ECONOMIC ASPECTS OF CARE FOR INDIVIDUALS WITH LEARNING DISABILITIES

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INTRODUCTION

This report was commissioned from the King's Fund Institute by the National Development Team for Mentally Handicapped People. Against the background of profound change now affecting the British health and social care system it examines economic aspects of the support of people (particularly adults) with severe learning difficulties in England, and their implications for future service development. It briefly outlines ideas and data relevant to:

- * the evolution of service funding and delivery.
- * the nature and role of economic analysis.
- * the findings and implications of recent studies on the (UK) delivery of care for people with learning disabilities.
- * future policy options and the outlook for the learning disabilities service sector during the 1990s.

It is hoped that the report's contents will be of interest to, and will facilitate discussion between, a range of service purchasers and providers in the health and social services. These include NHS Regional and District General Managers and local authority Directors of Social Services; finance directors and business managers, including those in NHS Trusts; unit and patch managers concerned with services relevant to the needs of consumers with learning disabilities; and those in other leadership roles with responsibilities in this context, including members of health (RHA, DHA and FHSA) and local authorities.

No review document of this sort could reasonably aspire to be entirely comprehensive in its coverage, or to be able to provide unequivocal answers to questions like 'how much ought our society to spend on care for people with severe learning disabilities?' But it does seek to identify significant issues, and point to probable ways forward towards desirable outcomes. For example, one of the most important general messages to be derived from Western economic theory is that the achievement of consumer sovereignty is one of the single most important steps towards ensuring economic efficiency.

The material reviewed during the preparation of this document suggests that this is also likely to be true in the specific context of learning disabilities; investing service users, their families and their immediate agents with more information about and choice between different forms or sources of support is likely to promote increased welfare and better value for public (and private) money spent. The fact that there are particular problems associated with extending 'consumer sovereignty' in the learning disabilities arena does not mean that it is not a worthwhile end. Indeed, overcoming barriers to it may be considered one of the essential purposes of care for people with learning disabilities in Britain in the 1990s.

SERVICE DEVELOPMENT SINCE THE 1960s

During the last 20 to 30 years the shift away from large institution based support for people with learning disabilities (and other forms of long term disability) has tended to dominate the service development agenda in Britain. There has also, of course, been a significant movement in support of other forms of 'normalisation', both in ideological and practical terms. And there have been variations in the rate of change - in Scotland there has been a relatively slow decline in reliance on traditional institutions. Nevertheless the main drive of policy since the Ely Hospital scandal of the 1960s and the publication of the White Paper 'Better Services for the Mentally Handicapped' in 1971 has been towards developing better alternatives to the large mental handicap hospitals.

In the last decade increasing attention has been paid to 'ordinary life' approaches to the support of people with very severe learning disabilities and/or challenging behaviours. The provision of more normal housing and the vigorous pursuit of objectives such as involvement in everyday community life and gaining individual skills, dignity, and choice has improved the quality of life enjoyed by a significant proportion of service users. Part of the pressure towards this development, however, stemmed from awareness of the limited success of other efforts to enhance care standards, including those pioneered in 'mini-institutions' in areas such as Wessex in the 1970s.

Statistical indicators provide evidence of substantive progress in reducing the hospital population and increasing community based provision, albeit that the nature of the residential care available outside hospitals still varies from large, relatively isolated, units to smaller ones in more normal settings. Between 1971 and today the English mental handicap hospital and larger NHS unit population fell from 57,000 to around 26,000. In the same period the number of Adult Training Centre places rose from 25,000 to some 55,000. Most dramatically of all the number of people aged under 16 in traditional mental handicap hospitals has fallen to virtually zero, compared with over 5,000 in the early 1970s.

It would be wrong to deny the value of such changes, or to underestimate the effort put into achieving them. The benefits derived from some of the innovations (and research) achieved in this and other countries have been considerable; it is now possible fairly clearly to identify the elements required to provide good learning disabilities services. However, the actual extent of, and degree of benefit derived from, the developments of the 1970s and 1980s should also not be exaggerated, or protected from critical evaluation. For the purposes of this document there are in this context three sets of key points to stress:

* the objectives of reducing dependence on hospital based care have not always been clearly defined, and satisfactory methods of quantifying the benefits and costs of such change have not universally been agreed. Notwithstanding the moral/ethical arguments underpinning many calls for reform, the sociological advantages of moving away from a large, isolated institution based service have been of importance. To the degree that smaller, more intimate care settings reduce social distance between staff and residents, helping to prevent the devaluation and block treatment of the latter and stop the unobserved neglect of 'difficult' and/or more profoundly handicapped individuals on back wards, their provision will help raise the standards of life for service users. So too will the adoption of overt service principles and quality indicators based on measures of community presence and participation, and individual choice, respect and ability acquisition. But some individuals in authority may have supported hospital closures merely because they thought that, either nationally or locally, they would save money. This is unlikely.

Similar tensions exist in the arguments underlying the move away from a medical to a social care model. Doubts in the minds of people like politicians and some family members about the purposes and end results of the transition from larger hospital based services may also have been raised by factors such as the communication difficulties between proponents of 'normalisation' and certain groups of consumers and providers, including professionals in health and social care anxious to maximise resources available for other worthwhile caring activities. Families uncertain about the security of funding for new alternatives to traditional care may naturally worry about the price they may eventually have to pay for hospital closures, particularly as at present the latter play a part in providing respite, as well as long-term, support. (See page 25.)

* overall reliance on adult residential care services has not fallen, and

the quality of alternative 'beds' is uncertain. Despite recommendations such as those of the Jay Report (HMSO 1979) few people with severe learning disabilities live in their own - as distinct from their parents' - homes. As resident populations in traditional hospitals have declined the number of people in local authority and - particularly since revised social security payment arrangements - voluntary and private homes has risen. In England the total number of such places is now about 30,000; that is, approaching 25,000 more than in 1971. There is little doubt that appropriately financed and managed community residential facilities can provide those living in them with an enhanced quality of life. But without adequate investments of human and material resources this cannot be certain. Results generated by a recent major survey of community residential facilities (by researchers based in the Universities of York and Manchester - see page 16) indicate, for example, that people living in a proportion of the latter may in the context of leisure activity be no better off than those still in hospitals.

* **much of the money spent on people with learning disabilities is still 'locked' in hospitals.** Although the total amount of money spent on NHS mental handicap hospitals has fallen slightly (in constant price terms) since the mid 1980s, it still reportedly represents 60 per cent of combined NHS/LA (social service department) mental handicap spending. Calculations by the Audit Commission suggest that this figure would fall to around 40 per cent if social security payments to 'severely mentally handicapped' people were to be included in the spending total. Further adjustments in relation to factors such as community charge exemptions would reduce it somewhat further. However, it is still a very substantial slice of the learning disabilities 'resource cake', given that in England only 15 per cent or so of the total number of individuals with severe learning disabilities are in receipt of direct NHS hospital care at any one time.

It is perhaps understandable that public debate about economic issues related to learning disabilities has mainly been confined to a few 'hospital transition' centred questions. These include:

* 'what is the (average) cost of community care, and how much more - or less - is it than hospital care?'

* 'how can health and social service authorities best deal with the period of 'double cost', during which hospitals (with relatively high and stable expenditures) remain open but with reducing populations, and other services (with costs increasing in line with numbers served) must be expanded?'

* 'has the expansion in social security spending on residential care since the early 1980s been justified in value for money terms?'

* 'are health authority funds being fairly and appropriately transferred to other care agencies as people leave hospitals and other NHS facilities?'

Economic studies relating to such issues are considered in subsequent sections of this paper. Here, though, there are two important sets of background points to stress. First, concern over hospital closures should not be permitted to obscure the fact that service development for people with learning disabilities who have never lived in institutions is now - at least from a demographic as distinct from a management viewpoint - the most important care provision issue in Britain. At present, the information base needed to establish what levels of funding might reasonably be needed in any given locality or context, and how best to achieve overall value for money, is not satisfactorily available. Examples of further data requirements include:

* **more sophisticated epidemiological information on the numbers of people with learning disabilities by severity of impairment (including other conditions like epilepsy, blindness, incontinence, severely challenging behaviour etc).** The number of individuals with 'severe mental handicap' is in the order of 3-4 per 1000. This implies an English total of some 160,000 people, of whom around 30-35,000 are aged under 16. It is also believed that the distribution of severe mental handicap likely to require residential care or intensive domiciliary support is even across social classes.

