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4 THE VALUE OF INDEPENDENT LIVING
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International Exchange of Information in Rehabilitation

ABSTRACT

This paper examines some aspects of independent living for handicapped people from a cost-benefit standpoint, within the context of the UK system of social services and benefits. It outlines some current issues and developments of interest, and suggests possible lines of approach which could be helpful in the different circumstances of the United States.

Dollar exchange rates for appropriate years were as follows (based on IMF statistics):

1973	1974	1975	1976	1977	1978	1979
2.4	2.3	2.2	1.8	1.7	1.9	2.0

PREFACE

ABOUT THE INTERNATIONAL EXCHANGE OF INFORMATION IN REHABILITATION:

In order to put this particular piece of writing into perspective, it is important first to cite the legislation to which the International Exchange of Information in Rehabilitation is responsive:

REHABILITATION ACT 1973

REHABILITATION, COMPREHENSIVE SERVICES, AND DEVELOPMENTAL DISABILITIES AMENDMENTS OF 1978 RESEARCH

Section 202 (b) 5.

Conduct of a program for international rehabilitation research, demonstration, and training for the purpose of developing new knowledge and methods in the rehabilitation of handicapped individuals in the United States, cooperating with and assisting in developing and sharing information found useful in other nations in the rehabilitation of handicapped individuals, and initiating a program to exchange experts and technical assistance in the field of rehabilitation of handicapped individuals with other nations as a means of increasing the levels of skill of rehabilitation personnel.

To develop this project and implement the law, a series of considerations were addressed by the World Rehabilitation Fund. These considerations took into account the following: (1) What are the knowledge and method gaps which would satisfy the information needs of the rehabilitation system in the United States? (2) In what form could information developed in other countries be presented? (3) What are the key transmission points/target audiences for sharing knowledge in the U.S. rehabilitation community? (4) What foreign resources can be identified to develop and share the information? (5) How can one evaluate the effectiveness of the program? (6) What steps could be taken to build on utilization of the materials?

The International Exchange of Information in Rehabilitation project is designed to facilitate the sharing of rehabilitation information transnationally by commissioning a series of brief monographs by foreign experts on topics which reflect knowledge gap in rehabilitation in the

United States. The design for the project emerged as the result of determining that a need existed for information to be made available transnationally to targeted groups of U.S. rehabilitation personnel at a length which would make information accessible and readable while at the same time satisfying curiosity about the particular subject.

In May 1978 a Transnational Conference was held by World Rehabilitation Fund to which four foreign rehabilitation experts (generalists) and eight U.S. "centers of influence" in rehabilitation were invited, including representatives from the State Vocational Rehabilitation system, the American Coalition of Citizens With Disabilities, a Research and Training Center, the National Rehabilitation Association, Rehabilitation Counselor Education, and the Rehabilitation Services Administration (now the National Institute of Handicapped Research), as well as the World Rehabilitation Fund's Officers and Consultants.

The primary goals (as they related to the International Exchange of Information) of this meeting of the Advisory Council were to:

1. Decide on the knowledge gaps in rehabilitation in the U.S. to which this project would be responsive.
2. Obtain nominations from the foreign advisors present for potential monograph authors (individuals from their countries who could expertly address the topics).
3. Determine the target audiences for the monographs.
4. Develop the evaluation component of the program.

Final selection of five monograph authors for the Project Year '78-79 was made by World Rehabilitation Fund staff and consultants and these authors were then commissioned to prepare monographs over a six to eight month period of time. An initial first draft was submitted for U.S. and foreign peer review. The resulting reviews were then returned to the author who had the opportunity to make use of any comments, suggestions or criticisms in the preparation of the final draft.

Also, where utilization conferences were held (the project design called for the holding of conferences to promote research utilization and knowledge transfer on three of the five monographs), authors made use

of feedback from conference participants to make final alterations in their material.

In some cases, the individual monograph will stand alone on its merits. In other cases, we are including United States commentary relating to the monograph itself and to the particular topic. This commentary emerges out of the peer review and participation research utilisation conferences.

The World Rehabilitation Fund, Inc. is indeed pleased to be able to present this Monograph Series to the United States rehabilitation community with the hope that the monographs will help to promote the continuing exchange of information trans-nationally toward the ultimate goal of enhancing the quality of life for the disabled in the United States and all over the world.

It must be said that the World Rehabilitation Fund, Inc. took the philosophical position of allowing complete freedom in the preparation of these monographs. Therefore, the views expressed (and the knowledge and information conveyed) are those of the author, the sources the author has selected, and the national socio-economic context from which the material emerges.

Howard A. Rusk, President
World Rehabilitation Fund, Inc.

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Many thanks also go to our project officer, George Engstrom, for facilitating the development of the International Exchange of Experts in Rehabilitation.

We also wish to thank all the participants at that conference who heightened the meaningfulness and usefulness of Ms. Simkins' work through their involvement before, during and after the conference.

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- INTRODUCTION

If you have lived to the age of 30 in various institutions without ever being able to choose what time you will have your lunch-and then find yourself running your own home, married and expecting a baby like any ordinary woman not dependent on a wheelchair, you find it hard to believe that anyone could doubt the value of independent living for people with handicaps.

In this monograph I hope to show, however, that

(i) the value of independent living is being questioned;
(ii) some of the conclusions must be of concern to all those in the rehabilitation

constituency, whether as service providers, policy makers or people with handicaps, and their families, on the receiving end;

(iii) part of the concern about the cost of services results from leaving out of the cost-benefit calculation whole chunks of the equation (such as the costs which are pushed onto the consumer, his or her family, and the community, including those costs created by doing nothing).

To bring this to life for readers working in a US context, examples illustrated by case material have been drawn from the fields of (a) assistance to overcome self-care handicap; (b) education and the mechanism of job placement; (c) special services in the employment sector and (d) housing. Developments of particular interest have been outlined.

Finally I have posed a few questions which may serve to bring out some ways in which these issues arise in circumstances which differ from those of the UK, and briefly considered implications for policy makers.

The serious questioning of the value of independent living by people of the utmost commitment to its ideals was focussed, for me, by a paper examining the experience of a number of West European countries (1) by Dr. John Noble, Jr., of the Department of Health, Education and Welfare. In that paper Dr. Noble has shown that the benefit-cost ratio arising from investments in rehabilitation is in danger of net reduction from at least three main directions:

- (1) current developments in the employment situation for the whole labour force;
- (2) the way cost-sharing arrangements between various government agencies providing benefits and services lead to inefficient targeting of resources and poor goal attainment;
- (3) The effects of high inflation upon both the costs of providing rehabilitation services and the opportunity costs* of that spending.

In addition, the apparent costs are being magnified because technological advance is in some cases leading to ejection from the labour force of less able and adaptable workers who have no intrinsic handicap. In communities where disability payments are more socially acceptable than unemployment benefits there may be a deliberate policy of adding such people into the numbers in receipt of disability payments when conditions suggest there is little or no chance of re-employment for most of those so ejected.

Part of the problem is precisely this one of the difficulty of obtaining a true picture of either the costs or the benefits of spending which is specific to the intrinsically handicapped. (That is, people affected by physical, mental or sensory impairments in such a way as to be handicapped -see (2).)

The use of cost-benefit analysis in the context of services for handicapped people

In a pure form, cost-benefit analysis seeks to apportion a value to everything and, by discounting, to identify a rate of return or net present value for any line of action. Complete quantification is not possible where such factors as independence, quality of relationships or psychic well-being are involved, and this monograph should rather be regarded as an attempt to view the subject from a cost-benefit standpoint. The value of such an approach should lie in the extent to which it helps to identify more of the costs involved, even though they cannot all be quantified. For the most part the benefits are more difficult to measure in money terms than the costs. Many of the external costs are only too obvious (though there are some costs, too, which are frequently ignored). If, because they are easier to measure, cost arguments are allowed to dominate the equation, the wrong conclusions may be drawn. Cost-benefit analysis should be used as a learning tool, a means of making the best possible

information available to decision-makers, not as a mechanical basis for churning out readymade decisions.

In this paper, the examination of cost-benefit aspects of independent Living has been undertaken in the context of the situation in recent years in the UK. Let me briefly outline that situation.

The UK background

Independent Living Programs, in their US form, do not exist in -the UK. Many aspects of their approach

- *assistance to overcome self-care handicaps,*
- *provision for access to appropriate education,*
- *employment and*
- *suitable housing, and*
- *opportunities for leisure and social activity on a par with that of their non-handicapped peers are, to varying degrees, intended and believed to be provided for.*

In its National Health Service, Personal Social Services and system of cash benefits, the UK has, on the face of things, excellent support for people with handicaps.

Nowhere, however, is there an accurate overall figure of how much this support costs. Some attempt may be made to put together the main elements, but each of them has fuzzy edges.

Total spending on the National Health Service and Personal Social Services for England and Wales in the year ending March 1978 was estimated at roughly \$12.5bn. (just under £7 bn.). This was equivalent to 5.4 per cent of Gross National Product-a proportion which had changed little over the preceding five years. Many of the provisions of the National Health Service, however, cover the whole population (examples include routine dental care, family planning services, midwifery and child care and, of course, treatment of acute episodes which leave no lasting handicap). Hence only part of that expenditure relates to people with handicaps.

Special employment services for disabled people in 1977/78 had a budget of something like \$114mn (over £64mn). There are also, however, other unemployment and retraining provisions which have shifting margins that take in many socially disadvantaged people, including some handicapped people some of the time.

The largest overlap is in respect of concessions and services to people over retirement age. For these, eligibility is on the basis of age not of condition, and although it is estimated that roughly two thirds of handicapped people are over retirement age, one can only hazard a rough guess that something over one-fifth of resources allocated to the retired are therefore going to people who are handicapped.

The place of the handicapped within this support complex is shown schematically in the illustration.

(It is even more impracticable to show the comparatively small proportion of spending on education which represents special expenditure for handicapped people over and above the normal costs of education, and there is also some expenditure on housing which will not be covered, though spending on adaptations by local authorities is included under Personal Social Services.)

The best estimate I know for the overall cost of supportive and rehabilitative care for our handicapped people is some \$5,400mn (£3,000 mn-1977 basis) of which two-thirds represented social security benefits (3). This sum does not include the proportion of retirement pensions which is paid to people with handicaps. From the economic standpoint all such benefits are transfer payments (that is, payments not made in return for a productive service, which in effect merely transfer income from one section of the population to another). Nevertheless, because of their significance in the support situation it is arguable that they must be taken into account. The relevant figure for retirement pensions would be in the region of \$1,800mn (£1,000mn).

Size of visible costs causing alarm

It is the size of such sums and the way they have grown in recent years that is worrying many authorities. Some fear that social welfare is in danger of transferring the "crippling" effect from the individual to the economy. (in the Netherlands, by 1976, it was being pointed out that for every person working and adding value to the-national income there were four who were too young, too old, sick or for other reasons not working (4).)

Often, detailed, studies of individual situations can show clear advantage for a particular course of action. A project which began in Coventry in 1975 has been studying the effects of substantially

increasing the resources allocated to one of its domiciliary services. Even at the pilot stage it showed substantial savings for the community from the use of these extra resources. The savings were chiefly in the form of reduced hospital costs. (Coventry Home Help Project-Report of Proceedings of One-Day Workshop, May 1978)

The costs that get forgotten

Even where a clear benefit: cost advantage cannot readily be demonstrated, however, there is another aspect which is too often not considered. It is not long since Dr. Noble and I were both members of a United Nations group discussing these problems, and among the many significant statements in the draft report of that body are the following:

"the costs of disability accrue regardless of whether or not rehabilitation services are available"

and

"one of the effects of rehabilitation is to reduce the costs of disability"
(5).

The second of these points can sometimes be clearly demonstrated-for example, by the successful restoration of a fracture case to full independence and employment through the relatively short-term use of orthopaedic surgery and physiotherapy. Even where the arithmetic is not so simple, closer analysis can often throw new light on the real ratio between benefits and costs.

Many of the costs to which the first statement (above) points as unavoidable are costs of dependence-both personal and economic-so in fact they are the costs of providing something that is not only expensive, but is not even desired by those on the receiving end.

It is true that there are some who become content to lapse into invalidism (sometimes for reasons which are themselves not unconnected with our service delivery mechanisms), but for those who do not want dependence it is important that the cost implications of independence should be fairly represented.

A great proportion of the costs with which cost-benefit studies necessarily concern themselves, such as medical, nursing and custodial costs, will be incurred in some form in any civilised

society whatever the conclusions about cost-benefit ratios. One real net benefit, therefore, is the difference between the costs of not doing all that could be done in the way of rehabilitation, and the cost of what is done.

It may help to express this schematically:

A		B
X	costs incurred either way (essential care, accommodation, daily living)	Y

A = "negative" costs i.e. the cost of what is not done

B = costs of what is done

x = the costs of avoidable extra dependence, e. g. more attendants or more active nursing needed as a result of lack of mobility aids; aid in kind because of nil or abnormally low earnings; institutional care because suitable housing not made available; costs in respect of dependents

y = the cost of what is done to aid independence: e.g. the cost of self-care training; aids to mobility (physical and financial aids); the provision of suitable housing; help to obtain employment including extra costs for basic education, training and job procurement.

Net benefit arises whenever the amount spent on y leads to a reduction in x which is equal to or greater than y. If y is spent without achieving any reduction in x (e.g. by inappropriate delivery mechanisms), then costs may be

$x+y+C$

Since C is always incurred, the real benefit possible is the difference between x and (x minus the results achieved by y).

The tricky part is to ensure that y actually does achieve the maximum reduction in x. Otherwise x will emerge as excessive social welfare costs as surely as damp emerges through plaster and wallpaper.

The cost of doing nothing

To see how the above works, take the case of the family having a 14 year old child with arthritis and a housing problem, quoted (Appendix 2) from Maureen Oswin's book *"Holes in the Welfare Net"*. The costs of not rehousing this family (x) include tying up of skilled nursing time and hospital resources beyond the requirements of the girl's intrinsic physical condition; "blocking" of a hospital bed against someone on the waiting list; costs incurred by the family in visiting; unnecessary pain for the girl and exhaustion for others whenever she did make home visits; and the incalculable cost of her boredom, deprivation, lack of privacy and isolation from ordinary life.

