joint planning has not taken place in the past can be traced to differences in philosophies and professional approaches between the medical and social services establishments toward the care of groups such as the mentally handicapped. Also it might be questioned whether the recurrent cuts in public expenditure might dampen these collaborative efforts, leading health officials to protect the hospitals and the rest of their territory. These questions will be answered only as the joint financing scheme develops and future expenditures on health and the personal social services might be compared.

## 5. beyond community care

When plan is laid upon plan, reorganisation upon reorganisation, one sees that the weakening of the "community care" ideal has been the distinguishing feature of social policy for mentally handicapped people in the 1960s and 1970s. There have been improvements in traditional services, to be sure, and uneven development of some community services. This is not surprising: the succession of Elys, Farleighs, South Ockendons, Whittinghams and Normansfields was bound to stimulate changes of some magnitude in a clearly out moded system of care. Yet these marginal developments should not be over estimated: they cannot be mistaken for the radical transformation of policy that conditions demanded and optimistic rhetoric promised. And few would argue that they have been a liberating influence on those traditionally shunted from the community for disability of mind.

A curious footnote to the period has been the performance of Labour with regard to the mentally handicapped. The 1964-70 Government not only presided over the storm of publicity regarding conditions in the subnormality hospitals, but in the late 1960s actually cut local authority loan approvals for training centres and residential provision for the mentally handicapped (Nicholas Bosanquet, "Inequalities in health," in *Labour and Inequality*, Fabian Society, 1972). Despite Richard Crossman's tireless campaigning in demonstrating the need to improve conditions for mentally handicapped people and his implementation of stop gap measures to reduce the inequalities between the subnormality hospitals and other institutions, the Labour Government's long term policy on mental handicap failed to emerge before its defeat in the 1970 general election. In view of these past performances it is peculiar that the present Government would be satisfied with a reaffirmation of the Conservatives' conception of reform.

The victims of this failure in policy are of course mentally handicapped people. What is not clearly understood is that a policy can be successful in improving living conditions of handicapped people,

yet fail to forge the desired links with non-handicapped members of the community. Segregative aspects of life in the long-stay hospitals are familiar, and no one has yet demonstrated how the expensive upgrading programmes will lessen the social isolation of hospital patients' lives.

While the recent report of the National Development Group for the Mentally Handicapped made many important recommendations to the Government regarding the mental handicap hospitals (among others, that an independent inspectorate be established to inspect all services for mentally handicapped people; that a more radical shift be made from hospital to community services; that a method be found to earmark central government funds for local authorities for mental handicap services; and that the role of the mental handicap hospital should be reappraised by the Royal Commission on the National Health Service), it failed to explain how a hospital can be "first and foremost a home" for people who live there (*Helping Mentally Handicapped People in Hospital*", DHSS, 1978). No amount of domestic upgrading, staff training and attention to minimum standards will create the pattern of personal relationships, continuity and familiarity that characterise real homelife. Mentally handicapping conditions are not medical conditions, and no one has explained yet why hospitals, whether they have 200 beds or 2,000, are appropriate places for mentally handicapped people to live out their lives. But in addition a growing body of research is describing how deprivation and handicap restrict persons already living in the community from full participation in community life.

With mentally handicapped people and their families this means sharp restrictions of choices in living, working, education, economic and domestic decisions that not only isolate the handicapped person, but restrain those living around him.

An effective policy must not only provide accommodation and occupation; it must go beyond present conceptions of "community care" to deal as well with the wider issue of the enhancement and pro-

tection of the handicapped person's place in the community.

The principles underlying an authentic community care policy are, ironically, familiar: they were formulated and elaborated upon in the report of the Royal Commission, and many were incorporated in the "general principles" near the beginning of the White Paper. They can be summarised as follows.

### **principles of community care**

*Community care is a social, not a medical concept.* Traditional patterns of medical care, with their suggestions of sickness, ill health and abnormality, are inappropriate models for the care of mentally handicapped people because mental handicap itself is a disability, not an illness. Supporting services therefore should concentrate upon the effects of this disability, seeking to contribute to the individual's social development and ability to participate in the life of the community. This concern with the functional consequences of mental handicap suggests that opportunities for sharing domiciliary and community occupational, transport, and domestic services by elderly, physically handicapped, mentally ill and mentally handicapped people should be investigated and implemented wherever possible. This new emphasis upon the severity of a person's disablement as the criterion to be used in allocating services might rationalise demands for the creation and expansion of services and lessen the likelihood of competition for scarce resources between representatives of various populations in need of assistance. medical needs of mentally handicapped people should be met by the same medical resources used by non-handicapped people, and should not be used as a rationale for the long-term separation of the handicapped person from the community.