  However, the population of people with severe learning disabilities can be seen to be heterogeneous, particularly when additional problems are taken in to account. In planning care - at least in respect of broad levels of resource which should be available - it would be useful to have a clearer picture of those with very special needs. Also the ageing of the population with learning disabilities has not been definitively described, and nor has the impact of preventive interventions introduced in the last few decades. These could alter the distribution of conditions like Down's syndrome between social classes and ethnic groups.

  Furthermore, it has long been known that the incidence of 'severe moderate' learning disabilities is strongly class skewed. (That is, there are relatively more individuals with IQs in the 50-60 region in social classes IV and V than there are in classes I and II.) This often ignored group has considerable support needs. The plight of more able individuals who for undefined social and/or biologically determined reasons have mild learning disabilities - that is, are on the low end of 'normal' intelligence - is usually even more neglected. Full recognition of the employment, family care, educational and health problems of this section of the community would carry significant resource implications over and above those considered in this report.

* **information on care costs linked to levels of user incapacity and the outcomes of support.** The potential value of such material should be self evident, as is the fact that it would be unrealistic to suppose that it could ever be comprehensively assembled and maintained. The identification of needs to assist in making decisions on resource allocation priorities is a strong element in the current health and social service reform objectives. Yet it should be stressed that currently available epidemiological data cannot provide adequate insight into the service needs of the learning disabled population. And notwithstanding the information generated by the studies reviewed in subsequent sections of this paper there are substantial areas of uncertainty relating to funding requirements, both at macro and micro levels. In the latter context the most glaring relate to the situation of severely mentally handicapped people living with informal carers,

> typically their parents. Unless more adequate investment is made in quantifying the options for and benefits of improved services for supporting people in such situations then the allocation of resources can be based on little more than guesswork guided by political expediency. Given the truth that throughout history the interests of people with learning disabilities and their families have rarely been perceived as a priority by mass electorates, this is an unsatisfactory state of affairs for all those concerned to achieve more adequate levels of provision.

The above should not, of course, be taken to imply that progress in policy and provision cannot be achieved until 'further research' has been conducted. Rather, it demands that action be taken to enable services to develop as robustly as possible, given the limitations and uncertainties which must affect planning at present. The theoretical implication of such observations is that service providers at the interface with users should be given maximum possible levels of local information together with freedom flexibly to respond to individual demands within identified resource constraints. Elsewhere system managers (of equivalent rather than superior status to service managers) should monitor developments and where possible identify and help resolve care failures. But they should not be in a position to impose rigid patterns of resource use on the basis of indirect information and priorities determined without close consumer contact/participation.

The changes introduced, or due to be introduced, as a result of the 'Working for Patients' and 'Caring for People' White Papers and related legislation could go some considerable way to promoting such arrangements. For example, separation between purchase and service supply functions in health and social care is a logical move from an economic standpoint. Depending on the degree to which purchasers are genuinely committed to and have incentive to pursue service users' best interests it should break down any past tendency for bodies like district health authorities and local authority social service departments to be influenced more by provider group concerns than by consumer needs. But the second set of background points to be made here relate to the widespread uncertainties and fears of perverse outcomes which have accompanied the government's programmes of reform. In the specific context of this brief study on economic aspects of support for people with severe learning disabilities major considerations include:

- **lack of a single care purchasing agency.** During the early and middle 1980s there were increasing calls for some form of budgeting unification right across the 'community care' area. In relation to learning disabilities Glennerster et al (1983) suggested that there might usefully be created joint LA/NHS sub-authorities in each locality, to operate single 'earmarked' budgets derived from both health and social care funds. The Audit Commission (1986) in its seminal report on community care recommended that social services be given sole responsibility for the field. The objective of such unification would be to stop 'buck passing' between agencies operating discrete budgets in overlapping fields.

  The 'post-Griffiths' health and social care plans do not fully resolve this issue. Although the objective of current reforms is over time clearly to distinguish agency responsibilities and to place all social care functions with social service departments considerable NHS commitment to the support of people with learning disabilities will be needed over an extended transition period. The health service may, indeed, always retain primary responsibility for the care of a small - but undefined - number of individuals with very heavy nursing/health care requirements. Many observers fear that this will mean that 'border disputes' will continue to undermine care provision for the foreseeable future, and that to the extent that both health and social care suppliers are encouraged to pull back to their 'core' functions significant numbers of individuals with learning disabilities could be left stranded between the two sides.

  Sentiments such as 'the mentally handicapped have had their share of extra resources, now its the turn of the mentally ill', the impact of the 'poll tax', and even a desire on the part of some local authorities 'not to go out of their way to make Tory reforms work' could all serve to exacerbate such difficulties. It may thus be necessary to accelerate the process of financial control transition in some way, a point returned to in the final section of this report.

- **lack of 'ring-fencing' of resources for learning disabilities.** From 1993 significant proportions of the social security monies paid to individuals in non-hospital residential care as an 'as of right' personal benefit - the residential care allowance - may be transferred en bloc to local authorities. This move was primarily designed to allow greater flexibility in relation to the support of elderly people, and to ensure that those who might prefer to remain in their own homes are not subjected to perverse incentives not to do so. Under existing arrangements some service users may have no choice but to move to residential care, even though this may be a relatively costly option in public spending terms.

  However, most people with learning disabilities are in their parent's homes. There is a reverse danger of inappropriate pressures being applied on them to stay there, regardless of family costs. For a significant number some form of residential support may well provide the best chance of satisfactory adult life. Also, it is still not known how the overall level of transferred funds or their allocation between local authorities will be set. Any capitation formula will clearly need to take appropriately into account not only any variations in the prevalence of learning disabilities, but factors like deprivation in housing. There are additional anxieties as to the extent which such resources will be used to finance activities other than support for people with learning disabilities.

* **shortfalls in capital funding.** Throughout the last few decades there have been recurrent difficulties with capital resource allocation in the public sector. On top of this the recent declines in the property market have meant that NHS authorities wishing to sell older hospital sites face reduced returns. This has implications for closure programmes, and the capacity of health authorities to transfer capital resources into alternative forms of support for people with learning disabilities. In some Regions all new NHS sourced capital investment in community care facilities has been halted, preventing the exploitation of opportunities to purchase ordinary housing at favourable prices. Other problems reported in this context relate to the (denied) use of Housing Corporation funds to provide housing for individuals leaving hospital, and failures to facilitate cross regional movements of NHS capital monies to support revenue 'dowries'.

* **limitations in the 'dowry' system, and funding mechanisms for non-hospital residential care.** The Audit Commission (1987, 1989) has drawn attention to problems with the 'dowry' payments made to health authorities receiving patients moving away from traditional hospitals, and their subsequent use to fund other forms of either NHS or social service/private/voluntary sector provided residential care.

It has, for instance, been observed that dowry payments may stop with the death of the recipient. In transferring resources from the NHS to other providers it has also been argued that the initial sums and/or the subsequent inflation adjustments made to them have been inadequate, and that real growth in the resources available to the NHS overall has not accrued appropriately in relation to either the internal health service dowries or to the payments made by Districts to meet non-NHS service providers' costs.

However, in some localities (for example, Hillingdon and Somerset - see page 30 and Spencer and Macdonald 1989) relatively sophisticated health to social care resource transfer arrangements have been pioneered. It should also be noted that the intended future shift to weighted capitation Regional and district funding will make the dowry system redundant. But if this is so significant questions then arise as to how the interests of people with learning disabilities are to be protected in all localities. One issue to be resolved is the extent to which need for residential facilities might vary between differing parts of the country because of social factors. Very clear Regional policies on the funding of existing services and future expected levels will be needed. There have also been uncertainties in relation to payments such as the Hostel Deficit Grant and housing benefits to people in local authority as opposed privately or voluntary sector owned residential care. However, in relation to the HDG a recent intervention by Sir George Young appears largely to have removed fears of resource withdrawal; the new Special Needs Management Allowance system now promises to have some advantages over the former arrangements, not least in removing from some agencies a temptation to distort the balance of their reporting about the costs of their various services.

* **lack of clarity as to future 'case management' arrangements.** The ideas presented in 'Caring for People' offer the prospect of social service departments acting as enabling agencies for those whom they seek to support, with 'case-managers' helping individuals to gain the most appropriate package of care possible. But the exact position of

case-managers as purchasing agents or as employees of a provider body needs to be established, otherwise distortions in relationships may occur. Some commentators fear that in practice assessment and case management arrangements may be developed more as mechanisms for SSDs to limit entitlements to support than to measure and meet legitimate needs. Also it is uncertain how many severely mentally handicapped people will actually gain individual case-managers, and from where people of appropriate skill and knowledge will be drawn.