Either in hospital or re-housed she would have a roof over her head, food, clothing, warmth and essential physical care (the C costs). By spending the money required to re-house the family (y) the local authority would take over part* of the C element, but even if new building were involved it is unlikely that, spread over the normal period of years, the annual costs of that housing-plus a possible element of domiciliary service-would be equal to (x), and that leaves aside the possibility of employment for the girl herself at a later date, which will not come about unless she returns to the community

It would, however, be possible to allocate new housing which was quite inappropriate to the needs of this family, and the girl might then wind up back in hospital-and the $x + y + C$ formula would apply.

So often, however, in calculations of the costs and benefits of various forms of intervention, it is assumed that doing nothing incurs no costs. In our recent study (6) of cash provisions for people with handicaps in the UK, however, we illustrated the fact that this is very far from being the case. From one example of a man refused financial help to overcome his handicap in respect of travel to work it was clear that the annual cost to the Exchequer of not making such a payment was at least \$4,400 (1975 basis) as a possible payment from government funds towards his travel to work was replaced by a much larger payment from the same funds in the

form of benefits, to which must be added the loss of his contribution in tax on earnings and National Insurance payments. The job he failed to reach was not a specially created one in a sheltered situation, but a genuine one in open employment. As a result, he no longer contributed to GNP-his earnings would have been some \$4,800 (£2,180) after tax. Although the actual job may have been filled, the result was still a net reduction in the available labour force-in economic terms the value of that would depend on the local employment situation. However, since the cash benefits he received would not equal the income he failed to earn, there would also be a drop in consumer spending power.

In the same study we also illustrated the waste which can result from the wrong sort of action, such as supply of an inappropriate hoist: the initial cost of the item supplied may be lower, but not only is there a direct waste in that the equipment lies idle, the administrative cost of supply is wasted and so is the opportunity cost* of resources tied up in this way. It is also true that the ultimate economic consequences may be much greater: the need for which the aid was allocated is not met, a husband, wife or elderly parent continues to lift a severely handicapped person unaided, and before long the disabled person and the caring partner may be a double cost-one in residential care, the other in an acute ward in a hospital as a result of damage to the heart or back or perhaps of a hernia or prolapse.

The costs to recipients

Top heavy administration also introduces costs which have no corresponding benefit-a phenomenon which I am sure is not unknown in US experience. There is another aspect of administrative costs, however, which is less widely recognised. In counting the costs of administration, many studies take no account whatsoever of the administrative contribution exacted from the handicapped persons and their families. Too often systems are designed for the convenience of the administrators without regard for the data providers (requiring, for example, the preparation of documentation up to six or seven times a year for overlapping means tests, some on a monthly, some on a weekly and some on an annual basis (7).) No administrative costs, however, is assigned to the recipient families in analytical perspectives.

These costs do not cease to exist merely because they are ignored. Indeed the opportunity cost* of resources of time and human energy in such households is in reality often very high (in terms of caring functions

forfeited, child care, or the health maintenance of the carer put at risk)-higher than the resources required by routine work in government offices.

The value of social benefits which do not contribute to return to paid employment

Simply because they are so resistant to efforts to quantify them, time and again, studies are forced to leave out of calculation those social benefits which arise from various measures to increase the independence of people with handicaps. As a result, they are too often not even taken into consideration, nor any real effort made to analyse them. The UN group referred to earlier was more realistic about their significance. Representatives from widely differing national backgrounds found a common starting point for considering these costs in the diagram set out here (see next page).

While the services we are discussing may sometimes yield a net social cost rather than a gain if calculated in conventionally measurable economic terms, even in the present unfavourable economic circumstances the drive towards independent living should be maintained as far as possible because in the long run it helps to sustain the psychic well-being of a much larger number of people than are themselves handicapped; increases their satisfaction with life; preserves intact families which, if they break up, throw costly burdens on other services; it can reduce medical, nursing and custodial costs and increase the number of people having the prospect of a normal, economically productive course of life in the next generation.

My personal experience made me more than usually aware of these points, and of the arithmetic which is so rarely done regarding the cost of not providing support, or of inefficient targeting, and this study *has* given me a further opportunity to probe these aspects in the experience of a number of handicapped people *who* are living in about as near to Independent Living conditions as you will find in the UK. What follows is a look at the way this wider range of benefits and costs works out for major areas of Independent Living.

I - ASSISTANCE TO OVERCOME SELF-CARE HANDICAP

For eight years, until his death in 1974, I was married to a graduate electronics research engineer who had multiple sclerosis. For us there was no Independent Living Program, and the UK structure of support was then less adequate than now. By the time our daughter was five, Geoff

had been unemployed for 5½ years, could no longer speak or feed himself, and had very little voluntary movement. So it was with considerable personal interest that at that point (1972) I became involved in a study (8) carried out by The Economist Intelligence Unit of the costs of caring for handicapped people in their own homes, with supporting services, as compared with costs in various kinds of institutions*.

The illustrations show the costs as we found them (based on data for financial year 1971/72). The running costs for an in-patient occupying a bed in an acute ward in a London teaching hospital were close to \$250 (£100) a week-to which should be added the capital costs. Care in long-stay wards worked out at \$100 (£40) a week, while in modern residential homes it was just over \$80 (£32).

To compare costs in a domiciliary setting, alternative "packages" of services were allocated to our hypothetical clients-ranging from the constant attendance and intensive service package required by people such as those dependent upon a respirator, to the relatively modest services far more often required to enable less severely handicapped people to live in the community. Even where constant attendance and an intensive package of services was required for a handicapped person living alone, care in the home was \$10 (£4) per week below the cheapest residential care, and where domestic care was in a family setting, in which accommodation was shared and only a modest service package was needed, the cost came down to below \$40 (£16) per week -a striking contrast with the hospital and institutional costs quoted above.

Although the actual level of corresponding costs has more than doubled since we did that report, there is no reason to believe that the relationship between these different costs has been reversed.

Effects of shortcomings in service delivery upon costs

Moreover, we have pointed out the costs of care in the home were being unnecessarily raised by the form of service delivery. The system of community nursing provided in the UK used fully qualified nurses, much of whose time was spent on care functions which had no essentially medical content. In parallel, there was the Home Help service, which provided a level of domestic assistance which varied from authority to authority rather than according to the need of the recipient, covered a specified range of cleaning and shopping tasks, but did not include personal care tasks. As a result, uneconomic use was often made of the time of highly trained medical staff because there was no one else to do

such things as getting up or putting to bed a handicapped person living alone.

Many problems were also being created for families using these services by the fact that both operated an ordinary working day. So their earliest call was too late to help people who went to work, and handicapped people living alone were forced to go to bed at 5:00 or 6:00 p.m.-before the district nurse went off duty. Nor is our national Home Help service an unmixed blessing. Some of its users have reacted with wistful admiration to my account of the US idea of hiring (and if necessary firing) one's own Personal Care Attendant, on the basis of a job description determined by the client. The Home Help service, too, tends to be operated for convenience and supposed efficiency of *administration*. This is one of the services administered by local authorities, and the extent of service available varies according to where you happen to live. Those who depend on the meagre 2 or 4 hours a week (which is all it is usually possible to get) for the jobs they themselves cannot do may suddenly find there is a break in service, sometimes for several weeks, without advance warning or replacement. Administrators may regard this as an inevitable and minor irritant. It does not work like that for the client: one young wheelchair user who runs her own home and works a normal day in a very responsible job normally puts her washing into the machine before she leaves home on the mornings the Home Help is due. By the time the helper arrives the washing is done, and it is she who sees to the drying and folding. The girl, who had polio when she was only 10 months old, can strip her bed, but not make it, as she has weak arms and a short reach. Imagine her dismay and weariness when the Home Help did not turn up, and she arrived home late, not only to find the flat uncleaned, but the machine still full of wet (and hence heavy) washing and the bed bare of bedclothes it took her 1½ hours and all her remaining strength to get the wet things out of the machine and make some attempt to drape them where they would dry, and she had to sleep in a half made bed because although she uses a duvet for lightness and ease of making, she cannot put its cover on, and as the bed is against the wall she cannot tuck the bottom sheet behind it from the wheelchair. She eventually managed to put an underblanket across it, after a fashion, and pull the coverless quilt over her.... but even two weeks later no-one had bothered to notify her when the Home Help would be back, or why she had not turned up.

The very extent of the stress caused by such failures is in a way a measure of the benefit of some such service to those who are struggling with such determination to maintain their independence. The gross unit

cost per hour of the Home Help visits (i.e. without deducting payments made in some areas on a means tested basis by recipients) in the 1978/79 estimates was only £1.66, or around \$3.00.

Breakdowns are not, however, the only drawbacks to this service from the users' standpoint. Some local authority Home Help organisers have a policy of shifting round their helpers just as they have become familiar with the ways of a given client. In some areas this is dictated by the idea that helpers should not become too "involved" with client households. Other authorities laying down this policy are inspired by ideas of fair distribution: that is, not leaving the same Home Helps for too long with the heaviest care cases or the most difficult personalities. They do not seem to appreciate the disturbance caused to the users-particularly if they are liable to be at work for all or part of the time that the Home Help is at their home, or in cases where taking to school or collecting small children is part of the Home Help's function. If a helper is hired on the basis of a correct job description the relationship can be clear, lasting and reliable. Having had experience of trying to care for a tiny baby, work, and provide the care and safety of a near-helpless man, I have experience of both types of arrangement and those who object to the Home Help system are right in all cases where the client is not incapable of exercising such decision and control (and in those cases the confusion arising from such repeated disturbance is likely to be even greater).

Once again, you will observe, we are back to the one significant omission from my list of aspects of Independent Living Programs that are covered by the UK structure-namely independence itself, and the measure of control over their own living exercised by handicapped people under the systems which supposedly serve them.

A New Form of Service Delivery

Since we wrote *Care with Dignity*, however, a new service has sprung up which in many ways offers the best of both worlds. It is known as the Crossroads Care Attendant Scheme.

Crossroads is the name of a UK television serial which has a large following. The TV company responsible (ATV) gave its financial backing to this experiment in service delivery at the beginning because the scheme grew from ideas sparked off by contact between the series' medical adviser (Dr. Richard Hudson Evans), the producer, and a tetraplegic* viewer. An early account of the

Crossroads scheme is eloquent of the gaps that existed in the UK network: (my emphasis)

"if the disabled are to be cared for at home, the families need additional help beyond that provided at present by the statutory services ... help that can be relied upon at any time in the 24 hour period, including weekends and public holidays. They need to be assured that the help will continue for as long as they need it and will not be withdrawn at a moment's notice." (9)

The viewer who offered the benefit of his own experience when an accident to one of the characters was written into the series provides a classic example of the need for support of the caring household. Then aged 34, a diving accident two years earlier had left him paralysed in both upper and lower limbs. He lived at home, cared for by his widowed mother who was in her 60s. He had a fulltime job for which he had to leave at 8:00 a.m. but the care routine for anyone paralysed to this extent is vital, and his mother was having to get up at 5:30 a.m. to prepare him to leave for work. National Health Service nursing services did not function at such times! At the other end of the day there was a half-hour spell to put him to bed-usually about 10:00 p.m.-plus whatever care was needed in the night. The continual strain on his mother was evident.

Under the scheme created at Rugby, and similar ones which are springing up around the country (see map), a Care Attendant can be provided who in this case stays overnight, arriving at 10:00 p.m. and leaving when the son goes to work at 8:00 a.m., as many nights in the week as necessary (usually three or four). The attendant takes over the mother's duties completely, so that she can have several nights' normal sleep. On that basis she is able to manage the rest of the time, and to continue doing so over an indefinite number of years. Under the conditions described in 1973, she would have collapsed before now.

But 40 hours of care a week is by no means "typical". The great virtue of the Crossroads scheme is its determined flexibility in response to the needs of individual families, and even of the same families at different times. Another family had two boys, aged fifteen and eight, both affected by cerebral palsy. The parents rarely went out because the special care the boys needed made it risky to leave them with ordinary babysitters. The mother became a Crossroads client when she herself fell ill, but now needs only occasional help to have an evening out or a shopping expedition with a mind free of worry. The peace of mind given

by the knowledge that fully competent help is available on demand is beyond price to this family.

Another man, with sole responsibility for a physically handicapped partner, was in danger of cracking up because he was afraid to take a holiday away from her. He was persuaded instead to take time off on a regular basis, going in the summer to watch cricket, and now keeps going on just one day like this at regular intervals, sustained for the rest of the time by the prospect of the next such break.

Its costs

The amount of care attendant time required varies from 40 hours a week down to an hour or two a month, and averages have little meaning. The benefit in all cases is the provision of relief at the time and *in the way required by the recipient* and with the greatest possible stress on *reliability*.

As more Crossroads schemes are being developed in different parts of the country, however, a pattern is emerging: £7,000-10,000 (\$14,000-20,000) will set up a scheme and provide 100 hours of care a week, which typically means that the number of families being assisted is about 20. Just one of those caring relatives who suffered a heart attack, a breakdown or physical damage from unrelieved strain could very quickly use up that sort of sum in hospital resources plus the cost of institutional care for the handicapped person thus rendered unable to live at home. (In a study for the Cheshire Foundation (10) we found that the breakdown of the care situation by the illness or death of the caring partner was the most common reason for admission to the home being studied.) If the cost of taking even one child into care from these 20 families (£3,700-\$7,400-per annum, 1979 basis, purely for the costs of the responsible local authority) is added in, the *economic* value of the scheme quickly becomes evident. The cost of keeping the original paralysed Crossroads viewer out of hospital has never been more than £40 (\$80) a week, and is at times no more than £20 (\$40).

The costs given above include administration of the scheme, which consists largely of the salary and overheads (including secretarial help) of an organiser for each area, who assesses the requirements of new clients, selects and arranges the training of Care Attendants, and maintains the work schedules and financial paperwork. It is worth noting that the cost per hour of care under the Crossroads schemes works out at less than that of the Home Help service (around \$2.50 compared with just over \$3.00),

yet the effective value to the client in cases like those quoted is very much higher for a Crossroads Care attendant. Generally there is no real basis for cost comparison, since the precise service provided by Crossroads was simply not available from any other source.