*Community care aims to integrate handicapped and non-handicapped people.* Specialised, segregated services for mentally handicapped people have in the past meant inadequate, under-financed ser-

vices. They have been stigmatising also, emphasizing differences between handicapped people and other people rather than their similarities. Services should therefore be based in the local community and seek to preserve the handicapped person's links with his family, neighbourhood and community. Whenever possible, handicapped people should use the same services and community resources as ordinary people. Community services should be provided regardless of severity of handicap. Inequalities between handicapped people should not be created by the provision of community facilities for the most able and institutional care for the most handicapped.

*Community care is preventive and regularly applied, and it not crisis oriented.* Traditional services have served as an alternative to the family: the State assumed responsibility for the handicapped person when the burden of care became too great for the family to bear alone. Community care recognises family units as the keystones of the care system and offers regular assistance, guidance and specialised skills that reinforce the family's own efforts. Residential accommodation in small, domestic units or ordinary housing in the local community also is an important element of community care. Residential assistance can be used as short term care, to provide relief; as accommodation while the handicap person receives specialised training or medical treatment; as a family substitute for handicapped people without families of their own, or as an aid to the natural progression of the family cycle when the handicapped person wishes to leave his home to lead an independent or semi-independent life.

### **proposals for community care**

A new community care policy must begin with the abandonment of the 1971 White Paper. Its replacement should contain a cogent statement on the needs of mentally handicapped people and discussion of the ways in which these needs might be met. This would take the form of a national development plan for the men-

tally handicapped, setting objectives for family support, assessment and education, residential accommodation, income maintenance and the long-term issue of vocational rehabilitation and training. It should outline responsibilities of central government departments concerned not only with health and the personal social services, but housing, education and employment as well. The development plan should contain an analysis of the causes of past failures in this area of public policy; a discussion of views on the role of mentally handicapped people in modern, industrial societies; consideration of the rights of handicapped people; an elaboration of the philosophy underlying its objectives and plans, and an expression of renewed commitment on the part of central and local government to community care.

The national development plan would be only an initial step however. Other actions must be co-ordinated with it to create an effective community care service:

1. The DHSS should commission or carry out a national census of mentally handicapped people in the community to supplement corresponding data in earlier censuses of handicapped people in hospital and residential care. The census should collect detailed information on the living and family circumstances of handicapped people, the nature and severity of their disabilities, their instrumental needs, and their use of and experience with the health, social, education, training and employment services in their communities. Such census data would be useful in many respects, furnishing estimates of the extent of unmet need, an assessment of present community services and reliable information on the disparities in services between communities and regions.
2. As an urgent matter, the Government should publish a target date for the closure of all specialised hospitals for the mentally handicapped. Because of the size of the investment involved, health authorities should be given lengthy notice that in the future all handicapped people, even the most severely handicapped needing medical supervision, will be cared for

in their own communities. Proposals such as the ten year plan prepared by the Northumberland Health Care Planning Team to replace all hospital care with domiciliary services and housing in small residential clusters deserve every encouragement. Further expenditure in the long stay hospitals should be restricted to filling staff needs and developing training and occupation services.

3. As a step toward (2), the Government should announce that all mentally handicapped children aged 15 and under will be transferred from long stay hospitals within four years, and no further permanent admissions should take place from this group. Where conditions permit, children should be given the opportunity to return to their family homes, aided by full social support services. The remaining children should be placed in foster homes, local authority children's homes or in small residential units in their own communities.

4. Any programme that phases out the long stay hospitals must also find methods of redeploying present hospital staff in the community to take advantage of their particular skills in caring for mentally handicapped people. Training, occupational and rehabilitation staff might be attached to community-based training centres or workshops. Nursing staff with appropriate retraining could staff small community homes, short term care facilities or act as an in-home consulting service for families with handicapped members. A system of positive benefits should be developed to encourage hospital staff to transfer to community services without loss of seniority and employment status. Training programmes will have to be remodelled to prepare staff to work in the community rather than residential situations. The recent proposal by the Secretary of State for Social services for more child-care training for hospital staff should be questioned on the grounds that their specialised skills should be applied in the community; child-care training for hospital staff presumes that handicapped children will continue to be admitted to institutional accommodation in the future—and will make attempts to reform

present services for the mentally handicapped even more difficult.