As a final point it may be added here that all people with severe learning disabilities have normal health care needs, just like everyone else. But partly because of their communication problems there is evidence that these tend to be neglected, and that their sensory difficulties and needs in areas such as foot and dental care often pass unnoticed (Howells 1986, Taylor and Taylor 1988, RCGP 1990, Wilson and Haire 1990). Other examples of problem areas include failures to monitor and reassess medication programmes, and tendencies to assume that specific problems like, say, post menstrual tension (PMT) are 'just part of mental handicap' (Sayer 1991). Access to normal hospital provisions, particularly in relation to transient psychiatric disturbances, may also be restricted for consumers with learning disabilities. Attention thus needs to be paid to the medical case management of individuals in this user group, alongside their nursing care requirements in the community. (The latter also raise questions relating to staff transfers between hospital and other forms of care, and the viability of proposals such as the joint training of social workers and learning disabilities nurses.)

It is against the above range of current concerns that this report now turns to a brief consideration of the nature and role of economic analysis. Readers already familiar with such matters should turn to page 16.

THE NATURE AND ROLE OF ECONOMIC ANALYSIS

The goal of economic analysis is to facilitate efficient resource usage. In the context of health and social care this means generating the largest possible gains in health status/wellbeing with the money available. The techniques employed to facilitate this include cost effectiveness analysis (involving comparisions of differing means to achieving a given - constant - end) cost utility analysis (involving comparisons of differing means to achieve varying volumes of given 'items', like, say, vaccinations or hip replacements) and cost benefit analysis (involving comparisons of different means of producing different sorts of ends/benefits). The latter involves measuring - or trying to measure - not only direct financial costs but also indirect costs and personal or social gains which are not financial, but which for the purposes of comparison can be expressed in money value units. The common assumption that economists' findings are concerned just with money in the 'hard cash' sense is wrong; so too is the simplistic belief that economic efficiency relates directly to low costs, rather than an optimum cost to output/benefit ratio.

However, the difficulties inherent in achieving such evaluations in a consistent, generally believed and accepted manner are very considerable. (Which is partly why in areas like learning disabilities most economists confine themselves to cost effectiveness, rather than cost benefit, analysis.) Problems may also arise from the fact that when economists express the value of welfare generated or lost in money units naive users of their results may be disappointed to find that no such 'hard cash' actually exists. And for policy makers the most important point to stress is that economic analysis cannot in itself tell them what they 'ought' to do in an absolute sense: it can only inform them of the financial and estimated welfare consequences of pursuing alternative options, help reveal the values which would underpin one decision as opposed to another, and suggest the types of incentive and organisational structure/relationships likely to promote given objectives.

Before reading the 'bottom line' figures presented in economic analyses prudent users should therefore make an effort to understand the assumptions, empirical base, methods and reliability of the calculations involved. Otherwise they may take as solid fact conclusions which in reality are highly questionable. The primary objective of this brief section is to underline the standing of economics as a social, rather than physical, science. Its second main purpose is to outline some of the concepts used by economists and to indicate their relevance to this report on learning disabilities services and policies. Important economic ideas include:

* **supply and demand.** Against a background where all wants cannot, because of resource scarcities, be satisfied, the price of any good or service is in a market a function of the interaction between supply and demand. If the latter goes up then price will tend to follow, given that more money becomes available to purchase a given volume of items. In such circumstances profits rise, and this prospect of above average ('supra-normal') profit will eventually attract in more supply. As supply rises - it can also be stimulated by new means of production or luck, as in good harvests - price tends to fall, and profits to decline.

Thus in a market which is working well the returns on all forms of production tend to even out, the precise balance of activity and investment being led by consumers' expressed demands - that is, consumer preferences. But in the 'real world' perfect markets do not exist - and this is most certainly so in areas like the supply of learning disabilities services. The need for public or other third party funding means that the people paying the money are not the consumers whose demands should be served. Individual consumers may be uncertain about what they want/need. And professionals who act as suppliers are often also the effective purchasers, a situation which has obvious dangers.

In such circumstances economists can help guide public and private decision making by applying techniques which not only show the true costs of services, but also help reveal their value to the direct and indirect recipients. But in doing so they arguably have a responsibility to make others aware that the fundamental message of their discipline across the last two centuries is that systems which underestimate any group of consumers' abilities to judge their own best interests, and place heavy reliance on the guidance of 'the educated' and other elite groups, often fail efficiently to pursue the public good.

* **opportunity costs.** The cost of producing a good or service expressed in terms of the sacrifice of the optimum value alternative(s) foregone. The idea behind looking at costs in this way is that in 'the real world' money prices can become distorted so that they do not really reflect the worth of goods or services. In respect of learning disabilities it may

for instance be useful to examine the 'opportunity cost' of some professionally run services; the value gained using similar amounts of money directly to support family choices or voluntary activities could be considerable.

* **marginal and average costs.** The average cost of producing a good or service is the total cost divided by total output volume. The marginal cost is the additional cost of producing one more unit of output, which at some times will be lower than the average cost and at others - when more production demands more 'plant' - will be higher. For example, the cost of having one more 'patient' in a three quarters full hospital ward for people with moderate learning disabilities may be near zero, even if the average cost per place is around £20,000 per annum. But if an extra admission were to demand opening a previously closed ward its marginal cost could be very high indeed.

* **fixed costs.** Costs which do not vary with output. For example, it may cost as much to heat a half empty ward, or even hospital, as a full one.

* **economies of scale.** When larger production units can exploit lower costs at the margin to make a given volume of goods more cheaply than several smaller ones. An objective understanding of how real or illusory economies of scale may occur in the context of residential care for people with learning disabilities is vital.

* **diminishing returns.** The utility of a good or service is the satisfaction which its owner or recipient receives from it. The more of any commodity or service a person has, the less he or she is likely to value it. Eventually, extra items may even have a negative value. For example, too much personal attendance for someone with learning disabilities could get in their way and restrict their sense of freedom and ownership of their place of residence.

* **time preferences.** Most individuals will value receiving (if not paying for) something more today than they would the prospect of getting the same thing in 10 years time. One consideration is that they may not be around to enjoy its benefits a decade ahead. This 'time preference' means that economists discount costs benefits which may be generated in the future as against those available now. For societies, though, which are not mortal in the individual sense, different discount rates will be appropriate. And in the case of learning disabilities special considerations also come into play at the individual level. For instance, parents may have particular fears about the long term wellbeing of children with 'mental handicap', and what will happen after they have died. They may also be concerned about the possible consequences for siblings. Assured future arrangements here may thus be of great value.

* **incentives/perverse incentives.** Everyone reacts to incentives. This is not to say people respond only to money, rather than individuals seek that which they value. A perverse incentive exists when people are given a reason to do something which has consequences they or others involved in the transaction do not want. For example, to gain or keep social security benefits individuals with learning disabilities may be encouraged to display dependence and not to learn additional skills, even though the objective of the overall health and welfare system should be to maximise their abilities. Similarly, authorities may sometimes have a local incentive to admit people to expensive forms of residential care, rather than providing less expensive, more satisfactory support to service users living with their families.

* **cross-subsidisation.** If a supplier is producing a range of different

services or goods from the same basic facilities it may be hard to attribute costs accurately to each one. Either deliberately or accidentally earnings from one good or service may be used to subsidise the costs of another. This is undesirable in as much as it distorts consumption. In learning disabilities there may effectively be cross-subsidisation between services for people with varying degrees of dependence, and between different settings.

- **cost effectiveness and cost benefit analysis.** As noted earlier, cost effectiveness studies attempt to compare differences in cost between various ways of producing a given outcome. Cost benefit analyses compare differing production costs and differing patterns of outcome/benefit. They thus have to try to express their findings in a single currency, for purposes of enabling comparisons in the efficiency of welfare production. Controversy has often surrounded the methods used to achieve this, which may sometimes seem - and be - very arbitrary.

- **Quality Adjusted Life Years (QALYS).** A concept which can be used to link benefits to costs in health care. The methodologies available for calculating them essentially involve testing to reveal consumers' preferences for various health states which enable them to be placed on a scale between 1 (healthy) and 0 (dead). Depending on the approach used, states worse than death may score negatively. Costs can then be attributed to interventions which facilitate changes in health status over identified time spans, and the cost per QALY generated calculated. The results enable 'good and bad buys' to be identified.