As already stated, by accident of origin, Crossroads schemes are designed to help the families of those with physical handicaps, but relief care of this type could have particular value for families where there is a member with severe mental handicap, and perhaps most of all where a family has such a handicapped child among non-handicapped siblings – a situation in which the latter may receive less than they need of parental attention because of the ever-present necessity to give attention to the handicapped one.

What is to me most exciting about the Crossroads schemes is that they show we CAN still break out of the established patterns of service delivery. Sometimes, when one is on the receiving end, there is an impression that the arguments for the status quo are totally deafening to all administrators. I referred earlier to Dr. Noble's rather gloomy predictions about the involvement of so many independent sub-systems making it impossible to achieve a more coherent and effective system of delivery. I am very much afraid I agree, but in more sanguine moments I think of Crossroads and hope he may be wrong – because the Community Nursing Service is part of the National Health Service, the Home Helps come under Social Services administered by local authorities, and Crossroads has had funds not only from local as well as central government but even, more recently, from the Social Fund of the EEC.

The financing for each Crossroads scheme is worked out individually, and several are funded jointly by more than one of these sources.

The Effects of Service Delivery on Personal Mobility Wheelchairs

I wish I could say there was evidence of a similar real willingness to take a critical look at accepted patterns in respect of an element in self-care which is crucial for one particular section of handicapped people-namely wheelchairs. When a handicapped person said to me in passing (merely by way of explanation) that she had not been happy at one training school she was sent to "because she could not then get in and out of her chair", but when sent to a different centre *she was "given a different chair, from which the arms were detachable" and thereafter she was able to transfer in and out of it by herself*, the boundless vista of unnecessary dependence opened up left me speechless ... and what was required was no expensive special gadget-just detachable chair arms and the imagination to *see* what was holding her back!

Wheelchairs are "available" in the UK under the National Health Service to those who need them, and a recent survey carried out on behalf of the Department of Health and Social Security (11) concluded that over 90 percent of users (based on users of non-powered chairs) were "satisfied" with their chairs. The stated cost of the wheelchair service in 1977/78 was nearly £7mn or around \$12.5mn at prevailing exchange rates for the period. The number of chairs issued annually in England and Wales has now risen to just over 82,000 and the total on issue in mid-1978 was nearly 249,000, of which 13,500 were powered. The number of users is less, because something like one fifth of users have more than one chair (e.g. a powered chair usable only for indoors, plus a folding transit chair which can be used when going out by car).

Once again, however, service delivery is open to suspicion of increasing the costs (or decreasing the potential benefits *of* the present outlay, which comes to the same thing).

At the outset it must be noted that about 60 per cent *of* wheelchair users are over 60, many of these frail and with other accompanying handicaps such as poor vision, so that it is important not to think only in terms of the young-but that still leaves the 40 per cent of middle aged and young users. These include University staff (including at least one Vice Chancellor), people working in the Foreign Office, handicapped mothers with young children, teenagers struggling to find their own independence, and children, growing fast and needing to explore their personal abilities even more than non-handicapped children. Perhaps most readily forgotten, it includes multiple-handicapped children in long-stay hospitals. (12) In one of the hospitals included in a recent study "*confusion about who actually had administrative responsibility for repair and ordering of wheelchairs meant that some children remained without a chair. . . . 11-year-old Hugh's wheelchair was sent away to be repaired, but nine months*

later it *had* still not been *returned and nobody knew* what had *become of* it. *Hugh had a very large head and his wheelchair had to be specially weighted to prevent him tipping over.* Without the chair he could not go to hospital-school, nor be taken for walks around the grounds, he had to lie on the floor of the ward all the time. The nurses were worried that after nine months of *lying on the floor Hugh's* neck muscles would have lost the ability to support the weight of his head. . . . "

There are no extra costs in this case ... except to Hugh, who is thereby denied even those fragments of "independence" which were possible for such a child.

It is not only the most severely mentally and physically handicapped children who are caught in this particular administrative trap, however; one in six of all wheelchair users live in institutions of one sort or another.

Administrators tend to see merely that almost 1/4 mn wheelchairs have been issued "free" (that is, paid for under the National Health Service). As a result the system which provides and services wheelchairs is geared to maximum use of standard products. Nonstandard ones-given that someone tells you they are a possibility -have to be argued for and waited for. For growing children or people with deteriorating conditions they are often waited for so long that they are no use when they do arrive-a wasteful as well as cruel disappointment, and a further assault on independence.

Wheelchairs are "on loan" to the user, but unlike a true loan service, the user is not free to send back one model and try another of his own volition: it is necessary to have medical specifications. However, when these are sent they are frequently ignored or modified by engineers who are not familiar with the condition of the person the chair is for, nor his or her environment-so that a man whose arm strength diminishes abruptly as his arm is extended may receive a self-propelling chair on which the brake handle pushes away from him instead of pulling towards him.

Again, powered wheelchairs, which cost three or four times as much as standard non-powered models, are usually not allocated until the authorities are convinced that the intended user is unable to propel a non-powered chair. So the housewife with failing strength is no longer able to do even the lightest household jobs such as washing up or clearing the table, because she is using all her reserves just to get from

place to place and the man who, with a powered chair, could open the front door or answer the telephone, will find the caller gone by the time he gets there-and again must ask someone else to go for him, increasing not only his dependence, but the demands on those around him.

The people who administer the wheelchair service often have no personal knowledge of wheelchair use, and think of a wheelchair as a means whereby a passive occupant may be moved from one place to another. While for some very frail or elderly people and for portage use in hospitals this may be true, for many others it need not *and should not* be so.

New approaches to provision for Personal Mobility

I know of only one piece of research which has taken a really fresh look at wheelchairs and that is still looking for publishers. It was carried out by John Mitchell when he was at the Institute for Consumer Ergonomics at Loughborough (13). In his report he argues that the entire wheelchair concept needs re-examination.

Disability is the current yardstick for wheelchair and other mobility provisions. John Mitchell suggests a better way to assess the individual's role with regard to himself, his, household or his employment, and a way of revealing a more accurate picture of the costs both to the individual and in terms of special services, when that role can no longer be played: it is by relating the mobility needs of the individual to a series of responsibilities.

This accords with existing practice in that self care, care of the household, pursuit of education and employment are all of them responsibilities which in one way or another are recognised by Social Services as a basis for the provision of service or assistance. Impairment does not relieve an individual of his responsibilities (for example, as a parent, to provide for his family). To quote John Mitchell:

"The basic responsibilities considered are as follows:

Self care

Care of the household, indoors (e.g. housework)

Care of the household, out of doors (e.g. shopping)

Preschool and play activities

Education and employment

As an example, self care includes activities such as the consumption of food and drink, toileting and keeping clean, dressing and undressing and activities associated with keeping warm. These activities involve moving between different rooms in the house, including the bedroom, bathroom, kitchen, dining room, living room and the front and back doors of the dwelling. Various pieces of equipment and fittings are associated with these activities and are, of course, often used in particular rooms. Such equipment includes the bed, tables, the washbasin, the toilet, the bath, the TV or radio and fittings such as taps, window and door catches, electrical switches and so on. In fulfilling the responsibility for selfcare the need to move about within the home to carry out such activities using specific environments and pieces of equipment must inevitably determine an individual's mobility requirements. They should also be used to determine the performance of wheelchairs suitable for allowing such responsibilities to be undertaken by those with mobility handicap.

The responsibility to maintain social well-being is implicit in the list of responsibilities suggested. Many of these responsibilities will involve the maintenance of social as well as physical wellbeing which will only be fully met by activities outside as well as inside the home.

The types of environment which will be entered during the fulfillment of the social need will be too varied to allow a brief description. One factor, however, which is certain to be most common to most people is the need to make use of private or public transport in traveling between the house and other destinations." John Mitchell is also rare in appreciating that legs are used for more than a means of moving from place to place in a single plane: one of their functions most of us take most for granted is that of *adapting our height* to work at different levels. He recognizes that "the attempt to provide universal function in a single wheelchair may be self-defeating because its size, weight, cost and power consumption would be too great" . . . and suggests instead a modular system from which the range of functions required for a particular individual's responsibilities could be assembled by the supplier as required.

Of those who accept blandly that the wheelchair user who has no ergonomic training-is "satisfied" with current models, we need to ask what criteria they have for being otherwise? Many disabled people who are in employment spend an average 90 hours a week (11) in their wheelchairs. With no special training, about half of users in the official survey proposed ways of improving their chairs, especially in respect of comfort, propulsion and maneuverability-and they did not conceive of the possibility of height adjustment as one of their functions.

In the story of Terry Wiles, a thalidomide-damaged youngster who was abandoned to life without arms or legs and with no family, but who has been adopted by a man with engineering skills and a sympathetic imagination (14) there is not only the story of a most amazing family, but also of a series of inventions for which the criteria were precisely those of John Mitchell: what does this 21inch person with no arms or legs need to do? How can the engineering problems be solved? First came the shoulder-controlled powered mini-vehicle that gave the boy freedom to move in one plane; then the lifting device which enabled him to get in and out of it at will; then the feeding device to stop him losing weight because he wearied of struggling with the mechanics of feeding himself with artificial arms; the extra lift to allow him to get to a chair or table by himself. But when all were destroyed by fire, the only official alternative was a motorised wheelchair with a fixed seat (so he had to be lifted in and out), with poor maneuverability, slow speed (and that only on smooth surfaces)-and to get *this (i)* visits from 3 senior officials from three different parts of the country, (ii) a day of travelling and trying chairs at a distant hospital, and then (iii) another day of travelling for Terry and his family to a complete medical examination "to see if he was physically and mentally capable of driving a powered wheelchair" . . . at the same hospital where, a week earlier, he had driven every type of vehicle they possessed! Only *after* all that by several weeks was yet another official sent (iv) to inspect the cottage where he lived (if it was not "suitable" he would not have the chair)-when the chair was to be for use in school. Then, after two further weeks, the family received a parcel. A tray. With no covering letter. Later they discovered that the chair had been ready "some weeks" but was "waiting for a part." What part? The tray!! I recommend reading of that book to all administrators as an object lesson in the wrong way to arrange service delivery.

When, eventually, Terry's adoptive father was able to make a new model of the boys personal mobility aid, its relevance to the present discussion, in terms of every kind of self care, was immediately apparent. Now he could help his mother to clear or lay a table; he could put on the TV set, go into the bathroom and wash his face, into the bedroom and get onto the bed: he need no longer wait for someone else to get him up. He could open drawers, select books from shelves-even pick up a spanner from the floor faster than his father when it was dropped at the workbench. At school, too, he needed less help from others-an important factor since by this time he was attending a normal school.

Of all the changes it meant, what was most significant to Terry himself? "No more legs! ... No more chair legs and table legs and people's legs! I can start to live just like any other boy"(13)

The rejected alternative service delivery system

One possible alternative to the existing wheelchair service (which would have cut down the waiting time greatly in Terry's case) has been officially considered and rejected in the personal mobility sector. That is the option of cash, with which people could make their own choice of wheelchairs.

Of course there would be problems, chiefly (i) with the existing service delivery structure, which would become totally uneconomic if too many people chose the cash option; (ii) making sure that the money was properly used and (iii) ensuring that handicapped people and their families had access to proper advice in the selection of their wheelchairs (though it is open to doubt whether commercially-motivated advice from manufacturers who have an interest in consumer satisfaction would be any worse than bureaucratic decisions by those who will never be answerable to the patient). I suspect the real fear is that increased cost to the Treasury would accrue if attitudes to wheelchairs changed.

Personal mobility in the larger context

Yet a precedent has been established in connection with mobility. Pushed into phasing out Invacars* (Ref. 6, p 37) for reasons which had nothing to do with giving users choice, government balked at the Sharp enquiry's suggestion that minis would be no more expensive. They knew the total cost would rise because the end product would be, on design and social grounds, more acceptable than the Invacars.

Listen to a man of 32 who has struggled all his life with the gross distortions and handicaps, above all of communication, which fall to the very athetoid** spastic, and who achieved his ambition to drive an ordinary car (to the Institute of Advanced Motorists' standard!):

"My chief source of pleasure in life is driving my car. This ability also gives an independence that could not otherwise possibly be known.... If it is possible to become close to being "normal", I feel I achieve this ideal whilst I am driving my car ... I am able to participate in the pursuit on the same basis as *everyone* else and people pass by without *differentiating* me from anyone else . . . "(15)

There was also another factor, however, in the government decision: in the early 1970s those who were *more* disabled-too much so to drive themselves at all-received no help. So instead of a replacement vehicle, the Mobility Allowance was introduced (in phases, from January 1976). It was being paid, at the end of 1977, to 63,000 people and it is still gradually being extended beyond the first limited age groups. It was costing £25mn (\$42.5mn) at that date (annual basis) and represented an addition to recipients' incomes, at first, of only £5 (\$9) a week (£7-around \$12-by the end of 1977). There was immediate protest because such a sum went no way toward giving out-of-doors mobility comparable to that which the facility of a personal vehicle had offered to Invacar users (Ref (6) p. 208). Eventually, by the efforts of many organisations co-ordinated via the Royal Association for Disability and Rehabilitation, a financing operation was created, called Motability, through which a person entitled to Mobility Allowance could commute that allowance into payments for use of a car. Discounts of up to 18% on new cars and 17% per cent on car hire were negotiated with the motor trade. In effect, by this arrangement, National Insurance benefits, helped by mixed public and private sector finance, could secure a product (and a service) to the client's specifications. Here a "transfer payment" which the recipient never sees is used to buy a car or service in kind, and private finance is involved which is invested on a quasi-commercial basis. Threatened by Budget tax increases, the scheme has since been the subject of concession.

II - COSTS & BENEFITS-EDUCATION AND THE TRANSITION TO EMPLOYMENT

But let us look again at the story of Terry, the boy with so many other problems apart from mobility. That same book (Ref. 13) has much to say that is significant concerning not only Terry, but also another severely handicapped child, on another subject which is of crucial importance in determining the success or otherwise of transition to independent living-namely education, in its widest sense.