5. At the earliest possible date the Government should enact a comprehensive disablement income and allowance system, paid to mentally handicapped persons (as well as other disabled people) as a matter of right on the basis of severity of handicap. Such a programme would provide recognition of the substantial costs incurred by families in maintaining a handicapped person in their home, and the restricted life chances and employment opportunities of the handicapped adult.

6. To replace the hospital system, the Government should initiate a programme for channelling the financial means to local authorities to develop community residential, training and support services for the mentally handicapped. The programme must be generous enough in scope to emphasize the predominant role of the social services department in co-ordinating and delivering services. Departments might be encouraged to establish case registers of mentally handicapped people and their needs. Direct grant payments might be made to local authorities in proportion to the size of their case registers, or by increasing the rate support grant.

7. The DHSS should prepare and publish a long-overdue circular outlining the standards and specifications of a domiciliary care service for handicapped people. This should emphasize the importance of regular social work support when it is backed up by instrumental assistance. This assistance would include a comprehensive assessment and reassessment programme that is connected to appropriate medical, educational and training services; places in ordinary day care or day nursery facilities; a crisis-help service, perhaps based in a cluster of residential accommodation on the Northumberland model; a respite or short term care service provided either in the home or in community residential facilities; better use of the home help service; housing aids and adaptations under the Chronically Sick and Disabled Persons Act, and

transportation assistance where needed. The DHSS might fund demonstration projects on the creation and use of particular services, such as different combinations of domiciliary services, methods of organising voluntary groups in the neighbourhood and community to assist handicapped people and their families, fostering of handicapped children, the use of local authority children's homes by handicapped children, and similar community support programmes.

8. Cabinet Ministers responsible for housing and the social services should prepare jointly a blueprint for future community residential provision for mentally handicapped people. This housing programme, in accordance with the community care principles described earlier, should be locally based and flexible. Its emphasis should be on small domestic units. Lodgings, ordinary flats and houses, and converted sheltered housing should be used whenever possible. Central government departments should use their loan sanction authority to disapprove large, purpose built developments that stigmatise their residents.

9. To underscore the importance of domiciliary support, the DHSS should revise its current mental health returns, seeking information from local authorities on the basis of the individual handicapped person (a client based reporting system) rather than on the basis of the services provided (service based, aggregated returns). These returns, which could be collected every second or third year rather than on an annual basis, would provide more sensitive data on the numbers of handicapped people served by each authority, their disabilities, their family circumstances, their needs and services received.

10. Joint consultations between the central government departments of health, education and science, and employment should be initiated with the aim of developing occupational, training and employment goals for mentally handicapped people. Consideration should be given to such issues as which department should bear responsibility for the local authority

adult training centre and what should be accomplished there, the appropriate school-leaving age for mentally handicapped children, whether an employment assistance service should be established to aid mentally handicapped people, and the best method of developing opportunities in ordinary employment situations for handicapped people.

11. Efforts should be made at all levels of government, in all departments, to enlist the participation of mentally handicapped people and their families in the making of policy decisions regarding their lives and futures. Past decisions have been made in a patronising manner, with little consideration of their desires. In addition administrative re-organisations of the health and social services left relatively little latitude for democratic consultation and consumer expression. The experiences of Campaign for the Mentally Handicapped in conducting participation conferences with mentally handicapped people suggest that they are able to speak for themselves; it is time to give them a voice in matters that determine the course of their lives (see the 'Our Life' 'Listen' conference reports, Campaign for the Mentally Handicapped, 1972 and 1973).

Certainly implementation of these or other proposals leading toward a radical transformation of policy on mental handicap will require substantial public investment. But the additional costs may not be as great as one might imagine. Mentally handicapped people constitute a relatively small group in terms of the total society. And the central element of such a policy would entail a reallocation of funds, staff and other resources from the hospital services to local authorities, from increasingly expensive and out-moded institutional provision to forms of public expenditure with lower capital costs and debt interest. Also, evidence from other countries such as the United States and Sweden, indicates that current investments in occupational and rehabilitation programmes and housing services for handicapped people have long-term returns in productivity and decreased social costs.

