

NUFFIELD PROVINCIAL
HOSPITALS TRUST

THE TRUST'S
PROGRAMME
INTO THE CARE OF
PHYSICALLY
DISABLED PEOPLE

THE REPORT OF AN ASSESSMENT BY
DR. UNA MACLEAN

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PHYSICALLY
DISABLED PEOPLE**

**The Report of an Assessment
by Dr. Una Maclean
presented to the Trustees in March 1992
(including a commentary on disability research
and the problems of evaluation)**

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Foreword

In 1986 the Trustees decided that the Trust would develop a new major programme concerned with the organisation, improvement and development of services for physically disabled persons and the frail elderly, having been convinced that much required to be done for these groups. The programme from the start was primarily orientated at District Health Authority level.

The programme developed rapidly due to the enthusiastic response of those in the field; so much so that in late 1989 the Trustees decided that it had grown to the point at which a formal independent assessment was needed to give them some measurement of how well the very considerable resources involved had been and were being used. The Trust was fortunate that Dr Una Maclean was willing to undertake the task of reviewing and evaluating the many projects comprising this programme. The Trustees are most grateful to her and to the many individuals up and down the country who helped with her inquiry. I hope that they will feel in reading the report that their efforts were worthwhile.

In circulating the report to the grantholders of the programme, the Trustees hope that in providing feedback on each project they will also stimulate new contacts and reinforce existing ones. Given the gratifyingly high quality of so much of the work reported on, it would seem likely that there will be many further opportunities for the transfer of ideas. Although Dr Maclean's report for practical reasons has a cut-off point of December 1990, many of the projects have continued and new ones have been funded since then. I take this opportunity to confirm that the Trust's interest in this crucial area of care remains and will continue.

Sir Maurice Shock, Chairman

Contents

| | |
|---|-------------|
| Acknowledgements | 1 |
| Introduction | 2 |
| Methodology | 3 |
| Summarized assessments | |
| i) Information | |
| Royal College of Physicians of London | 4 |
| <i>Survey of Disability Services in English Regions and Health Districts</i> | |
| Disabled Living Foundation | 5 |
| <i>Handbook on the Provision of Equipment for Disabled People</i> | |
| Professor R. Taylor, University of Glasgow | 5 |
| <i>Organisation and Management of Services for the Provision of Aids for Daily Living</i> | |
| Disabled Living Foundation | 6 |
| <i>The Role and Distribution of Occupational Therapy Helpers</i> | |
| Dr. G. Cochrane, Oxford | 6 |
| <i>Development of Information Resource Concerning Physical Disability and Rehabilitation</i> | |
| Dr. C. J. Partridge, Kings College, London | 6 |
| <i>Physical Disability and Health Services: Perceptions, Beliefs and Experience of Elderly People</i> | |
| Professor A. Williams, University of York | 7 |
| <i>Eliciting Lay Concepts of Health</i> | |
| Professor M. Clarke, University of Leicester | 7, 8 |
| i. <i>The Health and Social Needs of the Elderly</i> | |
| ii. <i>Community Studies of the Elderly in Melton Mowbray</i> | |
| Mr. C. Petrokofsky, Oxford Regional Health Authority | 8 |
| <i>Oxford Disability Information Project</i> | |
| Dr. C. D. Evans, St. Michael's Hospital, Hayle, Cornwall | 9 |
| <i>Medical Data Index Development</i> | |
| ii) Co-ordination | |
| Mr. P. Colclough, Gloucester Health Authority | 10 |
| <i>Community Care Organiser</i> | |
| Ms. S. Price, Basingstoke District Hospital | 11 |
| <i>Development and Introduction of Information Services for Physically Disabled People and their Carers</i> | |
| Mrs. B. J. Banham, London | 11 |
| <i>Care, Facilities and Services for Physically Disabled and Frail Elderly People in Newcastle</i> | |
| Professor R. Langton Hewer, Frenchay Hospital, Bristol | 12 |
| <i>Disability Services Co-ordinator</i> | |

| | |
|---|---------------|
| Dr. C. J. Moran, Christchurch Hospital, Dorset | 13 |
| <i>Assessment and Monitoring of Younger Disabled People Living at Home</i> | |
| Mr. P. C. Jackson, Exeter Health Authority | 13 |
| <i>Working Together for Younger People with Physical Disabilities</i> | |
| Dr. I. Russell and Dr. S. Hamilton, University of Aberdeen | 15 |
| <i>Grampian Stroke Care Initiative</i> | |
| iii) Mobilisation of Services for Individual Patients | |
| Mr. R. J. Izon, Herefordshire Health Authority | 15 |
| <i>Herefordshire Personal Lifestyle Project</i> | |
| Professor M. Johnson, Open University jointly with Gloucester Health Authority | 16, 17 |
| <i>i. Care of Elderly People at Home</i> | |
| <i>ii. Dissemination</i> | |
| Professor J. R. Pathy, University of Wales | 17 |
| <i>Identification of Early Medical Breakdown among Old People: Follow-up Survey</i> | |
| iv) Services for Particular Client Groups | |
| Dr. J. H. Tripp, University of Exeter | 18 |
| <i>Appropriate Services for Physically Disabled and Chronically Sick Adults</i> | |
| Dr. A. B. Ward, Haywood Hospital, Stoke-on-Trent | 18 |
| <i>Multi-purpose Grant</i> | |
| Professor M. A. Chamberlain, University of Leeds | 19, 20 |
| <i>i. The Needs of and Effectiveness of Services for People with Head Injury</i> | |
| <i>ii. A Comparison of the Needs of and Services for Physically Handicapped School Leavers before and after the Establishment of a District Handicap Team</i> | |
| <i>iii. The Provision of Vocational Evaluation for Young Disabled People</i> | |
| Mr. A. Wall, Bath District Health Authority | 21 |
| <i>Audiology Services Manager</i> | |
| Mr. R. Clarke, National Deaf-Blind and Rubella Association | 21 |
| <i>Education and Rehabilitation Course for People with Usher Syndrome</i> | |
| Mrs. C. A. Lumley, Disablement Services Authority, Leeds | 22 |
| <i>Hostel Accommodation for Lower Limb Amputees</i> | |
| v) Other Studies | |
| Mr. B. Morrison, RoSPA | 22 |
| <i>Safety of Elderly People at Home</i> | |
| Dr. M. Floyd, City University, London | 23 |
| <i>Managing Physical Disability at Work</i> | |
| Mr. D. K. Seager and Sister M. McNally, St. Michael's Hospital, Hayle | 23 |
| <i>Establishment of ENB Course 913: The Care and Rehabilitation of Physically Disabled People</i> | |
| Mr. R. Lynham, British Geriatric Society | 23 |
| <i>Nurse Study Grants in the Care of the Elderly</i> | |

| | |
|---|----|
| Mr. A. Billington, Winged Fellowship <i>Volunteer Training Officers</i> | 23 |
| Dr. R. W. Jones, St. Martin's Hospital, Bath <i>Research Institute for the Care of the Elderly</i> | 24 |
| Dr. E. T. Etheridge, Royal National College for the Blind, Hereford <i>Project PICKUP</i> | 24 |
| Mr. V. Henny, Keep Able Foundation, Brentford <i>Ability Workroom</i> | 24 |
| Ms. N. Robertson, Prince of Wales Advisory Group on Disability <i>Conference on Independent Living and Housing for Physically Disabled People</i> | 25 |
| Ms. S. Dalby, Huntingtons Chorea Association (COMBAT) <i>Preparation of a Training Video</i> | 25 |
| <i>Theme Conferences</i> | 25 |
| Conclusions | 27 |
| Appendix: Problems of programme evaluation | 29 |
| Bibliography | 33 |

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Una Maclean

**Edinburgh,
January 1992**

Introduction

In the Twelfth Report of the Nuffield Provincial Hospitals Trust (1991) an account is given of some of the reasons behind the launch of this major programme of studies in the field of disability. It arose as both the public and policy makers were becoming more aware of the challenges to society presented by dependency and handicap and of the inadequacy of existing responses to demonstrable need.