In my researches among people living independent lives as handicapped adults, one fact which emerged is certainly not new, and with hindsight should be obvious on common sense grounds alone: those who have already received at least their primary education before becoming handicapped have a very much better chance of successful independent living. In this way at least, some of the most obviously physically handicapped- tetraplegic spinal injury cases, those who had polio as young adults-have, at least some advantage in coping with their situation. They had in many cases completed their education under ordinary conditions of fitness before becoming handicapped. Indeed, the very nature of the accidents which

produce so many spinal injuries-diving, playing rugby or driving-means that those who suffer them were fit and often well educated by the time the accident changed their lives.

If they have not had this particular advantage, then a key factor for those whose handicaps are of congenital or infant origin is the attitude of their parents and family-whether it was heavily protective, or robust-firmly expecting a full contribution, within his or her capacity, from the handicapped child.

In an effort to help those handicapped from birth or, early childhood, "special" education is available. It has to be remembered that only a very small proportion of handicapped people become disabled before middle age, and of those a still smaller number are children. We have an estimated 150,000 children in special education, many of them with multiple mental and sensory as well as physical handicaps, but for many reasons one cannot simply look at the cost of this provision as the cost of education for handicapped people.

First, in a country where education is paid for out of central government funds and is compulsory for every child, only the extra costs of special schooling should be counted as part of that sum for these youngsters. (That is, the cost of special buildings, equipment, staff ratios.)

Problems in service delivery-- academic standards

Secondly, there is some feeling among handicapped people that there is another amount to be offset against this because they have received less than a fair share of ordinary education because they were at special schools.

Before all those who labour long and hard for special schools descend on me, let us be quite clear about two things: one is that far more of the special schools are today attempting to reach at least some educational qualifications, offering 'O' or 'A' level or Certificate of Secondary Education (CSE) courses for those who are capable of them. The people I have talked to for the most part finished their schooldays 15 years or more ago, when the importance of academic achievement for handicapped children was much more rarely acknowledged.

-- the built-in problem

A second factor ought to be obvious, but is much less easy for those unfamiliar with handicapped children to appreciate fully: it is that the children who are in these schools have a severe, in many cases a very severe, extra task to do in order to reach the point from which ordinary children start the education race--and most non-handicapped youngsters are pretty fully stretched for most of the time in order to achieve "normal" academic standards by the time they leave school. So, for example, a child who cannot hear anything except what is specifically directed to him through special teaching aids and methods is therefore receiving only a fraction of the complex normal input of education for living; or a baby who has no hands with which to learn about spatial relationships or even his own body shape, or to feel the softness of fur or the wetness of water, can only do so if someone takes the trouble to help him to these experiences in some other way; and a child who cannot speak has perhaps one of the greatest of all handicaps to normal learning.

When all that is said, however, one is still left wondering if the system of special education does not sometimes impose extra handicaps on these already handicapped youngsters. How well would the ablest of us learn in these conditions--experienced by a young woman who left with no qualifications: "the classes were of very mixed ability, we were always stopping-for 'accidents', for non-readers, for people having 'fits' etc. Out of 15, only about 4 were of average intelligence . . ." No wonder another person interviewed said that at the special school she attended until the age of 16 "they gave little teaching above junior level", or that it took seven more years after leaving school before the man I quoted concerning driving was able to acquire basic qualifications to get a job. He said in another context "I'm not good, but I'm persistent" but how many people have persistence of such heroic proportions as to face seven years

of badgering other organisations, and perseverance, and disappointments, in order to secure the chances available to non-handicapped youngsters, and is there not something wrong with a system which imposes such a struggle on the handicapped, on top of all their other problems?

- location

Another problem with special education is where to locate it: many of those who had experienced special education have had to leave their families and travel long distances to residential schools to do so, in some cases at the cost of becoming alienated from brothers and sisters, some of whom were born when they were away, grew up largely without seeing them, and never really thought of them as part of the family at all. When these children leave school they have no local friends-and of that, more later.

Integration

Of course there are circumstances in which a handicapped child can only achieve independence away from an overprotective home situation, but the main reason is the small numbers of children involved: the total requirement of special skills and equipment for particular types of handicap is small and the number of establishments providing them is not enough for one to be near to every family which needs it. There are more special schools now which offer day facilities, but nevertheless there has been a swing of opinion in recent years towards endeavouring, wherever possible, to place handicapped children in normal schools. Much then depends on the attitude of the staff--the extent to which they prepare the ground among the non-handicapped pupils, the ingenuity and flexibility shown in making available to the handicapped youngster every school facility and activity that can possibly be attained (if, in some respects, with adaptations). Recently there has been some resistance from teachers' unions to what they regard as undue pressure to integrate education in this way, and certainly it cannot be the answer in all cases. However, for many less severely handicapped children, and some even of the very handicapped, integrated education is now the preferred way to prepare for independent living.

This of course further obscures any assessment of the extra costs of education for handicapped youngsters. There is no basis for dividing those "suitable" for integrated education from those who are not. Every case must be decided individually on the basis of a combination of physical condition, family circumstances, and the attitudes of local schools or the desirability of residential schooling at a distance if the appropriate special school facilities do not happen to be available locally. In the UK, education, like the Home Help service, is

organised by local authorities and the situation will vary markedly according to where the family lives.

Beyond school-leaving age-- mechanism or lottery?

Whether in special school or ordinary school, however, the handicapped youngster's troubles become even more apparent at school leaving age, when children who are not working for higher education (e.g. university entrance) cease to be the responsibility of the education authorities. The need to allow handicapped children to reach "normal" academic standards is not built into the system, and they are often obliged to leave without any qualifications. Whether they succeed thereafter depends very largely on whether they have the good fortune to encounter someone who intervenes. For there are further education facilities, including correspondence courses and specialist colleges and organizations offering training for handicapped people beyond school leaving age. Once out of school, however, it is largely a matter of luck whether they find anyone who is really interested in providing opportunities for them to go to their maximum potential rather than offering them a typing course or repetitive job with no prospects and a pittance of a wage. The stories of a few of those who have "made it" through this limbo will illustrate where so many others have got lost on the way.

During Robert's seven years between leaving school and entering employment he began by going on certain days of the week to a Work Centre, which provided occupational, educational and social facilities designed for those unable to obtain outside employment. He had a trial period at a sheltered workshop- not a success. He sent off many job applications for posts which he thought he had chosen with care, only to be disappointed. He describes as "disastrous" the first few years after leaving school, with no real sense of direction. He would have liked to transfer to a day college of further education. When he did succeed it was through finding the Midlands Council for Preparatory Training of the Disabled, through which he did three correspondence courses and passed examinations in bookkeeping, typing and 'A' level English, among other things. At last, at the age of 23 he began a probationary period in open employment so successful that he is with the same organization now, 10 years later.

The girl whose special school experience I noted earlier left school with no qualifications, went to a residential college for handicapped students, to learn typing, and expected that they would have a placement service at the end. They didn't, and by this time she was told she was too old for the Youth Employment Office to take any interest.

A girl handicapped by spina bifida, who attends a residential school, in 1979 became the youngest of that year's Churchill Fellowship winners, on which she chose to come to New Jersey to study Tri-chem art with the manufacturers, with the aim of teaching its use to other handicapped people in schools and hospitals. Her school "wanted her to work as a typist for .£4.00 (\$8.00) a She was encouraged to apply to the Churchill Trust by her mother, who "felt she could do more than that."

Another of those now living independently is a wheelchair user who had no education above junior level when she left her special school at 16. She was then trained in keyboard operation (typing and comptometry) at a residential college. She went to live at home for a year and hated both that and an uninteresting job. She talked a social worker into finding a solution-a hostel where there was work on the premises which was very poorly paid, but some residents worked outside. This became her base for 8 years (during which time she incidentally trained and was accepted as a volunteer in the Probation Service). She thought her keyboard experience might be useful in connection with computer operation, and applied to a commercial computer school for training. She was accepted despite access problems, but the specialists in training for disabled people refused her financial help unless she went back to do a six month residential course at her old college. The commercial course was 6 weeks. At length the commercial school said they would start her on the course while the fee battle went on and that if the money was ultimately refused, they would write off what she could not pay. Helped by her previous training, she completed the course promptly and at the end of 8 weeks the school's placement service had found her a job where she now earns over (3,000 (\$6,000) a year. Her friend, who took the residential course, was still jobless long afterwards.

A young man from a family of eight left school at 16 with a reading age of 13 or 14. The fact that today he is a graduate with a professional salary, a rewarding job and a flat of his own is largely thanks to a man in a lift and a college of nuns! He became a lift attendant. A regular user of his lift, shrewdly assessing how to secure his interest, led him on from soft porn comics to read Fanny Hill, and thence to other novels. He eventually got a place at a college which specialised in basic entry qualifications, but he still had to do bookkeeping and 'O' level examinations at night school. He got a job as a cashier and kept on with the studying. When the night schools were full, friends in the local Association for the Disabled found the nuns-who agreed to teach him privately. Eventually he found himself at a Polytechnic, where he took a degree in Social Studies.

Without financial help from the same local association, he could not have managed at college, nor obtained the first car which enabled him to get back and forth as he needed, nor eventually set up his flat: pure cash was the

determining factor. He is now doing a valuable co-ordinating job for other handicapped people and organisations, living independently ... *but the process of getting to that point took almost 14 years after leaving school.*

Implications

This young man's story raises some interesting issue. Like all the others above, it points to the waste which occurs unless we ensure that education and training for handicapped people, especially those handicapped from infancy, actually works.

When it fails because it is poorly done, or is not in the form that is needed, not only are the skills and resources squandered which are of potential value to the community, but also something even more difficult to evaluate: the time available to handicapped people for living to their full potential.

Effects on earning power

Even in cash terms these people are being robbed: when he left school at 16 in 1965, our interviewee earned £5 a week. With various tips and trading ventures of his own, he estimates he made another £5 most weeks. He lived with his family. By mid-1967, with his basic qualifications, he still earned less than £8 per week. By changing jobs he pushed it up to £10, then £11.50, then £12.50 and with paid overtime, this last job brought him an average of £18.00 a week.

His salary now is almost £77.00 a week (about \$150.00). If his after-school training had taken the usual 3-4 years, he could have been earning at a corresponding level for 10 years.

It is also worth noting that he now provides an example of a form of "reverse discrimination": no other member of his family has so much as a single 'O' level qualification, and had he not attracted attention because he was handicapped, he doubts whether he would have been given the chance to break out of that pattern. It has been suggested (e.g. by Dr. Noble in the paper referred to earlier (Ref. (1)) that rising wage replacement ratios of benefits will eventually mean that rehabilitation will be limited to "persons of higher socio-economic status", disqualifying from such expenditures those whose former earnings were low.

So who will decide the "socio-economic status" of candidates such as this young man? And on what basis? In all the cost/benefit calculations concerning education, training or rehabilitation for handicapped people no offsetting allowance is made for the lost potential contribution of those who are not adequately helped - because no one has any basis for assessing what they might

have done. If Dr. Noble is right --- and I very much fear that he may be - then there is a serious danger that the potential of others like this young man will be lost because of a policy which, looking at them in aggregate, will argue as benefit levels rise that because their previous earnings were low there is little opportunity for them to earn more than benefit levels in a slack labour market (and in the UK at least, unemployment continues to pull towards higher levels while unfilled vacancies bump along around a lower level). This assumption may be starting from the wrong premise if attitudes and services delivery in the education sector suffer from the kinds of problems outlined here for the UK.

Further and higher education

There is, in the UK, no exact parallel of the educational function of Centres for Independent Living which are associated with a university campus, but a growing number of universities are now opening up their facilities to handicapped people, and a coordinating role is played by the Handicapped Students Bureau. Perhaps the one great advantage in the UK is the Open University: conceived as the University of the Air, the OU uses TV and radio, a system of personal tutors, and short residential sessions, to react mature students, housewives and anyone else who can qualify for degree entrance and wishes to study at home. It has large numbers of handicapped people among its students, and in some respects may be said to be ideal for them, though some regard it as too sheltered an option and not as much help in integrating to the outside world as an ordinary university.

Service delivery

Of the further education establishments of various types which exist to help handicapped people, all but a few--mostly for the blind--are post war, many originated within the past twenty years. They were almost all started by voluntary organisations, and although courses 'are approved by the government employment and training services, which may help with grants for the course fees and subsistence, they remain independent.

Do they work? Do they give handicapped people access to the extra education and training they need? The answer is patchy. Some of them are described by former students as "more fun than work", others as very good and efficient, with excellent staff and a high success rate. Those who have something of an overview claim, however, that some do not keep abreast of the needs of industry and commerce: bookkeeping courses were still being taught in terms of day journals when offices wanted Kalamazoo and computer systems; new courses have been created in shoe repairing when there are fewer and fewer jobs in this trade because shoes now have synthetic soles and are more often replaced than

repaired; watch repairing is still being taught while the newspapers are full of ever-cheaper offers of quartz watches. In a sense, this is part of a more basic criticism that aims are too low-they offer qualifications inappropriate to the courses and jobs people want to go into. Among the handicapped people who have succeeded in reaching independence it often seems they did so only because they refused to accept the advice they were given.

Undermining the employment outcome

This problem goes right back into the primary and secondary levels of education: in the present state of the employment market, people whose concern is with handicapped school-leavers are worried because they claim there is an increasing tendency in both special and ordinary schools to assume that youngsters with disabilities will have no chance of getting a job. As a consequence, all the emphasis is put on developing their interest in some sort of pastime with which they will be able to while away their enforced leisure, such as gardening, and the development of non-remunerative occupations-in itself a good and healthy objective-is becoming an excuse for lowering the expectations of these youngsters, further undermining both their equipment and their motivation for future independence.

Certainly it would be quite wrong to give them a false picture of the ease with which they will be able to get a job, but is not the most economic course to equip them better than average, in order in some measure to redress the balance on which they compete with the able-bodied, rather than teach them to give up before they have begun? If "equal" education leads to lower performance, but a short input of better training could give at least some of them the ability to cope independently, the extra input would appear to be justified on economic grounds.