  Some authorities believe that QALY methodology cannot be applied to learning disabilities, particularly in comparing the value of investments made in that area with that of spending in other health and social care fields (Donaldson et al 1988). It may be argued, for instance, that learning disability is not in itself a defect in health status subject to 'treatment' and hence measurable change (Wright 1991) although this may not apply to the mental distress experienced by people with learning disabilities living in inappropriate circumstances. Other commentators object in principle to any methodology which might suggest that some lives are not 'worth' saving. But without techniques for aggregating economic findings so that policy makers can contrast the returns from money put into learning disabilities with those from alternative opportunities it is difficult to see how rational policy formation can ever be achieved.

  Another problem relates to who should be valuing whose life. For instance, it may be that more investment in intensive perinatal care will save a significant number of babies to live on free of disability, but at the cost of also increasing the number of severely impaired survivors. If each infant life saved is assumed to produce a number of future QALYs, such expenditure could well appear beneficial. But arguably a baby cannot attribute any value to his or her life at the moment of birth. If the parents are to be the judges, then what may have to be balanced is the cost to them of not gaining a new born baby against that of having a severely disabled child. It is possible that seen from this angle the number of QALYs generated for a given investment in intensive perinatal care would be very different.

- **production functions, production of welfare analyses.** For any process of production it is possible through statistical techniques to link observations about factors going into making something with others about what eventually is made. In the welfare economics/learning disabilities context, for instance, it is possible to compare data about 'inputs' like staff numbers, costs and the initial characteristics of service users with outputs related to the quality of life enjoyed by people in residential care. This can provide evidence of significant associations although too simplistic a reliance on or interpretation of statistics relating to quantitative data can result in erroneous judgements, particularly in cases where particular phenomena combine to influence a locality in a unique manner. Understanding exactly how a complex social system works may demand much qualitative investigation as well.

RECENT ECONOMIC ANALYSES OF CARE FOR PEOPLE WITH LEARNING DIFFICULTIES - FINDINGS AND IMPLICATIONS

Sources of economic data on services for people with learning disabilities include:

* the work of Wright and Haycox (1985) comparing the costs of care in small scale NHS units with that recorded in various wards of large hospitals.

* data produced by Felce (1986) and Felce and de Kock (1986) on the revenue and capital costs of various forms of NHS residential care.

* Shiell and Wright's (1988) analysis of the costs of child care in an intensive support unit run by Barnardo's, and in NHS care and foster homes.

* the study funded by the South Western RHA and conducted by Linda Davies (1988) on the costs and consequences of nine residential (and non-residential) service provision schemes.

* Wright and Tolley's (1989) costing of day care services provided in a sample of 13 local authorities conducted in association with the Social Services Inspectorate.

* the NIMROD service analysis of revenue costs by Davies at Birmingham and Felce and his colleagues at the University of Wales (Davies et al 1990).

* Korman and Glennerster's (1990) study of the politics and economics of the closure of Darenth Park Hospital in Dartford, to the south east of London.

* Ryan's (1990) HERU (Aberdeen) paper on the 'costs of alternative forms of care for the mentally handicapped' in Scotland.

* the DoH funded work of Pettipher, Raynes, Shiell and Wright - based in the Universities of York and Manchester - which compared costs of 125 'community' residential facilities for people with learning disabilities and produced a series of indicators/scales relating to outcomes.

* the study on the outcomes and costs of long stay hospital residents moving to the community produced by Knapp et al (1990), which presents the PSSRU evaluation of the nine projects relevant to learning difficulties in the DoH's Care in the Community Demonstration Programme.

* the various forms of information publicly available in government publications and reports such as those from the Audit Commission and House of Commons' Committees, together with that kindly supplied directly from individuals working in RHAs and a number of voluntary agencies and relevant findings from US, Canadian and other researchers.

Much of this material is complex and is not easy for non-specialist readers to interpret. Further, not all the studies and sources mentioned above are consistent one with another. However, the notes below represents an attempt to form a concentrated, balanced overview of and commentary on their findings. All costs are estimated in January 1991 prices, except where otherwise stated.

HOSPITAL CARE COSTS

Presently the average revenue (ie excluding capital) cost per person in a mental handicap hospital in England is reported to be in the order of £22,000 per annum. (This figure will vary between Regions.) As the hospital population has fallen so unit costs have risen, probably as a consequence of both rising fixed to variable cost ratios and an increase in the average dependency level of those remaining in hospitals. Although in constant price terms NHS current spending on mental handicap inpatients has fallen by around four per cent since the beginning of the 1980s (six per cent since 1983/84), the cost per 'bed' is about 60 per cent up - see HC 664. Yet reports from Regional and District NHS managers suggest that service standards are still limited, and may already in some hospitals have 'been cut to the bone'.

It thus seems imperative that, particularly if hospital to community care transition periods are in some Regions to be extended, further objective information on the quality of support in remaining larger institutions should be gathered as a matter of priority. The extent to which hospital costs are 'fixed' and/or should be maintained despite falling inpatient populations requires careful analysis. Without such action any policy decision to develop better services for people living at home (or in their parents' homes) in the absence of significantly increased resources for learning disabilities overall might risk a return to a poverty of care for those remaining in hospitals similar to that which resulted in the scandals of the 1960s; this would be highly undesirable, not least from a political viewpoint.

Clarification of the scale and pattern of NHS internal 'dowry' payments to

DHAs which have received patients from hospitals is also necessary. These outlays have not been monitored nationally; since they are not counted in the nationally available mental handicap inpatient cost figures (were this so it would inflate the latter, and could lead to a danger of 'double counting') it is not possible centrally to state the true proportion of total NHS resources going to support people with learning disabilities. Comprehensive data on how at local level DHAs have spent such monies - either acting themselves as providers or passing them on to other public, private or voluntary agencies - might also be illuminating, not least in preparing the base of information about existing services needed to open the way to nationwide weighted capitation NHS/LASS funding in the mid 1990s.

NON-HOSPITAL RESIDENTIAL CARE COSTS

Virtually all British studies support the broad conclusion that non-hospital residential care is more expensive to deliver than large hospital based care. (In some US analyses, however, hospital provision appears to be relatively more costly.) But this finding is subject to several caveats. It is, for example, difficult to ensure that like is being compared with like, both in terms of the service users and their needs and the outcomes of care. In some residential settings staff are clearly providing day care and activity opportunities unavailable in others; and even if non-hospital residential care is more expensive it may prove to be more cost effective/beneficial than traditional hospital provisions.

A vital point here relates to the apparent confusion between observers on the issue of economies of scale in the care of people with learning disabilities. Some are seemingly of the view that larger units are 'more economic'. Other commentators have nevertheless found that there is no evidence of significant economies of scale in this field over and above those related to the extra costs of intensive support facilities for just one or two people.

For instance, Shiell et al in their extensive studies of 125 residential settings indicate that above a size of six residents there are no consistent economies of scale. But Ryan's Scottish study seemed to show economies of scale in community care for less intellectually disabled people, while unequivocally concluding 'it is cheaper to care for severely and profoundly handicapped people in hospital ... economies of scale do appear to exist'.

However, Ryan's study does not include any attempt to measure outcomes and thus cannot serve as a guide to economic efficiency, only financial cost. She makes this point in the discussion section of the HERU publication, although its presentation is such that there is some danger that its significance might be missed by non-economists concerned with policy formation.

In fact, the most likely reason for these contrasting findings stem from the dominant role attributable to outlays on labour in most learning disability residential care facilities' cost structures. To the extent that certain basic consumer/carer ratios are desirable and met, these will tend to mean that expenditures will be independent of facility scale except in situations where only single or very few individuals are receiving intensive support. But if some organisations 'waste' labour (through, for example, having staff on duty at night when residents are asleep) their costs will be unduly high. And by contrast if others supply less than minimum standards of support to some - particularly high dependency - users, then their costs will be low.

The most probable interpretation of the data assessed during the preparation of this report is that apparent savings to scale in larger traditional hospitals mainly relate to a limited provision of personal support to higher dependency residents. As indicated earlier, this may be more likely to occur in such settings because of the relative invisibility of people with very severe disabilities receiving relatively little support. If similarly limited levels of provision were acceptable in smaller, more easily observed 'community' residential facilities there is little reason to suppose that unit costs would be much higher in units of,say, six people than in wards of 30, given that labour was otherwise used with similar levels of efficiency and that capital costs were also equivalent (Shiell 1990a).