The Office of Populations, Censuses and Surveys had been commissioned, in 1984, to determine the size of the problem. The Royal College of Physicians, in their Report of 1986, had drawn attention to major gaps in medical provision for certain groups, particularly the so-called 'young' disabled, between the ages of 16 and 64, and had made specific recommendations for improving services. Meanwhile, public opinion on this issue was being affected, at least to some extent, by such events as the designation of 1981 as the International Year of Disabled People, the launch of *Living Options* by the Prince of Wales Advisory Group on Disability (1985), and the growth of the disability rights movement.

Against this background the Trustees boldly decided on a unique experiment in funding, namely to develop an integrated programme of related studies and surveys, mainly concentrating upon services for the younger physically disabled, but also including some support for work on the frail elderly. The first phase began by planning, with the Royal College of Physicians, a large scale survey of existing disability services in the Health Regions and Districts of England and Wales. Begun in 1988, this was regarded as providing essential base line data for the present whilst permitting comparison with past and future provision.

The second phase of the research programme involved encouraging proposals from individuals and representatives of District Health Authorities, particularly from settings and centres of excellence which had already manifested competence, concern and innovation in this field of research of services. In the words of the Trust Report, 'The programme of grants was aimed predominantly at District Health Authority level and concerned the organisation, development and improvement in the delivery of services; and assessment of need, efficiency and effectiveness as a means of determining the priorities for further development.'

Once the programme was well under way, several Theme Conferences were planned, on subjects which were of central importance and involved numbers of grant holders, to encourage the fruitful exchange of ideas and experience. The three so far held have been on assessment of the needs of physically disabled people (Edinburgh, 1990), on developing services for physically disabled school leavers and young adults (Keele, April 1991), and a European conference on new initiatives in traumatic brain injury rehabilitation (Leeds, September 1991). A conference is to be held in Oxford on information services for the disabled in April 1992.

At the end of 1989, the decision was made to commission a comprehensive evaluation of the effectiveness of the entire programme. The account which follows describes the methodology of this overview, summarises the position in regard to each separate project, as it appeared in the first half of 1991, and ends with an appendix on the nature of evaluation in the field of disability studies.

Methodology

During January 1991, the files were examined to discover the main aims and objectives set out by the grant holders at the time they applied for funding. Their agreement in principle to an assessment having been secured by a letter of introduction from the Trust Secretary, a series of visits was planned, aiming to see the grant holders whose projects were already completed near the beginning of the tour. In fact the programme of visits, from Aberdeen in Grampian to Hayle in Cornwall, was partly constrained by geography and by the availability of the principal actors. Thus the stage in any new development at which direct questions were put varied from one place to another, with consequences in terms of recall and in regard to the actual individuals who were there to describe earlier events.

The visits lasted from a few hours to over a day and were set up with differing degrees of formality. In some cases only one informant answered questions; elsewhere, a committee or delegation of almost everyone involved presented themselves; in one university, the entire department welcomed the visitor. Often discussion was followed with a 'site' visit and the opportunity to meet field workers. Much written material was received at the time, in the form of internal reports, information sheets, survey results, discussion papers, published articles and so on.

Discussions with grant holders, service co-ordinators, general managers, therapists, social service personnel and others covered the following main areas:

- i* the background to the original proposal;
- ii* the stated aims, objectives and intentions;
- iii* the stages in the utilization of the grant; the principal researchers and key workers; progress, problems and accomplishments;
- iv* the effect of the project upon the development of local policy;
- v* the impact of the project on the wider community of professionals, workers and policy makers;
- vi* the dissemination of findings.

In view of the very wide disparity in the nature and setting of different studies or service innovations, no questionnaire was employed. Instead, the interviews were guided and in-depth, with full opportunity for following up topics and avenues as occasion permitted or initial responses indicated. The aim was to obtain a detailed local history of the research or the service modification that Trust funding had made possible and, without attempting an economic analysis of cost efficiency, to arrive at a balanced judgement regarding the project's success, effectiveness and contribution to new knowledge.

After each visit, field notes were made and these were later supplemented with the replies to further direct enquiries and, where appropriate, with interim or final reports and with related publications. The individual accounts which follow are necessarily brief and they can only summarise the more comprehensive data upon which they were based.

In the next section, the assessments of the various different projects have been roughly grouped into the categories used in the Twelfth Report when describing the second phase of this programme. It must, however, be appreciated that many examples do not fit easily into these boundaries but proved, or were actually intended, to serve a number of purposes. In this respect the programme as a whole did constitute a matrix.

Summarized Assessments

Category (i) Information

- Royal College of Physicians of London
- Survey of Disability Services in English Regions and Health Districts
- ▶ £151,400 during 1988 to 1990

Under this heading are included surveys of existing services, studies of the views about health and illness held by young or old disabled people, information about obtaining aids and equipment, and experiments in the development of information services for use by disabled people, their carers, professionals and others.

This investigation was intended to follow on from the RCP Report *Physical Disability in 1986 and Beyond*. It took the form of a large scale survey of the disability services provided in 180 health districts in England and Wales. Planned in conjunction with the Disability Committee of the College, it was co-ordinated by Dr. Felicity Edwards with the help of Dr. Michael Warren.

By November 1990, the 144 page document had been published, supplying detailed information on the organisation and management of the services by both Regional and District Health Authorities.

Information sought related to: management and planning arrangements; liaison and collaboration with other bodies; information sources; facilities available; services provided; staffing levels; training and education; research; and perceived deficiencies in the services. It is primarily a descriptive account and concentrates upon aspects of service provision for which guidelines were set out in the 1986 report. It does not cover local authorities, general practice or the paramedical professions.

For ease of consultation, the report is laid out in 25 sections, each with a summary, and the final conclusions and recommendations are succinctly expressed. Among the points highlighted are several which have now been put to practical or research effect in the main body of the Disability Programme. Examples are: the importance of employing more rehabilitation staff, including therapists and members of primary care teams; the necessity for improved arrangements for the assessment of disabled school leavers; facilities for rehabilitation following head injury and brain damage; improved liaison with employment services and employers; and the need for comprehensive systems of information on services for disabled people. Mention is made of the desirability of involving physically disabled people themselves in District planning and consultation procedures.

The following quotation is pertinent in the present context as it expresses the view of the authors on evaluation or audit:

"Any evaluative studies must take account of factors such as population size and density, geographical spread, and services available from other districts or other sources, as well as using reliable and repeatable outcome measures. An essential component of any measure of outcome must be the satisfaction and improvement in the quality of life of the disabled person and their carer."

The invaluable data which this survey provides can be compared now with the situation described, less systematically, five years previously and can be conveniently referred to in the future, when other overviews are undertaken. Participating in the enquiry has already been regarded as an educational experience by the Districts concerned, forcing them to look carefully at their own practice. It is somewhat tantalizing for the general

reader not to have any means of identifying the best and the worst authorities, but anonymity may have been a condition of participation. Meanwhile, the impact of this publication at the highest level is evidenced by explicit reference to this Report in the annex on rehabilitation services in *The Health of the Nation*, the Government's June 1991 consultative document. It noted that the Report demonstrated the lack of consultant sessions for rehabilitation and assessment in 48% of districts; the absence of young disabled units in 56%, of stroke recovery services in 66%, of special services for head injuries in 73% and of special services for amputees in 81% of Districts. Hopefully, the selection for mention of three particular deficiencies could be a pointer to future national priorities.

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- Disabled Living Foundation, London
 - Handbook on the Provision of Equipment for Disabled People
 - ▶ £19,261 over one year, 1989/90, supplemented by successive grants in two subsequent years

The aim of the DLF was to produce a handbook aimed primarily at prescribers of aids and equipment for the disabled, but which would also assist other professionals and policy makers.