Moving on to employment

A study of the experiences of handicapped school-leavers (16) carried out by the National Children's Bureau, sheds some light on the unquantifiable costs of the double handicap represented by disability and its effects on educational attainment, in a bad employment situation: proportionately more disabled than non-disabled young people are without jobs; those who are out of work remain so for longer (and many of the most severely disabled are not even included in their calculations because they were not considered eligible for open employment).

One thing clear from Column A is the extent to which the non-disabled are concentrated in the shortest unemployment period especially in the case of the

immediate post school age group (under 18s). They quickly drop down to relatively small percentages. The disabled group as a whole, and the under-18s particularly, were much less likely than their non-disabled peers to be placed in this time, so that 6 months later (column C) we find 20-25 per cent in all age groups still unemployed. And beyond a year (column D) only 1 per cent of non-disabled under-18s were left, but almost 13 times as many disabled.

Unemployed disabled and non-disabled young people out of work for different periods of time

Percentages, except column E.

Duration in weeks	U p to 13	13-1- to 26	26+ to 52	52+	Total number
Age groups					
Disabled					
Under 18	46.3	15.6	25.2	12.9	449
18-19	38.5	20.6	23.3	17.6	1,417
20-24	32.6	19.0	22.2	26.2	3,645
All under 25	35.2	19.1	22.7	22.9	5,511
Non-disabled					
Under 18	88.7	5.4	4.8	1.0	267,911
18-19	58.9	18.1	16.3	6.6	120,469
20-24	51.4	19.2	18.9	10.5	221,205
All under 25	69.3	12.9	12.2	5.6	609,585
Column Ref.	A	B	C	D	E

Source: Department of Employment (16)

Job placement mechanisms

Over all groups---handicapped and non-handicapped controls -the most important source to which school-leavers turned for information about jobs was within the school (38 per cent); next came parents; then newspapers and friends; then other relatives and then Careers Officers (only 19 per cent). The Youth Employment Service seems to have performed a very limited role in helping these youngsters to find work.

The importance of informal contacts in job seeking was especially marked for handicapped school-leavers, while the non-handicapped tended to go after advertised vacancies more.

This gives particular significance to an earlier comment, that children going away from home to special schools do not form the network of local contacts which helps their home-based peers to hear about job vacancies.

While there is a good deal of discussion about integrated education, job placement services after attendance at further education or training establishments for the handicapped are rarely considered as a determining factor in the benefit-cost ratios of such training. Yet it is clear that they can play a crucial part in deciding the effectiveness of transition from education to employment. With a few exceptions, the official agents of the Department of Employment do not seem to be very highly rated by the disabled, either school-leavers or more mature job-seekers, and if you consider the matter from the standpoint of the average employer, it is not hard to see why. If you, as an employer, have a call regarding a job applicant from a Disablement Resettlement Officer, or a named college which you know to be a specialised one for handicapped people, from the moment you identify the caller you know they are offering you someone with a problem. That the applicant may also have the skills you require has yet to be proved.

If, on the other hand, a commercial agency calls, and it is one you have dealt with satisfactorily in the past, you discuss the applicant's abilities first, and only after you are interested, the fact that he or she has a handicap.

III - EMPLOYMENT--SPECIAL SERVICES FOR HANDICAPPED PEOPLE

Before considering how specialised employment services for handicapped people affect independence I will briefly outline their structure. You may remember they cost an estimated £64mn in 1977/78 (around \$144mn at the exchange rates prevailing then).

This was made up of:

Sheltered employment	£28.0mn
The Resettlement Service	£13.8mn
Employment Rehabilitation Centres	£10.5mn
Training services for disabled people	£10.9mn

There would also be a small overlap from non-specialised employment services, but since these are provided for non-handicapped people also, they do not strictly belong to the category of services with which we are concerned.

The administrative structure for these services comes chiefly under the Department of Employment, and its main features are shown in the diagram on the next page.

The services provided fall into the following broad categories: First, and probably with the longest historical roots, is job reservation. This, however, has never been very important, since the designated occupations were those of attendant in car parks and lift attendant in electric passenger elevators. Handicapped people themselves have been opposed to the further extensions of this scheme because the two occupations associated with it were of such low status that they gave backing to the idea that disabled people were only capable of menial employment.

Second, there is a quota scheme whereby a percentage (for many years now, 3%) of the jobs in any firm having more than 20 employees should be filled by disabled people. Companies which are below quota are not permitted to engage any employee without first obtaining a permit, which will only be granted if no suitable disabled person is available. In common with other quota schemes in other countries, this one was introduced at a time when there were many war-disabled, readily identifiable, and manpower was urgently needed for war effort or post-war reconstruction. Over the years, the proportion of people with mental handicaps and age-related disabilities has grown. So has the appreciation that disability is a dynamic process--it may deteriorate, or it may be transitional rather than permanent--and that the line between disability and other forms of employment disadvantage (arising, for example, from personality problems or social handicaps) is not a clear one.

Not only are we faced with handicaps which are less visible and clearly-defined, but there are now much higher levels of unemployment in the workforce as a whole.

The Register of Disabled People- shortcomings

In addition, the quota system depends on employers being able to draw on a register of disabled people. In recent years, however, there has been increasing reluctance on the part of people with handicaps to categorise themselves by registering as "disabled", and in the case of some mental handicaps, doctors are strongly opposed to registration, feeling that it implants the false idea that the condition is permanent and non-susceptible of improvement.

There are other objections: many feel it is a positive disadvantage when seeking employment to admit to registration. Certainly since 1965 the unemployment rate for registered disabled people has been between 2½ and 5 times the general unemployment rate. Again, the register is supposed to include those whose disabilities constitute an appreciable handicap in getting or keeping employment: when a spastic whose physical handicaps are apparent for all to see is in a job he secured by his own efforts and has held for 10 years, should he still be so described? But if, as it were, the successful "graduate off" the register, that makes nonsense of the quota requirements, leaving the very companies which are best at integrating handicapped people in breach of the quota requirement.

In 1951 there were over 900,000 people on the register. By 1978 there were less than 500,000. This decline does not indicate a comparable fall in the numbers of people eligible for registration among the workforce. Many of the special employment services outlined here are available to non-registered handicapped people as well as to those on the register, and there is ample proof that there are now more unregistered than registered disabled people looking for work, and probably more unregistered disabled people in the workforce as a whole than there are registered. As a result, even if all unemployed registered disabled people were to be taken on by firms falling under the quota obligation, the national rate of quota compliance could only rise to 2.1 per cent—in other words it is no longer possible for all employers to fulfill their quota obligation of 3 per cent.

The decline in numbers on the register has meant that permits (for below-quota companies to employ non-registered applicants) have had to be issued more and more often, and there is some evidence that for many below-quota firms permit application has become a matter of routine, so that in these cases even the educational function of the quota scheme has been lost.

In 1975, to test the situation, a strict enforcement campaign was undertaken for 6 months in 6 towns. There was an increase in the number of employed disabled people applying for registration (possibly reflecting pressure from employers anxious to establish their own position), and some increase in the number of firms applying for permits or satisfying quota. There was a small increase in the number of vacancies notified specifically for disabled people, and two prosecutions (fined £25 and £200)—but the basic objective, of getting handicapped people into employment, gained hardly at all: the trend in the placing of disabled people followed almost exactly that for able-bodied people. The conclusion was that strict enforcement is not justified in terms of the benefits resulting in relation to resources used.

The costs of quota operation in 1977/78 were £2.4mn (\$4.4mn) and some Disablement Resettlement Officers claim that 25 per cent of all their time is spent on administration of the quota scheme.

The scheme has lost credibility, particularly with MSC staff operating it. In any case, the one function it is agreed to have performed in its earlier days--that of breaking down employer prejudice which was based on ignorance--needs a fresh approach in cases where prejudice against handicapped people still exists (after all the changes in public knowledge and attitudes that have occurred by now) and in the altered labour market conditions of today.

Moreover, employment services for non-handicapped people have been modernised to provide fast and efficient service to jobseekers and employers, and the more ponderous and bureaucratic elements in the quota scheme can actually create problems, e.g. making it difficult for below-quota firms to have their vacancies put on self-service display. (17)

Positive Policies

In 1977 the Manpower Services Commission launched a campaign centered on a booklet "Positive Policies" (18), and intended to create a receptive mood among employers. The Positive Policies approach extends beyond the quota and covers all aspects of the employment of all handicapped people, registered and unregistered. It explains schemes such as "job rehearsal" (a trial, usually up to 3 weeks, for someone reaching the end of an employment rehabilitation course, with an allowance paid to the person involved by the ESD); or the £30-a-week "job introduction" allowance introduced in 1977 for employers who give a 6-week trial to a disabled person where there is some reasonable doubt about the individual's ability to do the job; the grants (up to £5,000-\$10,000) to assist employers with essential adaptations to premises or equipment necessary to take on or retain a (specified) disabled person. It also attempts to deal with misgivings about the inclusion of handicapped people in pension schemes and to explain the training facilities available through the Training Services Division and the use that can be made of DROs and BPROs.

This small army (500) of Disablement Resettlement Officers are usually to be contacted through Jobcentres, employment offices and some hospitals. Their function is (i) to obtain the cooperation of employers and potential employers in (ii) helping disabled people to find and keep jobs and (iii) to act as guides around the maze of training and employment schemes theoretically available, both for disabled people and for employers or would be employers. At least until recently, virtually all DROs were appointed from within the Civil Service and hence were people who rarely had first hand experience of industry or

commerce: the posts themselves were, moreover, from a career standpoint, deadends, lively minds in the civil service were generally not keen to take - although those who did frequently found them "interesting". All too many DROs, however, lacked the wide knowledge either of disability or of industry that are called for if a DRO is to be fully effective.

In consequence, DROs in general were held in low regard by handicapped people and it is significant that in a recent study (19) by the MS Society, (which has since been extended by a second part), only 26 per cent of respondents had had any contact with a DRO and only 4 per cent had found them useful.

Part of the reason for this has also been the (now acknowledged) failure to take account of the rising expectations of disabled people. The people I have interviewed frequently recounted variations on the story of one young woman who refused to apply for an unlimited future in an audio-typing pool, and eventually forced a reluctant DRO to look again-the result? She now holds a well-paid and infinitely more rewarding job as a personal assistant . . . , but the attitude that a handicapped person should jump at any job, however boring or poorly paid, still persists. My own husband -after his work on the earth-station end of communication satellites was ended because his vision and manual dexterity had been destroyed by multiple sclerosis-was torn between outrage and derision when all the DRO could suggest was a job repairing television sets!

New Emphasis

Those in the Manpower Services Commission who are responsible for policy, their lines of communication with users strengthened by the National Advisory Council for the Employment of Handicapped People (NACEHP) and many self-help organisations, are now aware of these shortcomings, and within the limitations imposed by resources their proposals for development are intended to give greater emphasis in the future to meeting them. In the programme for future development (20) published early in 1978, this approach was spelled out, particularly in relation to the resettlement service and the quota scheme (a review of which was published in mid-1979 (21)) and the fares to work scheme. The impact on mobility of withdrawal of the Invacar was mentioned earlier and it is, after all, no good providing employment for handicapped people if they cannot get to the workplace.

The review also notes that it would be valuable to have more research concerning the qualifications, occupational earnings and career development patterns of disabled people, and the manner in which these may be affected by participation in MSC schemes. Already a new attention to cost-benefit ratios is

evident, for example towards the Training Opportunities Scheme (22) and more significantly, in work carried out by the-London School of Economics and one of the Department of Employment's own economists, Peter Makeham (23), on the major sector of the employment services for disabled people not yet covered here-sheltered employment.

Sheltered Employment

With its origins in workshops for the blind and war-disabled, this sector of employment for the handicapped has perhaps been least expected to consider economics. People have been inclined uncritically to take gross costs as actual costs* - until, that is, costs reached such very large sums (£28mn in 1977/78- just over \$53mn at the rates then current) and sheltered employment was at the same time being criticised for making too small a contribution to the incomes of those who depend on it.

The MSC took over responsibility in 1976 for co-ordinating and developing sheltered employment provided by Remploy (87 factories), independent voluntary bodies (operating 26 workshops for sighted disabled people) and local authorities (with 37 workshops for sighted and 55 for blind disabled people, some operated on their behalf by voluntary bodies). (They are now also experimenting with about 20 enclave schemes, currently employing something over 100 people, in which groups of severely disabled people work on a contract basis in ordinary industry.) The range of products is wide, from furniture and industrial shelving to delicate assembly jobs, including contract packing work and printing. Products and services are sold on the open market. As well as providing employment opportunities which come as close as practicable to ordinary working conditions, the service is intended to enable those employees who can to progress to open employment. It is the aim of the MSC to encourage this rehabilitative aspect, but in practice it occurs relatively rarely.

In all, about 13,000 people are covered by the various sheltered employment schemes: 8,000 by Remploy, nearly 3,500 in workshops for sighted disabled people and 2,000 in workshops for blind people.

On the face of it, this means sheltered employment is "costing" over £2,000 (\$4,000) per annum per person employed. The recent cost-benefit study to which I referred (23) has shown, however, that in terms of resources there was a net benefit in the case of workshops for the sighted and Remploy--without attaching any monetary values to the social benefits, and that even in terms of financial costs there was a net cost to public funds of only £2.8mn (\$5.3mn). This compares with gross costs then quoted of £14mn (\$26.6mn). A study undertaken at the same time (24) of twelve people from one London workshop

showed the very considerable flow-back to the Exchequer which must be offset against the evident cost of subsidising sheltered employment. The average Exchequer gain per worker was £35 (\$66.50), composed of £13 (\$24.70) from income tax and National Insurance payment and £22 (\$41.80) from Supplementary Benefit allowance which would otherwise have been payable. The authors point out that even this understates the case, since the average weekly take-home pay of the sample came to £40 (\$76), whereas average weekly Supplementary Benefit would have been only £22 (\$41.80), so the average weekly private gain of £18(\$34.20) would be available for spending on goods, many of which carry Value Added Tax or other indirect taxes. In the absence of any sheltered workshop this extra purchasing power and potential added revenue would not arise. Even without taking this into consideration, however, there was an average Exchequer gain of £1,820 (\$3,458) per annum to set against that average gross "cost" of £2,153(\$4,091)--leaving a very different financial cost to the Exchequer of £333 (\$632.70) per place--a much more reasonable price to pay for the measure of independence which individuals in the sample repeatedly said was important to them and much "preferable to receiving financial assistance via the social security system" which they disliked, regarding it as "charity".