The studies noted above indicate that on average a community (ie non-hospital) residential place for an able individual with severe learning disabilities whose behaviour does not challenge others - that is, a minimum dependency place - is likely to be around £11,000-£12,000 per annum. An average medium dependency place will today cost in the order of £20,000 per annum, and a higher dependency place at least £30,000. In some localities costs will be greater, and for a minority of individuals with profound handicaps and/or very challenging personal behaviours annual care outlays may significantly exceed £50,000 per annum. It may be estimated that a quarter (or more) of the total adult population of people with severe learning disabilities (that is, around 40,000 individuals, including a majority of those still in hospital) have higher levels of need. The remainder is split 50:50 between those with lower and those with moderate support needs.

These figures allow for estimates of the capital costs of care, unlike the NHS hospital revenue data quoted earlier in this section. But a warning to note here relates to the difficulty in establishing accurately capital requirements/outlays. Although in future capital charging should allow a more realistic picture of such costs within the NHS, they will across the learning disabilities sector continue to be influenced by factors such as variations in interest rates, accountancy methods, 'special deals' for voluntary groups (eg 'pepper-corn' rents for some premises) and historic cost distortions related to property market movements and inter-regional property price differences. Although, for instance, the capital cost of a new community residential place may currently only be around £20,000 in parts of Wales, a realistic London figure could still be £50,000 plus. (Places in new intensive care NHS facilities may cost £75,000 in capital terms alone - Pashley 1991.) In general it appears that the available studies in this area may understate current capital costs relative to current revenue requirements. This observation has planning implications.

FUNDING COST DIFFERENCES BETWEEN HOSPITAL AND OTHER FORMS OF RESIDENTIAL CARE

During the transition away from a largely hospital based residential service three overlapping sets of funding problems have emerged. As indicated above these are:

* NHS authorities have been unable in the short/medium term to obtain savings in hospital care cost equivalent to the average cost of each place transferred, leading to the need for bridging.

* NHS authorities have in planning the process of care transition tended to restrict the resources they employ or pass on to other agencies to the (basic inflation adjusted) total recorded at the start of the 1980s. That is, 'mental handicap' services are in this respect missing out on real growth enjoyed by other elements within the health/welfare system, and to a degree on inflation adjustments.

* the average cost of alternative forms of residential support has, because of both quality and other factors, been in many contexts greater than the cost of supporting the same service users in hospital.

Shortfalls in the money available for transfer from the health service to meet the cost of alternative residential care has largely been made up by social security payments, plus resource injections made via arrangements such as the Hostel Deficit Grant (shortly to be called the Special Needs Management Allowance). As Korman and Glennerster have shown, around a quarter of all the resources needed to support people from Darenth Park in 'community' residential settings have been provided via social security payments, the most notable of which has been the residential care allowance.

The changes planned for 1993, which entail some or all of the monies paid in respect of the latter being rechannelled to local authorities, could alter the balance of funding significantly. For instance, if social service departments have full discretionary power over how these resources are used they could be allocated to other client groups, or to people with learning disabilities other than those wishing to leave hospital. Over 80 per cent already live elsewhere. It may be that some local authorities will conclude that more welfare could be generated by, say, providing better day services for all than by 'topping up' available NHS resources to enable just a few more individuals to shift their place of residence. If so, the end stage of the NHS hospital closure programme will run into difficulties and extra costs, including those of maintaining traditional institutions' physical fabric to minimum standards.

EFFICIENCY IN 'COMMUNITY' RESIDENTIAL PROVISION

The studies on which this report is based indicate that, independently of client needs and the scale of and service quality provided by caring agencies, costs in community residential provisions range quite widely. There are of course considerable technical difficulties in comparing care 'inputs' and 'outputs' in a reliable manner. But even so real, significant, efficiency variations appear to exist. As indicated above, 'wasteful' labour deployments are probably the main factor involved in creating unnecessary costs.

Research findings such as those generated by Shiell et al suggest a number of additional linkages. These include the possibilities that privately and/or voluntarily run homes may be 'better managed' than public sector equivalents; that having some more highly qualified staff at the user contact level can help keep down overall expenditures; and that systems which promote consumer involvement in decision making are more likely to be efficient than 'top-down' structures. However, the strength and explanatory power of such observations is limited, and they do not in any case conflict with the basic - in many respects obvious - conclusion that it is the appropriate use of labour which is the key to economic efficiency in residential care.

In common sense terms the empirical information available may be taken to bear out the theoretical view that 'loose-tight' management systems are most likely to generate value for money in residential care. These are characterised by committed, informed staff operating with considerable freedom and devolved financial power at the facility level, balanced by clear budgetary restraints, coherent incentive structures and explicit, system wide user participation and minimum performance criteria.

Where resource usage is determined by individuals who are distant from the day-to-day lives of those involved in care provision and receipt it is not surprising that the full use of local opportunities for savings and/or extra benefit is not achieved. In larger units, where budgets are big enough (in the public sector) to be seen as demanding 'senior level' management control, this is particularly likely to happen. Systems in which responsibility for outcomes is not seen to lie at the consumer contact level but with 'higher' echelons are also very vulnerable to the imposition of efficiency inhibiting procedures.

The point to draw from the above is that the management of social care provisions will, with the transfer of responsibilities from the NHS, come under increasing scrutiny. Attitudes such as 'management problems come from junior staff having too many bright ideas' will have to go. Delegation of more 'clinical' responsibility and authority to the field (as is the case with family doctors) and a thinning of intermediate structures is the most probable long term trend. Indeed, this reality is already becoming apparent amongst many of those examining the options for developing workable contracting systems between health and social care purchasers and providers.

THE COSTS OF HOME CARE AND ALLIED SERVICES

Compared with the work that has been done in relation to residential care provision, the support of people with learning disabilities who live in their own - or usually their parent's - homes is a neglected topic. So too, notwithstanding the work of Wright and Tolley (1989), is that of of day care provision, which may benefit everyone 'in the community'. There has been little or no thorough economic analysis of how and to what degree domiciliary and allied services in areas like leisure activity generate benefits for people with learning disabilities and their families, though pioneering studies are now underway in countries such as Australia (Korman 1991). Nor is there sufficient knowledge of topics like how the life experiences of people with differing socio-economic backgrounds but similar levels of intellectual impairment are likely to vary.

However, what can be said with reasonable confidence is that in public expenditure terms the costs of people with severe learning disabilities staying into adulthood with their parents are currently low compared with those of residential care. Average social security payments are unlikely to be much greater than £3,000 per annum, and additional day care and support costs (such as those of attending an Adult Training/Social Education Centre) are variable but appear on average to be in the same order, or perhaps a little higher. (See, for example, NIMROD data and Wright and Tolley 1989.)

Further analysis of existing levels of use in the community by people with severe learning difficulties of 'generic' provisions (social workers, GPs, evening classes etc) might increase the latter total, but not to a great extent. Rather, it is likely that new studies of this area would reveal considerable unmet need and opportunity for investment in service improvement. Fears that this would in turn lead to more pressure for greater public expenditure are understandable. But neglect of people with severe learning disabilities who are living with their families may ultimately create demand for otherwise avoidable high cost residential care provisions.

From an economic viewpoint efficient resource use implies investment where each unit of extra spending will generate the most extra welfare. However, in practical terms there are of course very serious difficulties involved in defining exactly where the highest levels of marginal return can be obtained, and then focusing activity appropriately. For instance, targetting of resources to areas where there is the most immediately visible need may be a sub-optimal strategy in that in some circumstances spending extra resources to enhance the lives of seemingly less 'needy' people (like, say, moderately disabled people presently 'getting by' with their parents) might in the long term generate more benefit than the same amount of resource spent on 'fire fighting' acute problems amongst those with very severe handicaps. But proving that this is so, and then transferring care facilities away from those who can be seen immediately to be gaining from them, is likely easier to be said than to be done. It is reasonable to conclude that the process of informing and then reforming patterns of service user demand and provider behaviour will inevitably be a gradual one.

Three final points to stress in this context are:

* **low respite care standards can precipitate crises which eventually result in people who might otherwise have been able to stay at (their parents') home being admitted to long term, high cost, residential care.** Despite the availability of studies indicating the potentially highly desirable impact of respite care provision on the lives of service users and their family or other informal carers (Gerard 1990) the availability of such services is very limited; also they are on occasions of disturbingly low quality (Hubert 1991).