The work of compiling this very comprehensive guide to an exceedingly complex area was undertaken by Michael Mandlestam* who had an ideal background, combining library and legal skills. Already available were the large resources of the DLF, but these required a great deal of supplementation and subsequent ordering. The resultant account covers the whole of the UK. The structure of the text is highly systematic and user friendly and it is well indexed.

Although the book describes matters as they are and does not venture to suggest how they should be arranged, close reading cannot fail to uncover the numerous anomalies, contradictions and absurdities which presently prevail. For example, the fragmented world of the statutory services and their definitions are not helpful to the disabled themselves, who judge the usefulness of equipment in terms of improving the performance of daily activities. The medical profession, whilst very knowledgeable about prescribing drugs, is mis-informed or ill-informed when it comes to equipment. There are uncertainties over which professionals, nurses or social workers should be issuing aids, for bathing, for instance.

This study, ostensibly of equipment, is in fact a basic guide to the dense jungle of legislation, practice and professionals. It opens up the whole field, at theoretical as well as operational levels, and represents an outstandingly good outcome of Trust funding, one which it is hard to praise enough. Published in September 1990, it is now into the second edition and it has been followed by a shorter handbook. The book was very favourably reviewed when it first appeared and should now be in general, regular use in many settings.

-
- Professor R. Taylor, Department of Social Administration and Social Work, University of Glasgow
 - Organisation and Management of Services for the Provision of Aids for Daily Living
 - ▶ £36,746 over 2½ years from January 1988

This study was inherited from the former Professor of Nursing and the 150 page report was completed by July 1990. It provides an account of the situation prevailing in two contrasting areas of Glasgow. The split responsibilities for the provision of aids, the thoroughly unsatisfactory storage and delivery systems and the waste of unused equipment in people's homes all added up to avoidable delays and general frustration. Modest reforms were recommended by the nurse researcher and these should be noted by planners in the city.

This work can conveniently be viewed alongside two related projects funded by the Trust, namely the survey among Occupational Therapy assistants and the substantial handbook on obtaining equipment (see

*How to get Equipment for Disability, compiled by Michael Mandelstam, Disabled Living Foundation, London, 1990.

above), both deriving from the DLF. They all deal with highly practical matters which can make a great deal of difference to the extent to which people with a disability achieve something like a normal life in society.

-
- **Disabled Living Foundation, London**
 - **The Role and Distribution of Occupational Therapy Helpers**
 - ▶ *£46,770 over 2 years from January 1988*

Since it was suspected that wide differences prevailed in the ratios, throughout the country of helpers to qualified Occupational Therapists, a study was proposed to discover the true state of affairs.

The Principal Researcher, Peggy Jay, carried out a detailed nationwide survey practically single handed. It covered therapists and helpers employed by both LAs and the NHS, and concerned the nature and circumstances of their work, with the emphasis upon the amount of training and supervision which OT helpers experienced.

The resultant Report, which has now been published by the DLF(1991)* has been well reviewed. It is a comprehensive account which should become the definitive resource and reference in this area. It concludes with a number of specific recommendations intended to rationalise the future employment opportunities of OT Helpers and increase the effectiveness of their contributions to care. In its original form the report was distributed widely, to all the co-operating authorities, and the project can be deemed to have amply fulfilled its objectives.

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- **Dr. G. Cochrane, Consultant Physician in Rehabilitation Medicine (now retd.), Mary Marlborough Lodge, Nuffield Orthopaedic Centre, Oxford**
 - **Development of Information Resource Concerning Physical Disability and Rehabilitation**
 - ▶ *£14,000 over 2 years from August 1989*

The modest support afforded by the Trust to this justly famous centre was for building up resource and reference materials on the broad subject area of physical disability, in a computerised data base. Following the retirement of Dr. Cochrane, comprehensive information has now been assembled by Dilwyn Jones and is available to workers in Oxford, to enquirers from a range of outside agencies or services and to interested individuals. Its usefulness has already been proven during the preparation of the present document. A final Report is on the point of submission. Provided that the existence of this facility is adequately advertised, it should certainly fulfil a need in both academic and professional circles.

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- **Dr. C. J. Partridge, Director, Centre for Physiotherapy Research, King's College, London**
 - **Physical Disability and Health Services: Perceptions, Beliefs and Experience of Elderly People**
 - ▶ *£46,880 over two years from October 1988*

This study was carried out by the Director and her psychologist colleague with the intention of providing a sensible basis for planning appropriate help for the elderly.

A socio-psychological survey of a random sample of 200 elderly people living at home was undertaken. In addition, 20 subjects having intensive rehabilitation from a day hospital were interviewed.

The questionnaire was well designed and systematically administered. Measures of disability, perceptions of health, disease, mobility and quality of life, use of and need for services and the extent of social support were all included. The main finding was that most old people felt themselves to be healthy. Disability, in the sense of not being able to do what one wanted, was perceived as more important than medical problems. The investigators advised that a standard service should not be provided for everyone; instead professionals must be sensitive to individual's perceived needs.

The results are being widely disseminated, through conferences and academic papers, and they constitute a valuable contribution to knowledge.

*Occupational Therapy Helpers and Assistants in Health and Social Services. Disabled Living Foundation, London, 1991.

At a time when assessment of many elderly persons or clients is about to become a responsibility of social workers and others, it is more than ever important that the views, preference and rights of potential recipients of services should be properly taken into account.

■ Professor A. Williams, Centre for Health Economics, University of York

● Eliciting Lay Concepts of Health

▶ £23,000 in 1989/90

This was a survey regarding the concepts of health and ill-health held by four, one hundred sized, samples of people:

- i* severely physically disabled young people;
- ii* able-bodied controls;
- iii* carers of the young disabled;
- iv* carers of able-bodied young people.

In addition, 200 members of the general population were interviewed. The Report was completed by September 1990 and a supplement followed in February 1991.

The investigation was well planned and executed. It did not demonstrate much difference between the young disabled and the rest, except that they resented their dependence on medication and on doctors. Their self-esteem and confidence were diminished. Carers of the disabled seemed concerned over "physical strain," but no more so than the carers of the non-disabled young. The grant holder appended some searching criticisms of the shortage and indifferent quality of evaluation and the inadequate outcome measures which, in his opinion, characterised the field of disability studies.

■ Professor M. Clarke, Department of Community Health, University of Leicester

● The Health and Social Needs of the Elderly

▶ £60,900 over 4 years from April 1985

The entire elderly population of the town of Melton Mowbray (aged 75 and over) was first surveyed in 1981. The first project in the Department of Community Health to be specifically supported by a Nuffield disability programme grant consisted of a randomised controlled trial of the effect of social intervention, brought about by a lay worker who co-ordinated individual packages of enhanced care, upon elderly people who were initially living alone in their own homes. Outcome measures were in terms of mortality, changes in physical status, demand for medical and other services and changes in certain subjective variables, such as loneliness and self-perceived health.

The study was meticulously designed and executed and the results are now to hand. The experimental group of isolated elderly people who received special attention were found, by 1988, not to differ significantly from the control group in any respect other than feeling better. In all, 38 people in the intervention group reported an improvement in health status as compared to 21 people in the control group.

This experiment in supportive visiting might profitably be considered alongside related projects in this programme, namely the work of Professor Pathy and his team in Cardiff and the Gloucestershire trial of advocates for the elderly in general practice, carried out by Professor Malcolm Johnson of the Open University.

Whatever the precise import of the findings and the policy decisions which might eventually be based upon them, there is no doubt that this particular project completely fulfilled its original aims. This first paper on the results has already gone for publication. In view of the extent of current interest in the nature, value and impact of supportive community care this admirably scientific study, albeit with somewhat negative results, should not only make an impression in Leicester but much further afield.