But investments in mentally handicapped people should not be justified solely on

grounds of economic costs and productivity. This is a question of equity as well. Expenditure on services for the mentally handicapped traditionally has lagged behind the spending on services enjoyed by non-handicapped members of the community. A compassionate policy must recognise that years of neglect of these services eventually must be paid off. In the end it becomes a question of the strength of our moral commitment to restore mentally handicapped people to the general pattern of life in the community. Richard Titmuss's warning is as appropriate today as it was in 1961 when he wrote "We may pontificate about the philosophy of community care; we may feel righteous because we have a civilized Mental Health Act on the statute book; but unless we are prepared to examine at this level of concrete reality what we mean by community care we are simply indulging in wishful thinking" (*Community Care: Fact or Fiction?*).



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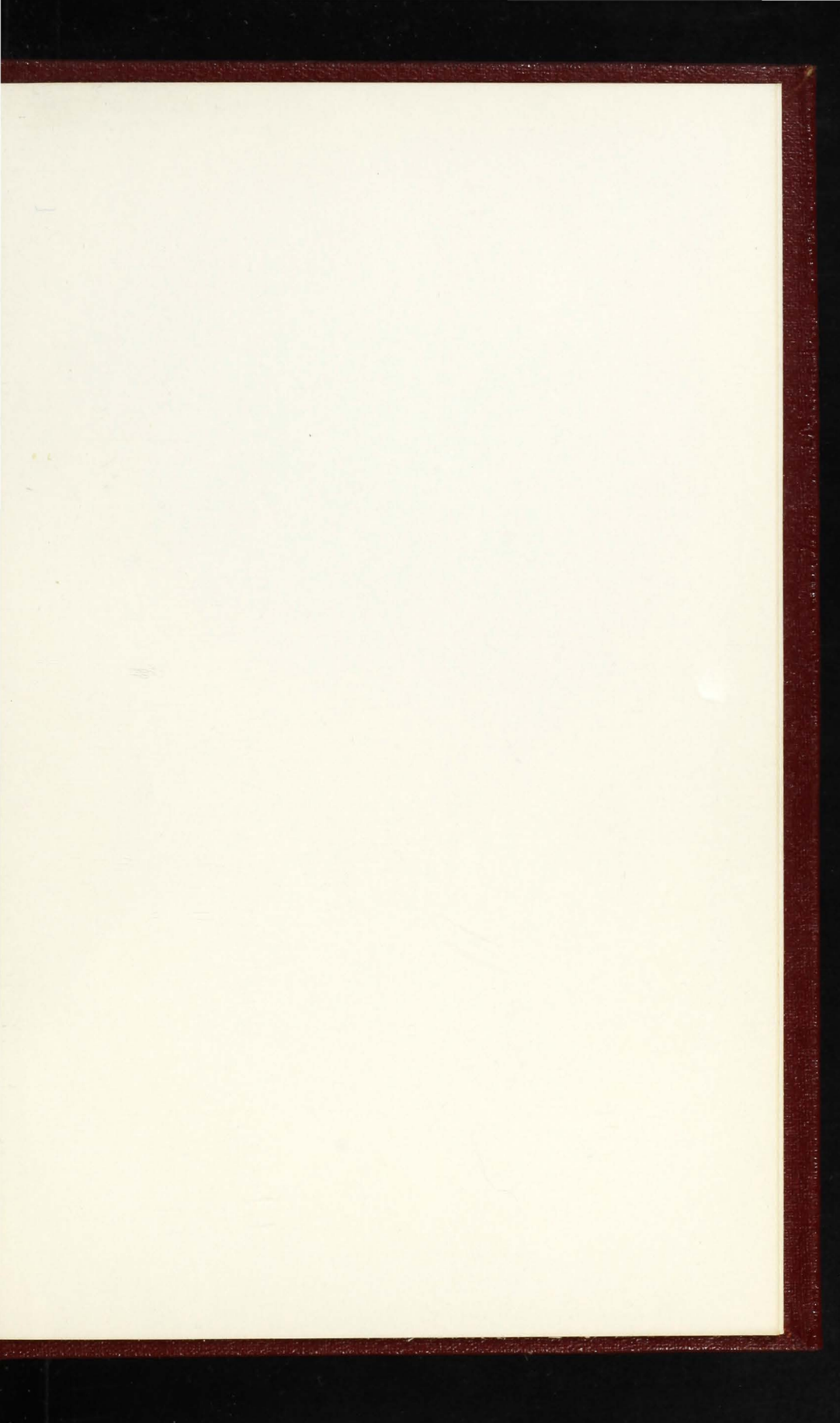
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