* **failure to appreciate the tangible and intangible costs incurred by informal carers is one reason why statutory authorities may under-invest in home based support services.** Various studies have shown that caring for disabled members imposes several distinct forms of cost on families. These include physical costs, including the direct labour involved in nursing care; opportunity costs such as lost leisure and employment prospects, particularly for women; financial costs, including income foregone (higher for dependent adults than dependent children) and the extra costs of living associated with disability; and psychological

costs, including increased levels of stress related illness. Following on from the points about respite care above, the gradual accumulation of such costs may ultimately force unsupported families into crises which result in disabled members entering permanent residential care.

- **the cut off in support available to individuals with severe learning disabilities after they leave school may result in an undermining of the substantial 'human capital' investments made by local education authorities.** Education authority spending on children and young adults with severe learning difficulties is not analysed in this paper. But it is worth stressing that the current lack of home, leisure and allied activity services in many parts of the country threatens to undermine the value of education spending for both those attending schools and colleges and, arguably, (poll) tax payers alike. If the training and support received in educational establishments is not subsequently built on efficiently and effectively to maximise individuals' abilities and independence, this must result in economic waste.

THE COSTS AND BENEFITS OF VERY HIGH DEPENDENCY CARE

A small minority of individuals with profound disabilities and/or behaviour which can be extremely challenging (or in the case of about one per cent of adults frankly dangerous) to others or themselves require care which is very expensive to provide. Costs and/or charges per place may be as high as £60,000 per annum, or in a some instances even more. It is reasonable to ask why such expenditures are needed or justified, not least when the supply of medical or surgical treatments by the NHS is limited by resource constraints such that sometimes interventions capable of generating a quality adjusted life year (QALY) for £20,000 or less are unavailable. Some commentators might conclude that it would be better to preserve the old Victorian institutions with only basic 'minding' services for this section of the learning disabled population.

But against this, experience has shown that it would be unwise ever to 'write off' people as incapable of feeling or functional improvement. Some informed commentators doubt the need for very high cost/charge provision for even the most dependent or challenging individuals. Their experience suggests that poor working practices and ill-informed planning (coupled with opportunistic pricing on the part of some agencies receiving 'crisis admissions') can needlessly drive up expenditure (Felce 1991).

Another point to add here is that extremely dependent individuals are not representative of the overall population with severe learning disabilities. Only 1,000-2,000 service users in England are likely to come into this category. Preserving all the large traditional hospitals cannot logically be justified by reference to the requirements of such a small group, particularly in the light of the conclusions earlier drawn in the broader context about economies of scale and service quality. Also, QALYs are usually calculated in relation just to treatment costs, not each individuals' total consumption in a year. The comparison suggested above is not, therefore, a valid one - see in addition page 14.

Further, it should not be assumed that the benefits of any form of care - for people with learning disabilities or other client groups - only accrue to the immediate recipient. The community as a whole can gain, as may an individual's family members and other social contacts. For example, the reasons for supplying high cost treatments to publicly visible groups such as those with renal failure relate not just to individual costs and benefits but also to the 'sociological significance of rescue', and the negative societal and social order implications of leaving such patients to die for want of a costly but ultimately affordable intervention. Many citizens of the UK may, realistically or not, believe that their tax payments entitle them to high levels of 'social insurance'; and politicians may understandably not wish to be seen to be failing to meet such expectations.

In the case of people with severe learning disabilities the possible benefits of care include:

- returns to service users themselves.
- returns to family members and informal carers, including parents and siblings.

- societal returns associated with shared values about the sanctity of all human life, and the belief that people who are vulnerable should not simply be rejected and/or left to their fate.

- returns to those professionally providing care and otherwise coming into contact with service users, including the value which the latter can personally add to others' lives.

No quantitative data is available on what these overall benefits might amount to. They are likely to be appreciable, although it is appropriate here to note two final sets of points:

- wherever efficiency enhancing economies of provision in relation to high dependency care can be made, they should be. **Close analysis of how these might be achieved is warranted as there is reason to fear that at present there is significant overspending in some cases, which damages service availability overall.** For instance, if from time to time an individual service user needs three staff to attend him or her, but otherwise only needs one person's partial attention, facilities should be structured to permit the best possible use of labour which is consistent with the objective of community care - that is, avoidance of block treatment and back-ward neglect (see Sheffield Health Authority 1988).

- the value of prevention, both in the context of physical impairments and that of acquired negative behaviours, is positively linked to care costs. **As these rise so do the financial returns to disability avoidance.** In respect of challenging behaviours there is some evidence from studies such as the University of Kent PSSRU Care in the Community evaluation that transfer from hospitals to other settings causes temporary exacerbations in some individuals. But in the longer term most are likely to adjust desirably, and amongst generations which have benefitted from enhanced support outside large hospitals throughout their lives the incidence and prevalence of very challenging behaviours may well fall (Blunden 1990). This raises important questions as to both the possible need for short-term supplementary support grants to cover extra care costs in the period immediately after transfer from hospital, and also the potential economic significance of lowered challenging behaviour prevalence rates in the longer term.

EMPLOYMENT

Employment and the income it brings can benefit people with learning disabilities in a variety of ways. It offers a 'normal', adult role in society; a sense of independence, and potentially of choice, in purchasing items with earned money; constructive ways of spending time; and a source of social contacts, made in an everyday context. In some economic analyses the importance of being able to substitute for public spending resources obtained by private labour is also stressed.

In fact at the level of national finances the advantages of encouraging disabled people to join the work force are often exaggerated. Given that there is usually a substantial pool of unemployment, increasing participation in 'real' jobs amongst one population group is likely to reduce it in another. (By the same token, if all sickness absence from work stopped one form of expenditure on benefits would fall; but increases in unemployment could largely cancel such a gain.) Nevertheless, the value of work to disabled individuals may often be greater than it is to other individuals, who may also be better equipped to use beneficially increased levels of free time. Also, many employers have found the contributions of people with severe learning disabilities rewarding from not just a production but also a staff morale viewpoint.

It is thus unfortunate that a number of perverse incentives can be found in relation to the social security benefits available to severely mentally handicapped people seeking employment. For example, recipients of Severe Disability Allowance may in some circumstances fear taking a job, lest it should subsequently fail and they face difficulties in reclaiming the benefit. In other cases, disabled people may to claim social security money be encouraged to demonstrate what they cannot do, rather than that which they can. In others they may lose social security entitlements as their incomes rise, suffering an effective marginal 'tax' rate of 100 per cent.

It has been pointed out, for instance, that even with the new Disability Working Allowance, the introduction of which is planned for 1992, perverse outcomes may occur. It is intended that claimants working 16 or more hours a week might use it flexibly to 'top up' existing earnings, and/or to carry them over periods of lost employment. But in some cases DWA recipients may stand to lose housing benefits, so putting them in a position where they could have to 'trade off' between their employment and housing interests (Davis 1991). Probably the only really effective way around such problems is to permit severely disabled people to retain benefits within a wider band of total income. This would increase some inequities and public costs; but it could also enhance the social security system's economic efficiency.

It is also unfortunate that (for a variety of reasons discussed by reports such as that of the SSI - 1989) the performance of Adult Training Centres in creating enhanced/new opportunities for employment has been to a degree disappointing. Place numbers have increased, but ATCs have in the main not as yet been able to function effectively as resource centres for promoting a wider range of appropriate workplace and allied activity options for those they seek to support. However, there are some notable exceptions to this observation.

For example, it has already been mentioned that the authorities in Somerset (due to the existence of strong 'champions' in the health and social services who were personally known to each other) developed in the early 1980s a comprehensive strategy for 'the care of the mentally handicapped'. It involved a phased block transfer of health service resources to the local authority; and the build up by the latter of a core and cluster service offering a variety of levels of support to people with learning disabilities. Some 350 such places have now been provided. (This programme followed the government's Care in the Community initiative. Audit Commission -1989- data indicate that by 1988 only 40 per cent of local and health authorities had any form of agreed strategy on hospital patient resettlement. One advantage in Somerset was that the hospitals intended for closure were situated within the coterminous county/health authority boundaries.)