● **Community Studies of the Elderly in Melton Mowbray**

▶ *£24,513 over 2 years from May 1989*

The second project was funded to enable a part time research fellow to carry out further work on the existing data base of information on the elderly population of Melton Mowbray, collected in 1981, 1985 and 1988.

This unique data base has, over the years, been yielding rich seams of information, on incontinence, cognitive impairment, indices of disability, changing mortality risks over time and other topics, none of which could so easily be studied in detail elsewhere. An immediately useful recent product of this specific grant has been a conveniently short screening card for use with the elderly and from which information is routinely transferred to the general practice computer. The system could well serve as a model for practices elsewhere, now that all are faced with the obligation to perform yearly assessments of their patients who are over 75.

It would be hard to overestimate the contribution to the epidemiology of old age which these Melton Mowbray longitudinal studies have already made, with the support of the Trust under one heading or another. It would make sense to contemplate this recording system for elderly people in a general practice in Leicestershire alongside the data management system being developed by Dr. Evans in Cornwall, also with Trust funding (see below).

■ **Mr. C. Petrokofsky, Senior Policy Analyst, Oxford Regional Health Authority**

● **Oxford Disability Information Project**

▶ *£62,500 over 2 years from April 1989*

Based at Regional level, this project was to reach out to all eight constituent Health Districts. The aim was to create a unified information service, on all aspects of physical disability, to help people lead more independent lives. Information and training would also be supplied for caring professionals and for volunteers.

This highly successful project has owed much to the tremendous drive, initiative and intelligence of Alison Clarke, the person appointed as Regional Information Broker. She has created new networks in some places and has re-invigorated existing groups elsewhere, bringing together large numbers of people who are disabled or are concerned with this issue throughout every one of eight Districts and four Counties. Working as unobtrusively as possible, she has followed the lines of the 1988 Coopers and Lybrand Report and has developed local "federations", which are in fact multidisciplinary working groups specifically responding to felt local needs. At the same time, links have been formed within and beyond the Region. The very difficult task of persuading people from different professions and backgrounds to co-operate towards common ends has been achieved by the Information Broker acting quietly, tactfully and persistently as a catalyst for change.

After the project had been going for six months, a conference was called in Oxford to allow for the exchange of ideas and, about this time, ODIP came to the attention of the Department of Health. Shortly thereafter the project was awarded a grant of £218,000. This has since been most judiciously disbursed, in effect it has gone only to those local groups which could demonstrate that they had a viable and appropriate plan for extending their activities.

Meanwhile ODIP has proceeded to "go live" across the Region, using different media and settings for disseminating information, in GPs' surgeries, libraries, post offices, community centres etc.

There can be little doubt that the signal success of this Oxford Region project, funded by the Trust, has influenced the Government's recent initiative in the field, signalled by the allocation of £3 million in 1991 to a new "National Disability Information Project."

It is to be hoped that the twelve other places throughout the country which have been chosen for similar experiments in information services (now popularly termed Federations), will take note of the lessons already learnt in Oxford, especially concerning the challenges of cross professional working and the vital importance of effective leadership. The Oxford project has produced a plethora of reports and papers so there is no shortage of material to use. In addition, the Trust held a related theme conference, at St Catherine's College, Oxford, in April 1992. It was attended by some 140 delegates from all parts of the country and has succeeded in giving appropriate publicity to ODIP's achievements.

■ **Dr. C. D. Evans, Consultant in Rehabilitation Medicine, St. Michael's Hospital, Hayle, Cornwall**

● **Medical Data Index Development**

▶ **£13,000 over two years from March 1991**

The Rehabilitation Medical Diagnostic Index which is being developed here will be part of the Medical Data Index for the Patient Administration System in use throughout the South West Regional Health Authority. Since 1984 the Regional Health Authority had been helping with the development of a limited data base relating to patients of the Cornwall Stroke and Rehabilitation Unit in Truro, intended to help with auditing the Unit's work. The present grant has paid for a researcher to up-date and extend the system, with the intention of shortly including multiple sclerosis patients throughout the County.

The system developed by Dr. Evans is comparatively simple and is maintained by his secretary turned computer operator. The information on each patient covers a brief biography, social and financial circumstances, definitive diagnosis (by ICD), and any complications. It notes events and investigations in hospital and ends with a dependency assessment, in terms of mobility, continence, communication and various measures of ability to perform activities of daily living. Measures of mobility are entered and the amount of support required, from people or equipment. Shortly before discharge the admission summary is added to the plans for further support which will be needed, at home or in OPD. This makes a rapidly produced document available to the patient and to their GP on the day of discharge.

It has necessitated accustoming medical staff to the use of code numbers in the case notes. The information on investigations and episodes during the hospital stay has been recorded according to the King's Fund Consensus Conference on Stroke. Whilst the co-operation of doctors on the wards has been secured, it has proved somewhat more difficult to persuade therapists of the adequacy of such simple dependency measures. At the time of visiting, the data collection for stroke was underway, the extension for multiple sclerosis was still in the planning stage.

This system has great potential for research, since it supplies a regularly up-dated record of the progression of a condition and allows for judgements to be made regarding the effectiveness or otherwise of various interventions. One problem relates to the paucity of previous detailed documentation on the natural history of stroke, making it difficult to decide whether any improvement can be put down to nature or to art. Effectiveness is notoriously difficult to measure, but the establishment of a data system like this should bring it nearer.

It is anticipated that future extensions of this system will involve assessments carried out in patients' homes by SSD and HA staff co-operating to produce "packages of care." There is reason to hope that, given sufficient publicity, the Cornwall rehabilitation data index could be widely used in other parts of the country.

Category (ii) Co-ordination

- Mr. P. Colclough, District General Manager, Gloucester Health Authority
- Community Care Organiser
- ▶ £22,964 over 2 years from September 1989

The projects in this category represent attempts to bring together services, voluntary agencies and carers, with the aim of improving the lot of physically disabled people in a District.

This scheme arose in a Health Authority with an established record for investigations into the needs of disabled people and with good joint planning. It had ambitious aims. It intended to remedy the prevailing poor co-ordination of and information about services for the physically disabled by appointing an organiser who would have the task of building links between various agencies and with the disabled. Central to this scheme was the intention to involve users and consumers as well as the providers of facilities.

The commitment of the Health Authority has been a vital element here, and it was manifested by the presence of the General Manager at the large, multidisciplinary meeting of people who assembled to meet the Trust's visitor, representing by far the biggest gathering encountered in the entire assessment exercise. The very capable Organiser, Sue Porter, has secured remarkable co-operation between different services, voluntary agencies and others.

The project has included what is termed a "disability audit". This has in practice meant that they address many issues, namely: improving access to services; encouraging advocacy for and consultation with the disabled; efforts to raise awareness of need, both locally and nationally; pilot case management projects in certain primary healthcare teams, using the concept of independent brokers or advocates; encouraging carers' support groups; the formation of six "locality groups" and two "implementation groups", to improve contact with the services for those referred to in a prior survey as "The Hidden 3000". Among user led initiatives in the District is a local branch of Living Options in Practice. The development of a networked information service for the County is underway. The term audit is obviously used loosely in this context and means that a range of different developments are being kept regularly under review. An excellent account of these activities is to be found in the first annual Report in the summer of 1991.

It is clear that a great deal has been started in Gloucester, drawing on much good will. But the persisting problem of achieving better conditions for the disabled are fully acknowledged. For instance, it is recognised that disabled people themselves may often require some training in self confidence and in how to act in public before they can actively participate in schemes for their benefit, such as information systems. Some carers' needs prove to be in conflict with those of disabled young people, who are struggling to achieve a life of their own. Only a minority of local GPs so far take an active part in these new initiatives, in spite of their key role in the management of disability. Possibly the most disturbing feature of the situation, in the eyes of the Health Authority, is the forthcoming transfer of responsibility for community care of certain of the disabled from the Health Authority to the Local Authority. But the good relations and positive strategies for joint working which have already been established here should, to some extent, counteract the disadvantages of the imminent dislocation. Here, as elsewhere, only time can tell.