These calculations also help to put into perspective the fear sometimes expressed among administrators that sheltered work may divert resources which could have been used for people capable of becoming wholly independent.

Joint Action

Most of the special provisions designed to help handicapped people into employment revolve around efforts to encourage employers to take them on for selected jobs or consist of some form of sheltered employment. With independence and cooperation between able-bodied and handicapped, something much more ambitious can be achieved. A man who broke his neck in 1965 in a motoring accident and became a resident in the Young Disabled Unit at Stoke Mandeville Hospital; set out to become a computer programmer. There are already numbers of handicapped people working in the industry, including over 200 blind programmers, and the British Computer Society has a Specialist Group for the Disabled, which he joined. Once trained, and with his new contacts, he began scrounging data preparation equipment--aided by the speed at which companies were replacing equipment as new developments took place.

His aim was to give other disabled people the opportunity to learn how to use such equipment, and he was soon joined by another paraplegic in the Unit. Then an able-bodied service engineer from one of their suppliers became involved. The Computer Society Group had been making strenuous efforts to secure

employment in computing for more severely handicapped people, but meeting resistance from employers. The trio at Stoke decided the only solution was to become employers.

Their efforts to obtain data-preparation work from companies were so successful that the workload became more than the paraplegic members available could cope with, so they enlisted the part-time help of fully-trained paper tape and punch operators working from home, and in April 1977 a limited company was formed whose aim is to become a viable self-financing organisation which will ultimately have sufficient scope to provide work experience for other disabled people before they move out into open employment. The company is known as EMPHATIC (Employment of Physically Handicapped and Able-bodied Together In Computing). It grew too fast to continue using the hospital as its base, and has an office on an industrial estate. (it is now looking for larger premises!) In terms of personnel the company is still tiny: only fourteen people are employed, of whom four are disabled. While some of the able-bodied work part-time, the disabled members work on a full-time basis, but because of the limitation on earnings under the UK system (of which more later) they have not been able to take out more than £44 a week as earnings. If they were on full salary, they would be expected to look outside the Young Disabled Unit for accommodation, and it is their hope that they may one day be able to do so, but they have not yet built the business up to the extent that would allow them to clear that hurdle.

The replacement value of the equipment they have is over £37,000 (\$74,000) exclusive of Value Added Tax, but much of it is by definition fast becoming out of date. They need to update their hardware if they are to continue to be compatible with the systems of their potential customers, otherwise they will not be able to keep the work coming in.

And if they failed? The alternative for one of them is enforced leisure at home, and for the other three, the poorly-paid and "phony work" atmosphere of the hospital workshop, while their able-bodied employees would have to look for other part-time work.

In the meantime, their experience underlines a number of points about rehabilitation. They emphasise the need to talk to people with spinal injuries while they are still work-orientated, as soon as they are over the initial acutely ill phase. For optimum cost-effectiveness, the timing of rehabilitation is always very important: from the patient's point of view in this case even more so. The mere possibility of a new career is valued as "something to think about while you lie there"--especially if the new arrival is only too aware that his or her previous occupation will now be out of the question.

A successful return to work is easier for those who have not been allowed to "slow down" and become institutionalised. To anyone who expresses interest after the first contact, programming training begins right away, during the period which spinal injury victims spend in bed until the injury is healed.

Once they are working, the group claims the quality of work done by handicapped people is often above average, and they believe this is because, like everything else, it requires from them more effort than from able-bodied people: they are therefore anxious to avoid having to waste effort by doing a particular piece of work over again. Hence they tend to think that little bit harder about what they are doing, and make the first attempt of a higher standard.

While the valuable experiment with EMPHATIC represents is still growing, the outreach of the team continues: working with the British Computer Society's Specialist Group for the Disabled, they have collaborated in the preparation of a study on the Employment of Disabled Persons in Data Processing.

Income Maintenance Problem*

Yet they, who are employers, seeking to establish their independence in an unusual way from an institutional base, find themselves restricted by the very provisions said to be "for" disabled people. I mentioned the limitation on their earnings. Were they to exceed the current limit figure (raised by a few pounds in November 1979), they would forfeit entitlement to the invalidity benefits which they at present receive, even though their business might only be able to provide total take-home pay substantially less than those benefits.

Meanwhile, on their present level of pay they could not cover the extra costs of independent living, plus the mobility called for by the business, and leave themselves a sum which would pay for suitable private accommodation and essential care.

It is often argued in cost-benefit studies, in respect of transfer payments, that too high a level of benefits deters people from returning to employment, but in the UK at least, this is to tell only part of the story. Far more significant are the terms on which benefits are withdrawn. For the recipient there are baffling difficulties at the margin of work, both in the initial period of becoming handicapped (where research (25) has shown that the financial hardships are often the greatest, but when higher "long term" rates of benefit have not been achieved) and between a period of disablement and a return to work.

Questions of Definition

In *Whose Benefit?* (Ref. 6), we suggested that the problems arise because the UK system recognises only two conditions-being "sick" (which means entitled to benefit, but also means incapable of work) and being "fit". If one can earn, it is argued, one can no longer be sick--therefore receipt of any invalidity benefit (except specific items such as Mobility Allowance) is fraud. Some attempt has recently been made to remove the anomaly we described (Ref. 6, p. 56) whereby handicapped people, even though seeking work, were advised to get a doctor to describe them as "sick"--so falsifying not only the doctor's declaration and their own but also their long-term health record-to avoid expensive and sometimes hazardous travel to present themselves regularly at local employment offices. The rules, however, still do not acknowledge the fact that, for example, a spastic or paraplegic may be as fit as an athlete, but can never stop being simultaneously handicapped, and that his problems in daily living, in getting around, and many limitations on his employment, are inextricable from that handicap.

The kind of waste which results from this situation is illustrated by the case of a man with a deteriorating condition of the central nervous system, akin to multiple sclerosis in its effects. He was married, with two daughters, and had worked in aircraft engineering. As he became too handicapped for his old job he went for a re-training course in technical drawing. For a time he did that, but as his condition worsened, he could not reach across large drawings, and it was suggested he again go for re-training, this time in tracing work, which can be had in smaller units. Meanwhile, union pressure was raising payment rates for these jobs. When we met him, he could not work because work that he could manage was only available sporadically, but as the rates had risen, even the smallest job he would be offered would bring in enough to disqualify him from benefit, yet not enough to keep him, his wife and two young teenagers and pay for his home and his travel. So a man who wanted to work keenly enough to re-train not once but twice for lowlier jobs was at the end forced into idleness.

Not only was his enforced leisure costing the State money every week in benefits and lost tax, but all that had been invested in his two rehabilitation courses was wasted--all because there is no system of tapered benefit or intermittent payment, without going through new "waiting periods" as though, after a brief interruption by working, a permanent handicap were as unconnected with what went on before as a broken ankle with a bout of 'flu.

It has been noted that in some countries "one level of government may label unemployed persons during periods of economic recession 'disabled' both to avoid politically embarrassing high unemployment statistics and to shift the

burden of unemployment compensation onto another level of government" (Ref. 1). Apparently in the UK our officials do not "embarrass" so easily: the tendency is in the opposite direction. As a result of practices intended to prevent fraud in connection with sickness benefits, handicapped people have found themselves classified as "fit for light work"-the effect of this is that they are technically unemployed, not sick, and their benefit will eventually stop, even though in the particular area where they live there may be high unemployment or a scarcity of any but heavy work (e.g. in steel-making or coalmining areas), making it exceedingly unlikely that they can find employment. Sometimes, too, this classification seems to be decided in complete disregard of their medical records. This practice is sufficiently common to be given a name by case workers: it is known as "shunting", and it is just one of the bureaucratic snares derived from the lack of a system which recognises a state of intrinsic handicap.

1V - HOUSING AND COSTS

In many senses housing is the key to independent living.

For the severely handicapped wheelchair user ability to move around, to discharge any household responsibility, to play a part in family life, even to manage self-care, disappears if narrow doorways/passages, steps between rooms, or high working surfaces stand in the way;

for the less severely and obviously handicapped energy may still be sapped, and personal safety endangered, by inappropriate housing, even though it would pose no threat to the able-bodied. This is true particularly for handicapped people who are responsible for the housework.

Of even wider application--for all handicapped people, if their incomes are cut by reduced earning capacity or benefit technicalities, "suitable" housing may be unattainable.

A sad little example came my way quite by accident: a total stranger came to our door to ask if I could help find somewhere to live, within walking distance of a nearby office, for the telephonist there, who was blind. He had been sharing a flat. The rent was being raised and his flatmate was moving. He could not afford the new rent, but could find no suitable alternative close by, and the only public transport is a bus service covering a limited route, and that none too often or reliably.

His only alternative was to give up his independence and .move to London. He had the offer of a job there, where he could live in a hostel, but he did not want

to go, because he had friends and leisure pursuits in our little town, he was happy with his employers, and they with him.

Variability of service-- the specialised few

As with Home Helps and education in the UK, housing opportunities for handicapped people are immensely variable between one part of the country and another. Many of my interviews for this study were carried out among the residents of two small developments in north London which belong to John Grooms Association for the Disabled. One is a private development consisting of a small group of purpose-built flats (on two levels, linked by lift and with covered parking, looking onto a small garden) with warden on call for emergencies. The other consists of a small number of ground-floor flats integrated into a larger mixed development of family houses and ordinary flats-- a joint venture between John Grooms and a local authority.

Up and down the country there is a scattering of imaginative developments like this, to varying degrees purpose-built for severely handicapped people, or clustered for mentally handicapped and the elderly, sometimes with a warden on call.

Mobility housing

The words "purpose-built" often conjure up visions of the maximum standards required for wheelchair housing: extra wide doorways, no stairs, flat thresholds, a great deal of extra space--especially around bath and toilet--special or adjustable height for working surfaces, split level cookers, and so on. While some of these features are valuable to people with other handicaps, it is estimated that only 2 per cent of handicapped people need all of these design features. The emphasis, in recent years, has been moving towards designing an increasing proportion of the general stock of housing accommodation to standards which make it usable, or easily adaptable, for any but the most severely disabled or for ordinary households, according to current demand in a given place.

Mobility housing has only three basic essentials (though certain other features are considered desirable): these are (i) the entrance door is at least 900mm wide and has a level or ramped approach (accessible by wheelchair); (ii) internal doors and corridor are at least 900mm wide (allowing for easy movement by ambulant handicapped people, including those who have wheelchairs but are not totally chairbound); the bathroom, Wash Closet and at least one bedroom are at entrance level. An estimated 15 per cent of handicapped people have needs which could be met by mobility housing.

The concept of mobility housing has this in common with Independent Living Programs, that it is intended to avoid the relegation of people who have handicaps to a separated existence in too-protective environments which do by gadgetry what forethought and good design could make unnecessary.

There is an economic spur in this: in the UK, local authorities play a major part in housing provision for all who cannot afford to buy their homes, and their building projects must be planned within financial limits laid down for them by central government if they are to receive support funds towards their financing; otherwise they must raise the finance from local taxes ("rates")-never popular with the electorate! Mobility housing must be able to be constructed without increasing overall dwelling size, or significantly increasing costs above the yardstick* price of equivalent ordinary housing (the original circular introducing it in 1975 created an allowance of only £50 per dwelling (\$110 at 1975 prices) and the 1978 level was only 20% higher (in sterling terms: because of changes in exchange rates the later price of £60 appears to be equivalent to only \$114).

There are some local authorities in the UK which have an excellent record as regards their housing provision for handicapped individuals and families, among their total housing ... and there are the others.

Quantifying the problem

Official figures in 1973 showed that at that date English housing authorities had constructed only one purpose-built dwelling for every 595 handicapped people known to them as being in need of rehousing, and in January 1979 it was argued (26) that the position is little better now, because greater awareness has been counteracted by economic recession.

Part of the problem is also that the authorities which are poor at providing for those known to them are often not good at discovering how many handicapped residents they have--and this affects their provision not only of housing, but all the other services, such as Home Helps and education.

A few full identification surveys have been carried out by the organisation called Outset, in pursuance of the 1970 Chronically Sick and Disabled Persons Act. These have been spread over very different areas, from the City of London to Belfast, and from the Scottish industrial areas to residential parts of south east England. One of the most significant results is the remarkably consistent findings of the prevalence of handicap they have recorded between 4 and 5 per cent of the population. The average UK household now numbers around 2.7! so

we are talking about at least 6 million, and maybe nearer 7.5 million of our population whose lifestyle is at issue. We cannot afford not to maximise the independence of these people and their families, but local authorities cannot serve those whom they have not located.

Yet the data produced by the Chartered Institute for Public Finance and Accountancy (CIPFA) for 1977/78 concerning 116 local authorities covering England and Wales, shows that only in seven areas does the number of handicapped people who have been located top 4%. (This includes hearing impaired, blind and partially sighted people as well as the broader category of "general" handicaps). Even on the basis of the survey published in 1971 by the Social Survey Division of the Office of Population Censuses and Surveys, which excluded children under 16 and people in hospitals and similar institutions, we would expect to find a proportion of 2.8% -and because of the exclusions noted, that must understate the situation.

From the diagram on the previous page, however, you will see that in no less than 96 authority areas the figure located falls below even that lower level. One cannot infer from the areas falling into each group that they reflect genuine variations in prevalence, or even the relationship between resources and the size of the problems any one authority has to contend with: an old industrial area such as Manchester, with almost half a million inhabitants and all the problems of an inner city, can locate 5.4 per cent, while a borough with half the population and a much wealthier image (Bexley) expects us to believe it has no more than 1.5 per cent, and the University area, Cambridgeshire, acknowledges only 0.7 per cent.

In all, 47 million people in England and Wales live under local authorities where the number of handicapped located is less than 4 percent.