Social service department staff in Somerset also pioneered a Community Placement Scheme, beginning in 1986. This has been developed to provide a community centred employment and leisure activity support service for people with learning disabilities. A 1989 review of this project - which was initially in receipt of 'seed corn' charitable funds - suggested several reasons for its early success. They included:

* selection of good placement workers without social work qualifications or experience in mental handicap, but above average knowledge of other areas of working life. This prevented long established prejudices and 'finely developed awarenesses of the impossible' from blocking progress and imposing an unduly risk-averse culture on the Scheme.

* effective senior officer championship and DHA/SSD collaboration, as noted above.

* team support. The placement workers together with their manager formed a close-knit team, the focus of which was outside the ATCs. This prevented staff institutionalisation and made the community the place where support was given - the placement workers all disliked the term 'outreach' simply because it implied the reverse. At the same time the presence of placement workers in Centres provided an information flow 'outwards' and a challenge to local management.

* comprehensive client and place-provider support. A special characteristic of the Scheme was the high level of post-placement support given to both clients and job providers. It is probable that other schemes have failed because they did not adequately provide this last.

A number of other important examples of innovation in employment provision exist, including the Mencap Pathway scheme, the Blake's Wharf project and the work of the Shaw Trust. But in relation to this analysis and the Somerset scheme the most important point to stress is the close linkage made between work and other forms of daytime and evening leisure and learning activities. The community placement workers made it their business to help their clients to access a variety of novel forms of support, both privately funded and provided in the public sector. In this they acted as enablers, and as 'resource extenders'.

FINDING ADDITIONAL RESOURCES

Over and above services specifically made available to them by health and social care authorities, people with learning disabilities may benefit from:

- social security payments (income support, housing benefits, attendance/mobility allowances, etc).
- 'generic' public services, as in primary health care and adult education.
- wages and other gains related to employment in either the public or private sectors.
- voluntary sector provided resources.
- family and other informal care labour and resources.
- self-help.

It is in the interests of both those responsible for care purchase/provision and service users themselves to draw as fully as they can on these additional, 'extra-budgetary', resources. Careful allocations of relatively small amounts of public funds allocated to learning disabilities may extend overall support significantly. For instance, local authority paid facilitators may assist claimants in maximising their receipt of social security entitlements; similarly facilitators in primary health care could help family and hospital doctors fully to understand the ordinary health care needs of patients with learning disabilities; grants to voluntary organisations such as friendship scheme organisers (see One-to-One 1990) can help them mobilise other appropriate help in their localities; and as stressed above flexible support to families can prevent crises and so extend periods of lower (public) cost residence in parental or sibling's homes.

An example of an apparently lost opportunity relevant to family sponsored care and the work of voluntary sector organisations is the retention of the 'Bargain/Bounty' rule (Churchill 1991). This stops charities for people with learning difficulties making clear contracts with parents or other family members, in which the latter might give donations to the former in return for the assured future support of their relatives. The argument against this is based on strict equity, and the need to avoid what might be seen as tax evasion. But the case for such arrangements includes the government recognised desirability of sharing public and private responsibilities to fund good quality support for severely disabled individuals, and also the fact that existing regulations encourage some people to make indirect deals. Although these may be less satisfactory for the participants, they can defeat the purpose of the rule.

There is thus a clear need for appropriate reform. This is particularly so as it may also be pointed out that charities supplying care in this area suffer not only penalties associated with VAT payment obligations which do not affect some 'rival' providers, but also operate at a disadvantage compared with charities such as those, say, concerned to foster research in areas like cancer. Briefly put, research charities often have the benefit of attracting donors able to give after an affected relative has died, and/or to transfer funds openly at the end of their own lives. But learning disabilities support charities are most likely to have potential donors whose affected relatives are still living; such people understandably want for their peace of mind specifically to be able to ensure their sons' or daughters' or brothers' or sisters' wellbeing after their own deaths.

However, interesting as the possibilities are for further creative interventions in such fields, it would be wrong to rely too much on private outlays and voluntary or other local enterprise and ingenuity to make up significant shortfalls in the funding of mainstream public services. For one thing too systematic an exploitation of 'loop-holes' which may work well on the small scale could lead to their being closed. And for another excessively vigorous attempts to exploit 'free' care opportunities could end up being resented by, and even harmful to the interests of, others in the community.

The most obvious danger is to families and siblings. As pointed out earlier the true costs to them of helping to care (for extended periods) for someone with severe learning disabilities will stand considerably in excess of simple financial indicators such as foregone family earnings. Economic analysis should take into account all issues related to the quality of life of carers involved in non residential community care, not just narrow agency financial costs and savings.

The point to draw here is that although it would be right for care purchasing agencies to in the future act more as enablers for people with learning disabilities, helping them to get the best from their everyday environments, such a function must, to be economically efficient, avoid inflicting unrecognised disbenefits on others. These need to be quantified, but so far have not been thoroughly investigated. And it would be naive to suppose that any insufficient funding of direct services for people with special needs could for long be made up by transferring special care costs to 'generic' providers. They will eventually protest and demand compensatory resources, which might well be drawn from 'core' learning disabilities budgets if the overall case for resources has not properly been made.

CONCLUSIONS - FUTURE POLICY OPTIONS

Considerable opportunity exists further to improve and strengthen learning disabilities provision in this country. For example, the development of a clear division between purchasing and providing functions within the NHS and social services should help to enhance their performance, providing that contracting and allied activities are conducted in a manner which permits appropriately the expression and achievement of consumer interests. The introduction of capital charging within the NHS is another illustration of a national development which will, in time, help stimulate a realistic awareness of full service costs and the relative advantages of domiciliary and institution based services. Moves towards more adequate needs assessment and so service planning are also encouraging, as have been many individual examples of beneficial service innovation since the start of the 1970s.

In the specific context of *severe* learning disabilities it is also a strength that the population in need of support is fairly small and well defined. Despite the caveats recorded earlier the scale and nature of this groups' needs is now also relatively well understood. This should simplify the planning of comprehensive care in the area.

But at the same time it may be observed that amongst many people experienced in the area of learning disabilities there is concern about the future, and fear that standards of support could decline. The main elements contributing to this poor state of morale are:

* a widespread belief that political good will towards, and backing for, the enhancement of services in this sector has fallen to a lower level than at any other time since the start of the 1970s. Factors involved in this include (paradoxically) the success of the programme to replace traditional hospital care for intellectually impaired children, which has removed an emotive consideration from the debate; the concerns generated by the community charge; and growing awareness of calls for retention of traditional facilities, which have in part stemmed from the uncertain and

geographically patchy nature of alternative learning difficulties service developments. Although not undesirable in itself, recent increases in attention paid to the needs of elderly and mentally ill individuals may also have helped to reduce awareness of and the priority given to learning disabilities. There are even suggestions, for instance, that in some localities authorities are considering cutting spending on the latter area in order to make the contribution necessary to obtain the government's new (ring fenced) mental health care grant.

- threatened reductions in the availability of non-NHS 'top-up' money needed to help move the remaining hospital based population to community settings. This is closely linked to anticipated changes in residential care allowance payments. Individuals could lose 'as of right' entitlements, while many local authorities may have little incentive to treat NHS hospital closures as a strategic priority. An associated problem is the lack of capital monies throughout the health and welfare system. It is probable that approaching £1 billion worth of capital outlays would be required to provide all those still remaining in hospitals with alternative places. There is also the fact that many existing 'community' facilities are large and of limited quality. Upgrading will demand significant second stage investments during the 1990s. Sales of existing hospital sites may not come near to meeting the costs of first stage (ie hospital closure demanded) capital stock reprovision, even if all the monies so generated are kept in the learning disabilities field.

- speculation about the impact on the NHS and the social services of the 'Working for Patients' and Caring for People' reforms. Whatever their long term objectives these may together create a divide between health and social care into which the delivery of care for many people with severe learning disabilities might tend to fall. Uncertainty about the future tactics of organisations such as NHS Trusts and private suppliers of publicly funded services, the levels of skill and motivation likely to be shown by purchasers, and timetable delays, have all helped to create doubts about the planned reforms. To an extent the sheer scale and burden of work generated by these changes may seem set to overwhelm the processes of everyday care supply. Perhaps the worst possible scenario for the future would be for SSD's across the country to be forced into severely curtailing the availability of residential care for all clients, relying instead on limited domiciliary support to disabled individuals living with hard pressed parents. To support the latter ATC's/SECs might drift into becoming little more than day time 'warehouses', permitting inappropriately large numbers of users to come to them simply to get them out of their families' houses for a time.