Meanwhile, Gloucester has been chosen by the DOH for one of its new pilot NDIP projects. And the success of a separately funded Trust project in three Gloucester general practices is mentioned elsewhere in this Report.

■ Ms. S. Price, Manager, Elderly Care, Basingstoke District Hospital

● Development and Introduction of Information Services for Physically Disabled People and their Carers

▶ £17,556 over one year from June 1989

The intention at the time when a grant was requested was to investigate and extend the information available to disabled people and their professional and informal carers. Proposals would be made to improve current arrangements. Finally, a model would be developed which other Districts might use.

Basingstoke District already had good intentions and plans for improving services to the disabled, and these were strongly upheld and commended by the Community Care Manager (Annette Clayson) when the hospital was visited. Contact is made with everyone on a local register of severely disabled people (240 in all) every six months.

However, instead of employing staff to develop information services, as originally proposed, the grant had been used to commission a local review and report on the subject by Coopers and Lybrand. After holding two large workshops the consultants produced recommendations along the same lines as those made to the government in 1988, namely that "federations" of providers and users should be set up. Subsequently, rather than proceeding along the lines followed elsewhere, for example in Oxford, the District went no further with the matter.

It appears that the original objectives were lost sight of in Basingstoke, probably on account of a number of intervening staff changes at District level. In consequence, the project cannot be deemed to have been successful.

■ Mrs. B. J. Banham and Mr. J. Luckman, Business Sciences (UK) Limited

● Care, Facilities and Services for Physically Disabled and Frail Elderly People in Newcastle

▶ £57,500 over 1 year from December 1988

The intention was to carry out "a thorough diagnostic analysis of existing services" provided for these two client groups and their carers by Newcastle Health Authority, the City's Department of Social Services and voluntary agencies. The resultant report was intended to form a framework for evaluating plans for organisational change.

The project report was published in June 1989. Entitled *Community Care: Partnership in Action*, it is a splendidly comprehensive account of the situation in one English provincial city in the late 1980s. It appears as though a fortunate combination of tradition and strong personalities in positions of authority were set to make Newcastle an example to the rest of the country. The city seemed to have a real pride in the standards of its public services and presented numerous examples of active co-operation between professionals for the benefit of clients or patients. The Report's many appendices include a care plan for the elderly and model assessment schedules, together with a detailed account of the intentions of the Social Services Department towards these vulnerable individuals. There is a Newcastle City Council Disability Working Group and also a Forum of the disabled, which has representation on the Group.

This well produced and illuminating document was sent to all Health Authorities in England and Wales and Scotland and to the appropriate Local Authorities. There have also been two related conferences, in Newcastle and London. At one time it looked as if Newcastle might pioneer an entirely new model of delivery of community care services, through some form of common agency, but subsequent legislation has precluded any such imaginative outcome. Time alone will show whether the town's civic pride and admirable spirit of co-operation can continue to promote favourable outcomes for the disabled of all ages. Unfortunately, with the best will in the world, it may be impossible even to maintain existing standards in the face of charge capping.

■ Professor R. Langton Hewer,
Department of Neurology,
Frenchay Hospital, Bristol

● Disability Services Co-ordinator

▶ £47,830 over 2 years from
August 1989

The job of the co-ordinator, for whom the grant was awarded, was to focus on the services for younger people (age 16–64 years) who had or were likely to have a continuing physical disability severe enough for them to require the assistance of another person in order to carry out essential daily activities. It was proposed to identify their numbers and their needs, to note the problems of their carers, to review existing services, to make recommendations for updating a District based data base and for a co-ordinated system of individual care planning, and to put forward ways of meeting unmet needs and making good existing service deficiencies.

This extensive and ambitious program was sympathetically regarded by the District Health Authority, but it was without specific managerial endorsement. It had the co-operation of a part-time consultant in Public Health Medicine. The post of service co-ordinator was filled by Wendy Patterson, an able and hard working individual who never wearied in networking among associated organisations and in seeking out disabled people for interview. A total of 109 interviews out of an estimated 202 in the defined category had been completed when the project was visited in mid-April (the expected numbers were derived from a Southampton survey). From the lengthy, three hour, interview it was hoped to develop a shorter one which health visitors or district nurses could subsequently use for long term surveillance of this group of identified disabled people. In the search for disabled people at home the local GPs had proved unresponsive. Meanwhile the project had spelled out how badly off Bristol was in terms of long-term care facilities for the disabled, without a hospice, specialist or sheltered housing, respite care or a Disabled Living Centre. User groups in the community were angry and unco-operative. The project results, when they had been put together, were intended for use as a tool to influence/pressurise the District Health Authority to make more provision for the younger physically disabled.

The process had been going steadily and reasonably well, but the question of how far its results could affect future developments in Bristol had been rendered uncertain by developments which had nothing to do with the competence or good intentions of the research team. Frenchay Hospital itself now has Trust status, and two adjoining Health Authorities were about to merge with Frenchay Health Authority to form a Greater Bristol Purchasing Authority. This development might make the position and prospects of the young disabled even less favourable. In the new circumstances, the Frenchay group who have been intent on co-ordination and on finding out from the disabled what they most need might be less influential in the three District authority. The Frenchay team have been assured that there is to be a Pan Avon Disability Services Group, representing both purchasers and providers from each of the three Health Authorities plus, it is hoped, representatives of Avon SSD.

However, a third year's funding for the post of co-ordinator has been secured from Joint Finance. This latter development does represent a resounding local endorsement of what has already been brought about by the Nuffield grant and it means that the data collection can go on until mid August 1992.

In conclusion, local circumstances have interfered with the early fulfillment of the broad objectives here but the final results may yet have an influence upon the decisions of the enlarged purchasing authority. It is to be hoped that they will come in time, be sufficiently specific and strongly backed.

■ **Dr. C. J. Moran, Consultant Physician in Rheumatology and Rehabilitation with responsibility for Young Disabled Services, Christchurch Hospital, Dorset**

● **Disability Action: Assessment and Monitoring of Younger Disabled People Living at Home**

▶ *£100,000 over 15 months from June 1990 (a supplementary grant of £55,210 was awarded in March 1991 and, with rescheduling, the project was later extended to March 1993)*

Drawing on experience gained with a pilot, this project has since been extending a monitoring scheme for regularly assessing the needs of the physically disabled which, it is intended, will eventually operate throughout half of East Dorset District. It has involved developing a questionnaire, which can be used in the homes of disabled people, by professionals or by lay people, including the disabled themselves. The availability of such information should allow the consultant to provide help at an early stage instead of simply responding to crisis referrals. In theory, this "paper patient" plan should lead to a more efficient use of hospital time as well as a better service to patients.

The grant went to pay for a specialist Disability Nurse, along with other nurses and therapists, together with specially recruited "link persons", who would regularly update the information on each disabled individual. In addition, there was the cost of computer expertise and the hardware necessary for developing the programme.

This was a very ambitious plan, involving substantial resources. It also claimed to include an element of evaluation. Although the disabled in question were limited to "those between 16 and 64 years living at home who were so handicapped as to require long-term support" yet the estimated numbers in this category amounted to some 1,500. But at the time of visiting less than 100 individuals in the experimental group had been involved and not all the items in the long assessment and monitoring questionnaire had yet been given scores for entering into the computerised data base.

As regards evaluation and the vexed matters of effectiveness or efficiency, the disabled who were under surveillance were supposedly to be compared with people who showed up spontaneously under the "old" system. But it appeared as if allocation to experimental and control groups was somewhat haphazard and that, in fact, most time and attention was being given to those in the new scheme. Plans were in hand to secure the help of Professor Phillida Parsloe, of Bournemouth College, to carry out an eventual evaluation, but the parameters for this exercise had not been decided when it was visited one year from commencement. Clearly, the results of any systematic, outside evaluation cannot be expected for some time.