The key role of housing

In no sector are the benefit-cost ratios which can be derived, more various than they are in relation to housing. When I turned to the question of costs and benefits with the people I interviewed, the answer was at once more difficult than for services such as personal care, and more simple: without special housing there was no sum to be done! Manageable housing can make or break the efforts of a family or individual to cope with handicap. Appendix illustrates this very well. Again, among my interviewees, the couple who had been able to start married life only when they were sure of their flat had, beforehand, been living in a hostel; the girl in a wheelchair who holds down a responsible job in central London could not go back to live in her parents' house since her injury, because there, she cannot get from room to room-even making herself coffee is

impossible; and for the handicapped mother who was shampooing the carpet from her wheelchair when I arrived, the right housing means she provides work (for a Home Help), her able-bodied husband is employed, not solely acting as a care attendant, and his tax and insurance contributions offset the cost of some of the extra services she uses; their little girl is growing up at home, not "in care", and the mother even cooks evening meals for a neighbour who lives alone. Without suitable housing, none of this would be possible and two members of the family would probably be in residential care.

The Coventry study referred to earlier has attempted some costings of the housing aspect which show the national cost within the relevant period to be only £400-£500 (around \$700-\$900) for local authority housing, and just over £1,000 (\$1700-1900) for owner-occupied homes.

The handicapped mother is particularly relevant, because her housing does not result directly in a return to paid employment. No group among handicapped people in the UK is more undervalued, or has had less research done regarding the real resource costs and benefits they generate, than the handicapped homemaker. Even the benefits introduced "for" housewives (after years of campaigning) is hedged about with conditions. As well as being unable to do paid work, she must prove her inability to perform "normal household duties". This is extra to criteria for benefit supposed to be of the same type for men or for unmarried women, and moreover the detailed questions, reveal an extraordinarily out-of-date idea of the role of a housewife. One of the anomalies of this benefit is that ability to qualify may well relate more to the house than the housewife.

Whatever happened to independence?

To sum up, I am sure it will come as no surprise in the United States to say that in the UK there seems to be an in-built antipathy to independence.

When it threatens to manifest itself among handicapped people, there are two main ways of containing it:

(i) wear it down by doing too little that is supportive

or

(ii) smother it with too much bureaucracy.

Seen from the UK the comparison with Independent Living Programs looks as I have depicted it here-with I LPs as a coordinated means of assisting get-up-and-

go, while the UK systems are a little like the second illustration: there is a great deal there, if you are nimble enough to collect before the bureaucrats spot what you are up to, or the administrators change the rules.

Contact with service providers and users both sides of the Atlantic, however, prompt me to pose a few questions which I hope will help to focus ideas:

Questions arising from the UK situation

The inequalities of provision in different areas of the UK have been noted: what is being done in the US to avoid the same lottery, between states and between areas with ILPs and those with none?

Do service providers ever get to see the effects of their policies and provisions in the daily lives of handicappers?

Is there enough comprehensive and reliable information about handicapped people and the services they need and receive? Without it, policy-makers and service providers have no feedback; those who need services will in many cases fail to find them; and the rest of the community has no check on whether its expenditure on handicapped people is doing a good job.

Are services organised for the providers' convenience? I suspect this trap is avoided in the Centers for Independent Living, but their clients are in a sense an elite among handicapped people --what about the others?

Your progress on access for handicapped people is envied back home, but do you, too, need to adjust your concepts of the purposes served by wheelchairs?

Disabled people may take longer to get started on education and training: do your rules about benefits, job and education age limits take account of this?

Are cut-off points on available benefits or services, by with-drawing them too soon, or failing to achieve rehabilitation, costing you success (which is the same as costing you money)?

Are there ways in which out-of-date bases among your cash benefits can foul up the outcome of other services and put down independence?

Does duplication of assessment procedures arise, and if so can it be reduced or eliminated?

Does your system of provision provide enough flexibility? Does it face the reality that, "sick" or "fit", handicap is constant?

Is evaluation of programs in terms of the wide and inter-acting social outcomes, not only-those affecting one individual or only those leading to employment (nor in terms of any employment that will close the case file!)?

Is the consumer's share of the administrative cost counted?

Summing Up

Perhaps the most valuable function of the Independent Living Programs is in coordination of the various services that need to be available to handicapped people if they are to achieve control of their own lives. More coordination in working with handicapped people is something we can do with on both sides of the Atlantic.

The other thing we need to do is constantly to clarify our appreciation of the way policies and theories and measures applied to handicapped people really affect their daily living. Cash benefit analysis is a waste of time if it cannot tell an administrator that it is an offense to human dignity to award 85p (\$1.70) a week to someone in consideration of the extra costs of both double incontinence and a fat-free diet! (6)

The abiding impression I have, which deepens all the time, is of the striking common attitude of so many of the handicapped people I have known - their boundless determination - often against the most daunting odds-to work, to run their own homes, and to wring from an unwilling world all the independence they can, and I would like to record my particular thanks to all those who, in the course of this study's preparation, shared the details of their lives with a "walkie-talkie neighbour".

SUMMARY

Those who have been able to benefit from Independent Living do not doubt its value. Policy makers sometimes do. If the cost of independent Living provisions is worrying, how does the cost of not making them available compare?

In this monograph the juxtaposition of economic analysis and insightful case material is used to highlight some aspects of

- (i) assistance to overcome self-care handicap;
- (ii) education and job placement;

- (iii) special services in the employment sector; and
- (iv) housing.

UK developments, of special interest are outlined, including the Crossroads Care Attendant schemes, the Mobility Housing concept, and cost-benefit analysis in relation to sheltered workshops.

The author contends that in some respects the costs of rehabilitative activities, including Independent Living Programs, are being magnified by technical factors....

that it is bad housekeeping not to know what is being spent on provisions for people with handicaps, and that the costs of disability accrue regardless of whether or not rehabilitation services are available

that policy makers and service providers need to be more closely in touch with just how their policies and provisions really work out in the lives of handicapped families and individuals

that the fact that costs are often easier to measure than benefits does not justify allowing them to dominate calculations of true outcomes since it presents the danger of wrong conclusions

that choice for the client implies flexibility in the service provisions. Services designed for ease of administration do not necessarily produce efficiency.

For the handicapped, their handicap is a permanent fact of living-being fit or not being sick is a variable, superimposed on it - and systems of cash support or other provisions need to recognise this.

For handicapped people to break out of their dependence, they need control over their income, over the services and aids which offset their handicaps, and to the maximum possible degree, over their immediate environment. If a partial picture of the costs and benefits involved is accepted by service providers (from tax payers to legislators and back through care attendant organisers) they may not get the chance.

REFERENCES

1. Rehabilitating the Severely Disabled. the foreign experience. Journal of Health Politics, Policy and Law, vol. 4 #f2 Summer 79 Dr.).H. Noble)r., Director, Policy Research and Analysis for Social Services and Human

Development, Office of the Assistant Secretary for Planning and Evaluation, Department of Health, Education and Welfare, U.S.A.

2. For the use of these terms see: Handicaps and the Handicapped a nomenclature and classification of intrinsic handicap. Dr. M. Agerholm, J. Roy. Soc. Health, p. 3. London 1975, and The Classification of Personal Handicap-paper by the same author given at 1978 meeting of Medical Commission of Rehabilitation International, September 1978.

3. Physical Impairment: social handicap-Office of Health Economics, London 1977.

4. The cash or financial provisions for the disabled in the Netherlands. Paper contributed to a Conference on the Financial Provisions for Handicapped People in the EEC, their philosophy, administration and practice. Sept. 1976, York (UK)

5. U.N. unpublished draft.

6. Whose Benefit? The Economist Intelligence Unit Ltd. for the Disablement Income Group and National Fund for Research into Crippling Diseases, 1978, London pages 127-128.

7. Ibid.

8. Care with Dignity: Economist Intelligence Unit Ltd., published by the National Fund for Research into Crippling Diseases, Horsham, Sussex, England. (revised edition, Jan. 74. currently almost out of print)

9. Descriptive paper on the Crossroads Scheme by the organisers, March 1976.

10. Unpublished study for Cheshire Foundation, 1975, The Economist Intelligence Unit, London, England.

11. Wheelchairs and their users-David Fenwick, OPCS, for the Department of Health and Social Security, 1977, London, UK.

12. Children Living in Long-stay Hospitals. Maureen Oswin. Research Monograph No. 3, Spastics International Medical Publications, London, Wm. Heinemann Medical Books, Philadelphia: J. B. Lippincott Co. (Especially p. 32 and the Appendix)

13. The Development manufacture and supply of powered wheelchairs Part 1-towards a description of mobility handicap and equipment suitable for its relief-unpublished draft produced at Institute of Consumer Ergonomics.
14. On giants' shoulders -Marjorie Wallace and Michael Robson, Corgi Books, 1977.
15. Living with Disability-from birth. Robert W. Lancaster-a paper read on his behalf by a speaking colleague, at a seminar on Understanding Disability-Solihull College of Technology, 10.4.79 and reproduced by the West Midlands Council for the Disabled.
16. Preliminary report on a study by the National Children's Bureau, Careers Quarterly, Vol. 29, No.1,1977.
17. The Quota Scheme-a discussion document published May & 1979 by the Employment Services Division of the Manpower 21. Services Commission.
18. Positive Policies (1977) Manpower Services Commission, (UK).
19. Survey by the MS Society of Great Britain, to be released later, when the second stage is completed.
20. Future Development Programme of the Manpower Services Commission, (UK).
22. TOPS Review 1978, Training Services Division of Manpower Services Division.
23. The costs and benefits of sheltered employment- Peter Makeham, published in Sept. 78 edition of Department of Employment Gazette, (Vol. 86, N. 9) HMSO, London, England.
24. A Sheltered Workshop- Gennard J. and Wright M., London School of Economics, published in Sept. 78 ed. of Dept. of Employment Gazette, (Vol 86, No. 9) as above.
25. The Extra Costs of Disabled Living- Mavis Hyman, for Disablement Income Group, London, England.
26. The Good, the Bad and the Ignorant-by Outset Director Stuart Mole, Published in Community Care, Jan. 18,1979.

27. Holes in the Welfare Net-by Maureen Oswin, Bedford Square Press London.

APPENDIX I

ON THE USE OF COST TERMINOLOGY

In its simplest terms, a "cost" is the measure of whatever must be paid in order to obtain a thing or service-but the word has many specialised uses. 'Cash', 'money' or 'financial' costs are those to meet which money (in some form), is actually spent.

If it is desired to compare the cost of a service today with that of purchasing the same service two years ago, or each year over a period, then the figures need to be adjusted to take account of inflation-thus producing what is called a "real" cost. "Real" costs can, however, also refer to the use of physical resources underlying financial measures of cost: where unemployment is high, the "real" cost of labour is lower than its money cost, because those taken on would otherwise be unemployed.

"Net" costs are calculated by deducting the value of benefits or inputs which in effect reduce the amount that is being paid. "Gross" costs take into account only the outgoings. (This is quite different, however, from the "apparent" costs referred to on P.1 of the monograph, where actual distortion of the presenting picture of expenditure for a given purpose is involved.)

"Running" costs are whatever is required to pay for the current part of an on-going process-"capital" costs represent payment for the long-term element (e.g. the price of the fuel used for central heating over a specific period is a running cost, that of the boiler and its installation is a capital cost, and since the boiler will be in use for years, the capital cost for a given year will be the total cost, allowing for wear and tear and maintenance where necessary, divided by the number of years reckoned to be its working life).

"Opportunity cost" is the value of the best alternative use to which any resource which is used could have been put-such as the opportunity to earn which is foregone by a wife deciding to undertake, herself, the full-time care of her husband.

The costs involved in independent living may be met by the handicapped person or their family (private costs). Alternatively they may be paid for out of Central Government (Exchequer) funds (as in the case of the costs of hospital care under the National Health Service) or from Local Authority funds (as in the

case of Personal Social Services)--to which Central Government, however, also contributes. (The parallel with program costs in the US will usually fall within these last two.)

"Resource costs" should represent the measure of requirements, for a particular purpose, of all the factors of production which are used in an enterprise, or a whole economy, to produce or distribute goods and services--land, labour and capital. Since the essential fact about resources is that in the short term they are limited, their allocation between competing uses is the subject of decisions at all levels--nowhere more so than in the area of social services, where the time of specialist staff, the buildings and finance used for one purpose thereby become unavailable for another.

"Social" costs are the total of all types of costs of any activity as they impinge upon society as a whole (or some complete segment of it, such as a local authority area)--not merely the individual or organisation carrying out the activity. Social costs include the opportunity costs of resources used, and the value of any effects caused to any other sections of the community, and such external costs can be incurred either in cash or in intangible ways.

"Visible" costs are as they sound--the ones that are evident. "Hidden" costs are those which find expression in indirect ways: failure to take advantage of a holiday offer may be the hidden cost of limiting the resources made available for proper management of incontinence.

APPENDIX II

A HOUSING PROBLEM

Mr. and Mrs. Barton's fourteen-year-old daughter, Jean, disabled by arthritis, was living in hospital because her family had a serious housing problem.

The family had a two-roomed flat at the top of a tall tenement house. There were six steps up to the front door from the road, and, on the rare occasions when Jean had a weekend at home, there was no chance of her going out because she was too heavy to keep carrying up and down the steps, so, once home, she stayed indoors for the whole weekend. The lavatory had three steps down into it, so she used a commode in the bedroom. There were three other sisters in the family, and one brother. When Jean had her weekends -at home, she slept with her three sisters in the one bedroom, mother slept on the settee, and father and brother shared a bed in the kitchen-living room.

Jean needed a warm bath twice a day, to ease the stiffness in her joints, but there were thirty stairs up to the one bathroom (which was shared with two other families). It was impossible to carry her up the narrow staircase so the family bought a large tin bath, and when she was at home they put it in front of the gas fire in the living-room, and filled it with buckets from the Ascot water heater. The family's attempts to give Jean this necessary treatment to ease her condition were thwarted by the fact that the tin bath was too short for her to lie fully stretched out in, so she could not do the gentle exercises that she was supposed to while submerging her body in the water.

Had Jean's parents been wealthy, with a roomy, centrally heated house, and adequate bathing and sleeping accommodation, she could have left hospital immediately, but her parents were very poor and had little hope of getting better housing so she would stay in hospital indefinitely.