There is little point in merely ignoring or denying the existence of such fears. Rather, their recognition should be seen as the first step towards allaying them, and putting in place local plans which will help ensure desirable patterns of service development. Open acknowledgement of such hazards should also help further to develop national level thinking in this complex field - government spokesmen have repeatedly stressed that the current health and social care reforms are not laid down in 'tablets of stone'. They will be adjusted and amended as experience demands.

Hence in conducting this examination of economic issues relating to learning disabilities services the ideas suggested below are intended to stimulate informed discussion. The findings presented in this report indicate that from an economic viewpoint the following guiding principles should be considered to be of central importance in health and social care management:

- wherever possible, budgets for purchasing (sole-use) services for a given client group should be unified, and allocated via a single, publicly accountable, agency. This stops 'buck passing' and inter-organisational boundary disputes, and promotes flexible resource allocation to the most productive ends.

- budgets for defined functions should be 'ring-fenced'. This permits the identification of unacceptable resource shortfalls and/or unrealistic development plans, and prevents diversion of funds to other ends for reasons which have not democratically been authorised. The principle that special functions should be funded from specifically allocated budgets should be respected. But so too should the principle that services intended to be available to the entire population should not be denied to individuals who happen to have special needs as well.

- service purchase and service provision should be kept as distinct as possible, although this does not preclude the possibility of providers 'sub-contracting' service elements, and so playing subsidiary purchasing roles.

- wherever possible service users should be in a position directly to decide between alternative services/providers.

- where consumers require agents to assist them in choice, these should be individuals best placed to understand users' personal preferences and interests. This demands the devolution of appropriate authority and economic power to family and 'field level' professional carers, where appropriate investment in education and human skills is consequently required. Responsibility needs to be devolved with authority.

- to the extent that informal/potentially freely given resources exist within the community to support groups with special needs, policy should be aimed at facilitating their release. This often demands professional co-ordination, and assured funding over time, for its efficient achievement.

- the objective of all health and welfare policies should be to pursue the efficient production of welfare. Wherever possible 'targetting' of resources should reflect this goal, rather than only responding to the greatest perceived need at any one time.

- the pursuit of equity is a significant value in current UK society. But where concern for equity clashes within that for efficient welfare production the former should not be blindly accepted as being 'right'. This may be relevant to areas like income support entitlements, and the framing of charity law.

- 'higher level' authorities have strategic planning and service standard monitoring roles. They should be in a position to commission research and investigations relevant to such functions. But staff in such bodies should not be able to expropriate status or levels of personal income, authority and responsibility more appropriately held at the consumer/provider interface.

Application of these principles to the particular issue of learning difficulties service provision would allow for a variety of approaches. One possible set of arrangements could be:

* resources for the purchase of all 'special' - that is, non generic - nursing and social care for people with severe learning disabilities should be transferred to local authorities or to new free standing local (severe) learning disabilities support agencies. That is, existing NHS revenue resources for all mental handicap hospitals and units, plus allocation sufficient to meet capital charges, should (together with all LA revenue and associated capital funding for learning disabilities services) be as soon as possible aggregated to form one budget. Initially, such funding should be set on the basis of existing service costs for the client population, wherever its members are located. In time resource allocation should probably move to weighted capitation, adjusted for local conditions.

* such monies (which would also include any transferred from the social security budget) should be ring-fenced. If held by local authorities they should be controlled by a director of (severe) learning disabilities services. She or he would be legally accountable for defined 'macro' service delivery functions, and could be locally accountable via a separate committee with statutory service user representation. In the case of a discrete agency this could again have a local committee structure involving user representation, perhaps selected in a manner similar to that used in the case of NHS CHCs. The director of (severe) learning disabilities services would have responsibility for purchasing all special (ie non-generic) care in the area from both NHS and existing social service providers as well as from other supply side bodies. The person concerned would also have a duty to facilitate, but not directly to fund, appropriate generic service supply.

* all people with severe learning disabilities would be enabled to obtain the support they need (within the resources and minimum rights set down) by 'case' managers working essentially as brokers (see Beardshaw and Towell 1990). Given that all delivery responsibilities, including those of day-to-day need assessment and service adjustment would be provider functions, and that many individuals with severe learning disabilities do not have complex needs, the number of such purchasing case managers needed in any one locality would be limited. There should, however, be enough service purchasers in any one locality for users/families to be able to express choice in accepting their help. They would have legal responsibility for all individual client level purchasing decisions; higher authorities should not be liable for professional failures at the client contact level.

* policies aimed at maximising the discretionary service purchasing power of individuals with severe learning disabilities should be pursued. Purchasing 'case' managers (perhaps more properly titled service purchasing advisers) should in time also have the authority to transfer to families monies for discretionary use.

* within 'preferred' provider agencies policies should also be aimed at maximising consumer participation, although in order to preserve flexibility and attract high quality staff to field level posts contracts should not be rigidly prescriptive. Rather, they should facilitate 'loose-tight' control of providers by purchasing agencies, and encourage similar managerial relationships between the centres and peripheries of larger provider concerns.

* monies may either be 'top-sliced' by the director of learning disabilities services for strategic encouragement of voluntary sector initiatives, or be allocated by purchasing 'case' managers in respect of services for individuals. Special professional training monies could also be top-sliced by strategic purchasers, and allocated in a planned manner.

* national and authority level managers should be responsible for identifying 'high welfare return' areas of investment in learning disabilities support, and informing field level purchasers, providers and service users of their findings. But such activity should not be seen as a substitute for field level freedom, flexibility and enterprise. Rather, it in the main represents a way of augmenting communication between actors in the field, and revealing perverse incentives which may encourage sub-optimal resource allocation.

* overall public spending restraints limit the ability of national decision makers to free social security payments from seemingly petty limitations, or to provide bridging monies to facilitate accelerated service pattern transitions. But in cases such as those relating to the loss of benefits 'severely mentally handicapped' people may suffer when they achieve paid employment some further easing may be possible. It is not simply that a little extra spending in this narrow area could increase the overall economic efficiency of the system. Savings in repeated assessment and administrative procedures could to a substantial degree cancel out the costs of providing a wider band of non-means tested benefit payments to this specific, uniquely disadvantaged, client group.

The above ideas may of course be regarded as contentious, and should only be taken as outline illustrations of the sorts of conclusion which the economic materials reviewed in this report may be taken to imply. They represent a starting point for discussion, not firm recommendations.

However, this is not to say that they are without merit. For example, the transfer of all NHS monies specifically spent on 'mental handicap' to a local authority or other free-standing purchasing agency could help focus policies about hospital closure more clearly. It might also encourage fuller recognition of the permanent entitlements of severely mentally handicapped people to 'generic' NHS services, both in respect of primary care and hospital treatment for medically treatable states such as psychiatric illnesses.

In addition, there appears to be substantial informed support for the concept of transferring monies directly to service users (and/or their families) to enable them more directly to choose and obtain the services they need. Moving towards achieving greater professional trust in the 'customer', and indeed recognising that a key indicator of professional success in this field is the extent to which consumers can be supported in exercising informed choice, would seem to be a particularly worthwhile objective.

Recent political debate has involved some consideration of the viability of establishing some form of single budget for learning disabilities care provision. However, this possibility has raised fears, as well as positive responses. One reaction has been that if it were centred in local government it might seem to say to health authorities that they should forget 'mental handicap' and pass it on to local authorities, even though the latter have in fact 'got quite enough to do for the time being'. Another quite separate set of concerns in this context relates to the issue of the community charge, and the complications which may arise from an extension of local government obligations and spending.

Such anxieties are reasonable, and again should not be ignored. But the point to stress here is that wherever a unified purchasing base for severe learning disabilities services might be established, this does not mean that in future providers in the NHS, social service departments or elsewhere would have their valued contributions to care 'shut down'. Rather, the incentives affecting the channelling of resources within the overall service provision structure should be adjusted so that the most effective possible welfare producing mix of inputs is more likely to evolve.

A unified and ring fenced budget for services intended uniquely to benefit people with severe learning disabilities and directly associated problems should, wherever it is held, create more motivation amongst those 'purchasers' responsible for its expenditure objectively to compare the costs and benefits of alternative patterns of provision, and select those most valued by their clients. And by and large the more power is in the hands of end-point consumers and their closest agents, and the less extraneous interests influence the behaviour of 'higher echelons' in relevant decision making processes, the more true efficiency is likely to be achieved. In the final analysis it is this type of very simple insight into the reality of the human condition which is one of the most important things economic analysis can provide.

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