Nevertheless, it is hoped by Dr. Moran and his energetic research manager that the entire system, questionnaires, computer program and recommendations about the necessary associated personnel, might prove to be a commercial proposition or "package", attractive to Social Service Departments, who will shortly be responsible for the non-clinical components of community care and who might welcome a ready made scheme.

This has been a project by a committed specialist in rehabilitation who is determined to rationalise the support and monitoring of young disabled people. It will be very interesting to observe its future development and whether it does turn out to be saleable to either Health or Local Authorities elsewhere.

■ **Mr. P. C. Jackson, District General Manager, Exeter Health Authority**

● **Working Together for Younger People with Physical Disabilities**

Several prior local initiatives made Exeter an obvious place for a grant to further improve conditions for the disabled in the community. The influence of David King, the former general manager, was still felt locally on account of his work with the community care of the mentally handicapped. The advocacy of disabled school leavers by Dr. David Tripp's research at the Postgraduate Medical School had already been supported by the Trust under the present programme. Devon County Council SSD was active on

► *£100,000 over 2 years from January 1990 (subsequently extended by a further year)*

behalf of disabled people and anxious to co-operate with the District Health Authority.

This award has had two parts:

- 1 To pay for six "development workers", to support and encourage local groups in trying to meet the needs of younger people with physical disabilities. Central to this project would be the close involvement of consumers.
- 2 To establish "Living Options East Devon", along the lines of the Working Party established by the Prince of Wales Advisory Group on Disability. A development worker would be funded specifically for this part of the project, to build up associations of consumer representatives throughout East Devon which would survey existing services and help recommend or plan new developments.

The six development workers have proved to be of high quality and most dedicated. They have enthusiastically promoted co-ordination between service providers and voluntary agencies in their localities, in some cases using existing groups and creating new ones elsewhere, to concentrate on issues of particular interest and concern. Many reports, resource materials and recommendations have already been produced and are available to anyone interested.

Peter Swain's leadership of Living Options East Devon has been inspiring. Himself disabled, he has set up and chairs a very large "Forum", of some 100 members, as an independent cross-agency body. It has concentrated upon these key themes: choice, participation, consultation, information and autonomy. Keeping these principles to the fore, its practical objectives have been to identify existing resources and gaps in services, to assist in the promotion of new initiatives and service plans, to help develop a centralized base for expertise regarding disability and to seek to find ways of conveying "the consumer viewpoint" to statutory agencies. In extending the grant for a third year, the Trust recognised Peter Swain as the grantholder for Living Options East Devon.

The impressive consciousness raising and information-centred activities funded by the Trust in East Devon have been greatly helped by the wholehearted encouragement of the District General Manager. As purchaser of specialist rehabilitation services, Peter Jackson related to the Development Manager for Disability Services, Christine Elliot, who herself functioned as a broker under the new arrangements. Fortunately, she was also in sympathy with the aims of the Forum and was in constant touch with related developments on the ground. When she moved to another position her successor was one of the two project workers on the Living Options East Devon arm of the project.

At least one, and possibly two consultant appointments are about to be made, and this will undoubtedly improve the clinical provision and plans for several categories of disabled people or patients. However, there is still some way to go, since ultimate responsibility for the community care of the physically handicapped, here as elsewhere, will depend upon the precise definition and division of future responsibilities of the Health Authority and the Local Authority*. The preparation of joint plans and the final solutions which are reached are bound to require adequate funding as well as good intentions.

**The prior existence of a Locality multi-disciplinary Rehabilitation and Support Group should help when hard economic decisions are being made about long term responsibilities as between the LA and the HA. Meanwhile, the latter has said it is willing to fund the District Disability Team.*

■ **Dr. I. Russell, Director, Health Services Research Unit, University of Aberdeen and Dr. S. Hamilton, Consultant Physician, Grampian Health Board**

● **Grampian Stroke Care Initiative**

▶ *£35,712 over 2 years from January 1990*

Based on the King's Fund Consensus Conference on stroke care, this project has aimed at creating a coherent strategy for Grampian Region. First, the stroke care co-ordinator, Jill Tweedie, visited everyone in Aberdeen concerned with managing this problem, in medicine, nursing, occupational and speech therapy, physiotherapy, the social work team for the elderly, the voluntary sector and private nursing homes. Working as a catalyst, she was well received by all who wished to co-operate with this new initiative for a hitherto relatively neglected category of people.

Meanwhile five multidisciplinary guideline groups were formed, each with quite specific tasks and a strict timetable for producing action plans. The topics were diagnosis, treatment and secondary prevention; assessment and rehabilitation; discharge from hospital; information for patients and carers; and, later, care in the community. Each group was also instructed to consider how they would set up a monitoring system for their new arrangements. So action plus audit were of the essence here.

There have already been important local effects. The interim report was at once distributed to relevant and interested people and has clearly succeeded in stimulating local responses. The Priority Services Unit of the Area is contemplating a stroke ward based at Woodend Hospital. The hospital guidelines have been produced and distributed by one multidisciplinary group and community guidelines are being prepared by another. Dr. Hamilton, Consultant Physician for the Elderly at Woodend, is joining the UK Stroke Audit Group and the Aberdeen project may soon be part of a proposed pilot to be run and monitored in Scotland. Although the Grampian Health Board will not be able to continue funding the Stroke Care Initiative when the Nuffield money is finished, this proposed national audit scheme may well prove to be an alternative.

The work of the highly successful Grampian initiative has been widely and regularly publicised locally and will be described at scholarly meetings and in medical journals. If it does feature in the national audit its influence will be even more significant. The dynamic and unique approach which it represents should form a model for other areas. It has been most ably planned and carried out by a committed, imaginative team, who kept strictly to their declared objectives at every stage of the process.

Category (iii) Mobilisation of Services for Individual Patients

■ **Mr. R. J. Izon, Unit General Manager, Community Services Unit, Herefordshire Health Authority**

● **Physical Handicap Services: Herefordshire Personal Lifestyle Project**

▶ *£41,525 over 2 years from April 1989*

These represent experiments with new ways of bringing services to people, through an advocate, intermediary or visitor, who may or may not have a professional qualification.

A project manager was funded, to extend work previously piloted. This had been based upon the idea that disabled people should each have a "personal lifestyle package", designed to offer them genuine choices about how and where to live and, hopefully, work. It had strong initial encouragement from the Spastics Society, but was designed to involve all relevant agencies and services for the benefit of everyone with a physical disability in the County. As well as identifying gaps in service provision it would establish criteria for selecting and training key workers. It was stated that the project would be evaluated.

Over the period of the grant the emphasis has shifted. The Lifestyles Co-ordinating Team have progressively distanced themselves from the

whole idea of case managers, whose business it is to arrange other people's lives. Convinced that disabled individuals desire and deserve autonomy above everything, the team members concentrate instead on empowering people, helping them towards self assessment and more active social involvement.

When visited, the Team had 40 "clients" who were in regular touch with the co-ordinator, Heather Coonick. Disabled people were on the team, together with some representatives of statutory services and voluntary organisations. By the end of the funded project efforts to increase inter-agency co-operation had continued, in spite of scepticism from some SSD employees and minimal involvement of general practitioners. The original intention to make an inventory of all local resources had been left to DIAL. A Personal Lifestyles Package had been designed for assessing school leavers, as a contribution to the work of the District Handicap Team for Children, and a start had been made towards links with the new District Handicap Team for Adults.

The most significant development by the end of the Nuffield funded period has been the decision of Hereford Lifestyles to go independent, as a company limited by guarantee. This frees them from any suggestion of being in league with service workers who are often under an obligation to ration resources and can only recommend a limited range of possibilities for a frustrated disabled individual.