Jean's parents felt that they were slowly sinking under their problem, since their appeals to the housing department met with total failure. An answer to one of their many letters which had asked for at least a promise of re-housing was: 'We cannot take on any more work.' This ambiguous answer might have meant that the local authority could not take on any more building, or that they were not even putting the family on to their already over-loaded building list. Whatever the answer meant, the result was the splitting up of a family and the unnecessary hospitalisation of an intelligent disabled adolescent who should have been taking her place in family and community life. The hospital was pleasant enough. There was a small school attached to the ward and Jean had, friends there, but it was nevertheless very much a hospital, where she faced long hours of boredom, little privacy, and where she was completely cut off from ordinary life.

APPENDIX 111

NOTE ON THE OPERATION OF THE HOUSING COST YARDSTICK

Detailed tables of what is known as housing cost yardstick figures have for some years been prepared by the government department responsible for housing (formerly the Ministry of Housing and Local Government, then the Department of the Environment). These indicate the costs per person (in £) of building to the approved standards for various types of dwelling at different densities (the number of persons to be housed in a given scheme, divided by the site area) and for averages of person-per dwelling from 2-3 to 5-6. Beyond this range individual advice can be sought.

If planned costs exceed this amount, the scheme is not eligible for government finance, which normally comes in 2 parts for specialised housing (such as wheelchair or Mobility housing, or old people's housing)- (i) for basic costs (ii) specified allowances for additional features.

There is a 10 per cent tolerance on the basic cost for certain admissible items. Additions can be negotiated, for example, for a particularly difficult site.

The additional allowances published in 1978 for wheelchair housing ranged from £700 (\$1330) per single person unit (in self-contained dwellings designed to the standards laid down for old people) to £1,600 (\$3040) in single-storey units designed for family (5-person) use. The additional allowance per dwelling for Mobility Housing was £60 (\$114) with further additions for hardstanding or car ports if these were provided for wheelchair or Mobility housing.

The yardstick is reviewed at quarterly intervals-the general level was raised by 6% in March 1978. Actual increases vary from region to region to reflect the local tendering climate. Similar guidance is issued by the Housing Corporation to Housing Associations.

The payment on eligible housing is reckoned to represent about 80% of the cost.

APPENDIX IV

U.S. Commentaries
by
Jean A. Cole John Worrall

COMMENTARY ON JEAN SIMKINS' MONOGRAPH AND ON THE
WORLD REHABILITATION FUND UTILIZATION CONFERENCE

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The World Rehabilitation Fund invited a British economist, Ms. Jean Simkins, to share some of her knowledge of Independent Living in the U.K. with the United States' audience. The Fund sponsored Ms. Simkins' paper plus a research utilization conference at which her findings were discussed in light of U.S. experience.

The Independent Living movement is alive and well in the United States. People with severe disabilities, as well as public and private institutions, have been developing and providing service delivery systems which in some instances enable choice between traditional and alternative programs, and in others provide new opportunities for people with disabilities to control their own lives.

Ideally, economists would like to calculate the costs and benefits of these programs. Economists would like to make statements about the programs' adequacy, equity and efficiency. Economists would like to point out who benefits from and who pays for these programs. Obviously, it is impossible to quantify the total benefits and costs of Independent Living programs. We are unable to put a dollar value on the increased social welfare which results from these programs. Vocational Rehabilitation programs lend themselves to partial quantification of benefits, i.e. we can compute wage gains (or resultant increases in output) for people who are restored to the labor market. But although many people may use Independent Living programs or services as transitions to vocational rehabilitation, others do not. There is no way to demonstrate objectively that the contribution to social welfare is greater for one group than another, nor to calculate the contribution to social welfare by either group.

We can make general statements about the adequacy, equity and efficiency of Independent Living programs. Is funding sufficient to provide Independent Living programs and services to all people with disabilities? No. Are there more pressing problems demanding our resources? This is a question which will be answered as we express our preferences through the political process. Are the programs equitable, i.e. are equals treated equally and unequals treated unequally? The answer appears to be partially yes. People with severe disabilities appear to have priority for receipt of services. We do not know if there is, an equitable distribution of services among the people with severe disabilities who are served by Independent Living programs. Are the programs and services delivered efficiently? We can give a partial response. We can not say that a given level of services are being delivered for the lowest possible level of cost, or that for a given level of resource use that we are delivering the maximum benefits possible. We can, however, examine those instances of comparable services being delivered at different levels of costs. We can say that

the lower cost package is preferred. Ms. Simkins gives an example of this in her paper.

The U.K. experience differs from our own. The U.K. does not have, as I see it, a unified Independent Living program, but, rather, a system which delivers some Independent Living services. The U.S. has both systems which deliver Independent Living services and unified Independent Living programs.

Ms. Simkins has chosen to address as wide an audience as possible. She has avoided esoteric terms, where possible, in order to make her topic accessible to the interested non-economist. Her choice was wise.

The World Rehabilitation Fund has stimulated discussion of Ms. Simkins paper through its research utilization conference. The comments I have made above were offered, sometimes in different jargon, by the conference participants. The research and writing of those who attended should be enriched by the experience.

John Worrall

COMMENTARY ON JEAN SIMKINS' MONOGRAPH AND ON THE WORLD REHABILITATION FUND UTILIZATION CONFERENCE

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With passage of the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978, independent living in the United States has made a quantum leap forward. From a series of scattered pilot programs it has now become a standard service entitlement, available at least in theory to handicapped citizens in all parts of the country. As this legislation is implemented, the cost and benefit issues raised in Simkins' monograph gain crucial importance. At a federal level, continued existence of the independent living program will have to be justified by a credible assessment of its usefulness, and funding levels of the federal program will surely depend on demonstrated effectiveness. As each state develops its independent living plan, the costs and benefits of alternative IL service delivery methods will have to be weighed in making decisions about how best to serve handicapped citizens of the state. At a local community level, IL program managers will need to speak definitively about costs and benefits in seeking financial support and local agency cooperation.

Participants at the utilization conference generally agreed that formal cost/benefit analysis of independent living is not a feasible goal. Though potential benefits of independent living programs and services can be made explicit in a systematic fashion and in some cases quantified, it is impossible to assign dollar values to many of these benefits. Though mathematical rigor is not attainable, this should not be used as an excuse for sloppy thinking about costs and benefits. Two types of systematic analysis seem useful. First, once a given outcome or benefit has been specified as a goal, it is possible to compare the cost effectiveness of alternative methods for reaching this outcome. Second, in weighing the desirability of alternative goals, it is important to consider systematically the broad and comprehensive implications of any course of action (despite the fact that this cannot always be done in dollar terms. We currently have some ways for documenting individual client outcomes of independent living services, but a comprehensive analysis of the impact of independent living programs requires consideration of non-individual benefits that accrue to various entities such as the family, the community, or the national economy.

These are the benefits that we currently find most difficult to document and measure, though improvement is surely desirable in our ways of documenting individual client benefits as well. A comprehensive analysis also requires a time perspective to account for long-term effects. In addition, it is important to consider carefully the cost of doing nothing which Simkins has examined in the United Kingdom.

Several actions were identified at the conference that would facilitate systematic thinking about costs and benefits of independent living in this country. In addition to improving ways to document and measure individual outcomes, major research is needed on ways to document the non-individual benefits of IL programs such as the impact of their advocacy efforts on community architectural accessibility or on public attitudes toward handicapped persons. There is also a great need to develop a standardized data collection and reporting mechanism so that comparable information is collected on services, costs, and outcomes of IL programs across the country. Such a mechanism will have to be designed to require a minimal burden of effort for the user, and program managers at various levels will have to be convinced of the value of spending time and effort on data collection and reporting functions.

Simkins' monograph examining costs and benefits of IL services in the United Kingdom raises important issues requiring careful study and concerted action in this country. This is essential to assure effective program management at various levels and to provide a solid basis to advocate for allocation of resources to independent living.

APPENDIX V

RESEARCH UTILIZATION CONFERENCE

Issues For Discussion

Sample Statements of Action Taken

Participants

Research Utilization Conference
Held at Michigan State University,
co-hosted by University Centers
for International Rehabilitation
September 14-15, 1979

In keeping with the format of the International Exchange of Information in Rehabilitation project, in three out of five cases, monograph authors are brought to the U.S. and are the key participants in knowledge transfer (research utilization conferences). One of the goals of such meetings is to promote dissemination and utilization of the monograph itself. Another goal, of course, is to promote discussion and interaction among a few of the potential major "disseminators and utilizers." Because of the keen interest in costs and benefits of independent living and because Simkins' monograph raised many critical issues, Ms. Simkins was one of the authors invited.

All conference participants received copies of a draft of the monograph in advance of the conference and were expected to have read it prior to the meeting.

The format of this meeting included an opportunity for Ms. Simkins to highlight key issues in her monograph. This was enhanced through interviewing techniques. Ms. Simkins' peer reviewers, Jean Cole and Jack Worrall interviewed her and raised issues on which they wanted clarification. These interviews stimulated discussion within the whole group on the issues and ideas regarding independent living and cost-benefits raised in the monograph.

Small groups were then used in order to pull together what had emerged in the large group. Each of the three small groups spent time discussing only issues designated to be discussed by that group.

On the second day of the conference, it was the charge of the small groups to come up with plans of action, general and specific. There were individual commitments to action made as well as general recommendations. Following "Issues for Discussion" in this section, there is an example of an action which has been taken.

It was generally agreed that it is extremely difficult (although a necessary challenge) to come up with a cost-benefit analysis of independent living for the disabled and that this monograph instead of being a cost-benefit analysis was rather a humanistic statement regarding the cost of not providing for independent living for the severely handicapped. Because of this, one action agreed upon by the participants was to change the title of the monograph from "A Cost-benefit Survey of Independent Living for the Severely Disabled: Some Hints from the U.K." to the present title.

WORLD REHABILITATION FUND
INTERNATIONAL EXCHANGE OF INFORMATION
IN REHABILITATION

Simkins Monograph and Conference

SOME ISSUES FOR DISCUSSION WITH REGARD TO INDEPENDENT
LIVING (IL)

- A. Defining Independent Living
- B. Measuring Cost-benefits: analyses/strategies
- C. Ethical-Political Issues in Independent Living
- D. Consumer Problems
- E. Other

A. Defining Independent Living (I L)

The definition depends on where you are in society. From whose point of view?

1. The Insider vs. Outsider Views

While the insider views IL in terms of optimizing choice of lifestyle, the outsider views IL in terms of the least restrictive and/or most productive environment. Usually they agree, but not always. For example, being able to balance a checkbook is more appealing as a benefit to the consumer but may not be relevant to the concerns of policy makers.

2. Adults vs. Children and Aged

IL has different meanings for people during different parts of their lives, e.g., the definition of IL in the case of a disabled child or aged person differs from that of a working age adult. How would one define IL for different age groups?

B. Measuring Cost-Benefits: Analyses/Strategies

- 1. Cost-benefit analyses applied to vocational rehabilitation are not equally applicable to independent living.
- 2. Qualitative analysis of benefits and costs as well as relative costs of certain modes of service delivery are feasible.
- 3. There is a need for further expanding the qualitative measures of the benefits of Independent Living.

4. There is a need for the comprehensive reporting of services provided and costs of those services.

C. Ethical Political Issues in Independent living

1. Human Rights. Human rights issues override some of the usual constraints in cost/benefit issues. The issue is not whether it is necessary to offer a program, rather it is what is the best way of doing it. It is important to define basic rights, to agree on the most fundamental right, e.g., personal care, and to search for a hierarchy of rights. If human rights override cost benefit issues, then we should study the costs of not providing services. How can we overcome disincentives to Independent Living?
2. Responsibility. Is an attendant responsible to the disabled consumer or to the counselor who represents the funding source? It is important to develop ways of dealing with situations where there is a conflict in dealing with differences in implementation as well as in principle.
3. Legal Issues. The notion of separate, but equal has been carefully examined in the legislation pertaining to minority groups over the past 25 years. With regard to the disabled as a disadvantaged group, it has been ignored. What can be done about this? How can we best appeal to the legislator/policy maker? Should appeals be based on cost benefits or case study approaches or both?

D. Consumer Problems

1. Who is the consumer? Is a disabled person who no longer needs services still a consumer?
2. What are the best strategies for involving consumers?
3. Are consumers more effective than non-consumers on boards, professions, etc.? This question has not as yet been subject to empirical test.
4. Not enough consideration is given to costs to consumers.

E. Other

1. Attendant Care. There should be an organized program for attendant care on a national basis. Should it be a separate identifiable program or part of

a larger program? Should consumers be given cash to purchase services rather than just be supplied with services?

2. Comparisons of United States and United Kingdom. There is a need for comparing definitions of IL in both countries.
3. Service Programs. We should study ways in which IL programs can be organized and the ways in which persons in need of services obtain them.

We should study model IL programs.

Significant Specific Issues identified and discussed at the Utilization Conference held on September 14-15, 1979 on Jean Simkins' monograph: "The Value of Independent Living-Looking at Cost Effectiveness in the U.K. (Original title of paper was "Cost-Benefits of Independent Living: Some Hints From the U.K.")

Possible areas for further discussion:

1. Need for defining Independent Living(U.S. - U.K.)
2. Consideration of the most advantageous Independent Living service delivery models.
3. The concept of the cost of not providing services.
4. How can (we) best appeal to the policy makers and legislators?
5. Who is to judge the benefit of Independent Living services/ programs/goals, etc.?
6. How should the cost burden be spread over society, i.e. who pays?
7. How should Independent Living services/programs be organized? How should persons in need of services obtain those services?
8. Would legislators/policy makers, etc. be more susceptible to a cost-benefit analysis, or to a case-study approach? Or to some combination of both?
9. What is the Crossroads scheme in England, and why does it seem to work?

10. Do certain "human rights" override the costs vs. benefits

11. How do we evaluate the effectiveness of Independent Living services/programs, etc.?

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UTILIZATION CONFERENCE

"Costs and Benefits of Independent Living –
Some Hints from the U.K. Experience."

Participants:

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