In summary, many of the stated aims have been fulfilled locally, albeit on behalf of a limited number of disabled people. The importance of this work lies in its whole philosophy, allied to the movement of disability rights in the broadest sense. It is only one of a number of similar Lifestyles projects, in Swindon, Salisbury, Trowbridge, Worcester and East Suffolk, for example. As part of National Lifestyles, members from across the country meet regularly to plan the further development of their ideas.

■ **Professor M. Johnson,**
Open University, jointly with
Gloucester Health Authority

● **Care of Elderly People at Home**
▶ **£50,000 over 2 years from March**
1986

The introduction of care or case managers to three Gloucester general practices was undertaken in order to improve the co-ordination of community care for the frail elderly. It exemplifies a project which was timely, well conceived, carefully monitored and written up in detail.

The concept of case management came from the United States but there have been disagreements about the precise role, background, responsibilities and accountability of such new workers and, in particular, whether they should be employees of one of the statutory services or should owe primary allegiance to the patient or client. (In Kent a somewhat similar experimental scheme gave a budget to each manager with which to buy in temporary assistance.) This OU project used the research funds to employ the care co-ordinators, but then they were independent, responsible only to the principal researchers and always acting as patient advocates.

The three women in question did not have professional backgrounds but learned as they went along the special difficulties of becoming accepted within primary health care teams whose members had clearly established ways of interacting. They assessed individual needs, using a novel biographical approach pioneered by Malcolm Johnson, and devised appropriate "care packages" to help the old people remain in their own homes. It was essentially action research, with the methods of working being developed and modified as the project developed. The co-ordinators kept diaries and these have since been used to compose a valuable handbook of case studies.

The research took place in a Health Authority with a good record of community care and co-operation with other services and agencies and the Trust recognised this by the award on another grant (see above).

Regular and detailed project papers have reported on every aspect of the programme as it progressed and these have ensured that it is now well known among students of the field. In addition, by featuring in the teaching material for related OU courses, it reaches a wide general readership.

The work has not only made the idea of case management more familiar. It has emphasised the importance of independent patient advocates, who act primarily on behalf of vulnerable people and who, because they are not representatives or servants of authority, are less likely to be seen as mainly concerned with rationing scarce resources.

This project was emphatically not conceived as a case controlled experiment. Instead, changes were successively introduced in the course of the scheme and assiduously recorded. It is to be hoped that many people will benefit eventually from the experiences of the Gloucester key workers.

● **Care of Elderly People at Home: Dissemination**

▶ *£19,545 for one year from June 1989*

This second grant was awarded for the specific purpose of producing a practical handbook about the experiences of the patient advocates in general practice during this Gloucestershire scheme. At the time of visiting the material was almost ready for publication. Although its actual production has been somewhat delayed, the book should shortly prove a useful resource for individuals from a wide variety of backgrounds who may have to function as case managers under the new arrangements for the home care of vulnerable elderly people.

■ **Professor J. R. Pathy,
University of Wales College of
Medicine, Department of
Geriatric Medicine, Cardiff**

● **Identification of Early Medical
Breakdown among Old People:
Follow-up Survey**

▶ *£6,420 in 1988*

This grant was awarded for a follow-up study, completing a three year research programme, which intended, by interviews, to assess the benefit of health visitor intervention or screening in the lives of people over 65. The objective had been to prevent early medical breakdown.

The investigation concerned the Cardiff population of 750 individuals, aged 65 and over, living in the community. Randomised into two groups, the intervention one was sent a postal questionnaire yearly about the current state of their health and social functioning. Depending on the answers, a health visitor would call and take action. The control group only received occasional crisis visits from a health visitor.

The results showed significantly fewer deaths among the "intervention" group. Domiciliary visits by hospital specialists to this group were halved. Both groups made the same number of visits to GPs but the intervention group required less home visits. At the end of three years measures of "life satisfaction" did not differ.

This was a reasonably executed study which brought out the relative advantages of employing an unusually good health visitor to contact and see half the over 65s in a co-operative practice. In other words, the circumstances in the two places being compared may not have been the same. However that may be, the conclusions were overtaken by events in the form of the new GP Contract, requiring yearly contact with all patients over 75.

The Cardiff work can usefully be considered alongside two related projects in this programme, namely that in Melton Mowbray by Professor Clarke, and Professor Johnson's study in Gloucestershire.

Category (iv) Services for Particular Client Groups

- **Dr. J. H. Tripp, University of Exeter Postgraduate Medical School**
- **Appropriate Services for Physically Disabled and Chronically Sick Adults**
- ▶ **£60,000 for 3-4 years from April 1986**

Services for physically disabled school leavers, people with head injuries, the hearing impaired, the partially sighted and others.

This multi-faceted project started from the observation that, whereas there were designated services for disabled children and for elderly people, the needs of "young" adults with a disability had been largely ignored. The grant holder, a paediatrician, set about initiating change by the very process of doing research, paying special attention to disabled school leavers and to post head injury cases. A prior survey in the District had demonstrated the size of the local problem and the extent of unmet needs among disabled school leavers.

The Trust money was used to employ a full time research fellow for three years, her task being to make contact with groups of disabled young adults, their parents and local pressure groups, supporting and encouraging them in their demands for more services of an appropriate kind. Interviews with young people provided opportunities for them personally to face issues in new ways and helped key workers to modify their own attitudes.

A comparison of the needs of those in long-stay residential facilities with comparable disabled individuals in the community showed that some more, well-designed long-stay environments would still be required. Attention was drawn to the desperately fragmented and inadequate follow-up service for those who had had a head injury, and this was leading to local improvements.

It does seem probable that this package of research initiatives has raised the profile of the young disabled locally and has gone some way towards empowering them. Evaluation of the work of an experimental Resource and Development Officer showed this post to have been highly effective. An additional bonus from the three year research programme was the promise of a place on the health executive for a disabled person.

Not all the impact of this action research programme has been at local level. The work itself and the argument for empowering the disabled has been widely publicised in academic publications and at conferences. All must have been contributing towards the more serious recognition of the needs and rights of disabled young people, an end which has also been pursued by the Hereford Lifestyles project with the support of the Trust.

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- **Dr. A. B. Ward, Consultant Physician in Rehabilitation Medicine, Haywood Hospital, Stoke-on-Trent**
 - **Multi-purpose Grant**
 - ▶ **£30,000 over 18 months from January 1990**

This modest grant was requested for four separate purposes: first, to look at the neurobehavioural and occupational consequences of brain injury as a preliminary to building up appropriate services; second, to evaluate the recently established service for physically handicapped school leavers; third, to produce a resource handbook for professionals from different backgrounds on how to obtain services for their disabled clients; finally and fourthly, to run several short training courses for health and social service staff working in the field of disability.

The grant holder is a clinician, a consultant in rehabilitation medicine, with an admirably systematic and efficient way of going about his work. The topics chosen, head injury, disabled school leavers and information services, were all in need of attention, as the RCP reports had attested. The funding requested was remarkably modest.

The controlled study of head injury cases compared clinic attenders with those who chose not to use this facility. After three months, those who had had a period of in-patient care had the same residual symptom scores as cases who had been sent straight home from A and E. There were marked financial implications of even minor head injury for both employees and employers. Incidentally, it appeared that a significant number of head injury cases had no memory of having received the obligatory head injury instruction or information about follow-up. Now a comprehensive local plan for a brain injury service has been drawn up, involving close co-operation with psychiatrists and the neuro-behavioural unit.

North Staffordshire had begun to develop a service for physically handicapped school leavers in 1989, and was in fact one of the first places to do so. The Nuffield grant made it possible to start assessing the effectiveness of the methods which had been set up. Ninety-nine young clients from various referral sources met a team consisting originally of nine people from different backgrounds. After each interview discussion led immediately to a definite action plan, with everyone being perfectly clear what they were responsible for doing. A key worker (the resettlement officer) then ensured that action did ensue. Information about further education and about employment prospects was particularly appreciated by the young people. Team members themselves feel that they have benefitted from the experience of joint working. However, it has not so far proved possible to measure the cost effectiveness of the scheme.

The plans for a handbook on services have had to be put temporarily on one side because of the preparations for implementing the community care legislation with its new allocation of responsibilities.

A start has been made with a series of half-day training courses, which have apparently been greatly appreciated by participants.

Meanwhile, with a separate NPHT grant, a National Conference on developing services for physically disabled school leavers and young adults was run at Keele in April 1991 (see below). This meeting, and the theme conference on head injury in Leeds, have both contributed to disseminating the results of work carried out in Stoke.

■ Professor M. A. Chamberlain
and Dr. A.H. Houston,
University of Leeds School of
Medicine, Rheumatology and
Rehabilitation Research Unit,
Leeds

● The Needs of and Effectiveness
of Services for People with
Head Injury

► £83,332 over 3 years from April
1989

The first of these projects has been directed towards a most important clinical topic and it is being addressed in the Leeds Research Unit in an admirably scientific manner which is likely to yield widely applicable findings. It can be described as action research, with a co-ordinator who acts as a "family advocate", funded by the Trust, and with the close involvement of community occupational therapists.

In the first year, much of the time went to local negotiations, establishing ground rules and preparing and testing the long questionnaire to be the investigative tool. This instrument should ensure proper evaluation of the rehabilitative programme. By the second year, it was possible to respond in a rational and much more co-ordinated fashion to the needs of head injured patients and their families.

The population has consisted of every resident of the city (16 years or older) who has spent 24 hours in a local unit after a head injury. A member of the team of OTs first carries out a comprehensive assessment of need, whereupon they can proceed with a treatment programme or the provision of aids or can refer the patient to hospital. The information collected on the first and subsequent assessments forms a comprehensive data base which ensures adequate follow-up and a "coma to community audit".

It is expected that the Social Service Department will shortly incorporate a version of this programme in the system which they are developing. The rehabilitation ward of one Leeds hospital will also introduce the electronic monitoring of cases. The use of the same software will at last make co-operation between SSD, community OTs and clinicians a reality. The system has been designed so as to pay special attention to the behavioural sequelae to head injury. Two cohorts of patients can already be compared to note the impact upon outcomes of the new approaches to care. These results are awaited with interest.

This whole research programme has already been the subject of numerous scientific articles and papers. A successful international conference on Head Injury, supported by the Trust, was appropriately organised and sited in Leeds.

● **A Comparison of the Needs of and Services for Physically Handicapped School Leavers Before and After the Establishment of a District Handicap Team**

► *£48,531 over 3 years from April 1989*

The second project from the Leeds Research Unit focuses on physically handicapped school leavers, a group who have so far been disregarded.

The Health Authority and the City Council set up a multidisciplinary team and this research was intended to evaluate its working. It was hoped to compare the experiences of two cohorts of sixteen years olds leaving school before the team was established with two subsequent matching groups in 1988 and 1989. The young adult team, set up in 1988, comprised a doctor, a social worker, a physiotherapist, a speech therapist and one half time occupational therapist. A psychologist joined in the spring of 1991.

The evaluator, funded by the Trust, began work in 1989 and initially found the task daunting. This was because it had been designed to be partly retrospective and there were, in addition, misunderstandings about the original guidelines for the multidisciplinary team as well as conflicting accounts of its history. Leadership had been problematic, with social service suspicion of medical dominance. Data collection had been un-systematic and it proved virtually impossible to reconstruct the experiences of the earlier cohorts. Referral to the team in its early stages had been arbitrary but, at the time of visiting, there were established links with schools, GPs, the social services and career services. Interview schedules were ready by the autumn of 1991. But by August 1991 only 30% of the school leavers were willing to be interviewed. The interviewing plans and the comparison groups have, however, been reconsidered with the focus on inter-group comparisons since the team has become established.

Over the research period the management context has altered several times, from a community base to Leeds General Infirmary Trust and then back into the community. Meanwhile, the two separate Health Authorities of Leeds West and Leeds East have combined. The project, which suffered from false starts, has thus been bedevilled by organisational changes and uncertainties. The final report, due in April 1992, will indicate how far these problems are ultimately resolved.

● **The Provision of Vocational Evaluation for Young Disabled People**

► *£28,443 over 2 years from August 1990*

The idea of providing vocational evaluation for young people, using a range of specially designed pieces of equipment, came from the United States and it has been put to practical effect in Leeds by the evaluator of the young adult team (see above) who learned the American method at first hand. It is intended as a way of matching people with jobs, according to capabilities which can be tested systematically during sessions at the peripheral, long stay hospital which currently houses the specialised equipment.

At the time of the visit, three months into the scheme, only 5 clients had been referred to this facility, although a further 6 were expected to take up the offer. When the interim report was written 2 clients were said to have completed the process. However, since then vigorous efforts have been made to advertise the availability and the advantages of systematic skills evaluation and the message is reported to be getting through. The equipment was intended in the first instance for young disabled school leavers known to the Team, but it might yet be applicable to other people. The ultimate success of this project remains to be seen. It must surely be acknowledged that the employment prospects of the disabled, poor at the best of times, are likely to be worsened during a recession.

■ **Mr. A. Wall, District General Manager, Bath District Health Authority**

● **Audiology Services Manager**

▶ **£29,459 over two years from Sept. 1989 (increased to £49,956)**

Bath has been famous for helping people with chronic and disabling conditions since Roman times. Of late, the District has developed important rehabilitative programmes and this particular project is one with which the General Manager has been closely identified. He became aware of the very long waiting times for appointments endured by the hearing impaired through a survey which indicated that one of the prime demands of local elderly people was for hearing aids. Accordingly the grant money was used to appoint a singularly well qualified audiology services manager, Andrew Reid, whose technical skills in the field were allied to management experience. He was given a budget and proceeded to employ some extra staff, whilst at the same time arranging a rota to see people in local community hospitals and providing domiciliary sessions when necessary. Equipment was upgraded and additional research grants sought and awarded.

The waiting time for hearing aids has dropped dramatically, from 13 months to less than 2 months and there is now a comprehensive range of services available throughout the District.

There can be no doubt whatsoever of the singular success of this project. It has already been reported in the *Health Services Journal* where it stands as an excellent example to others. In recognition of the importance of this work the District has now made permanent the post of audiology services manager and the Royal United Hospital in Bath has made the development of similar services a top priority.

■ **Mr. R. Clarke, National Director, National Deaf-Blind and Rubella Association (SENSE), London**

● **Education and Rehabilitation Course for People with Usher Syndrome**

▶ **£47,040 over 2 years from November 1988**

The funding was to make possible short courses of training for people with this rare and distressing condition. The courses take place in a specially equipped and decorated maisonette (Ashley House) in Birmingham. The Usher Syndrome Rehabilitation Officer, June Hoy, assisted by the Nuffield grant, has organised a series of residential courses for victims, having arranged for the prior involvement and instruction of the various workers involved.

Because this syndrome is exceedingly rare it has proved difficult to target the population who might benefit and they, in their turn, have had considerable problems over being funded by their social services or education departments. A communications course and a special youngsters course have been added to the series and a teaching video has been produced.

This is the first time that a grant has ever been made specifically for people with Usher Syndrome. It is now hoped that the Nuffield initiative will be followed by longer term assistance from elsewhere, possibly the EC.

■ Mrs. C.A. Lumley, Regional Manager, Disablement Services Authority (ALAC), Chapel Allerton, Leeds

● Hostel Accommodation for Lower Limb Amputees

▶ £9,900 over 15 months from September 1989
(Supplementary grant to March 1991 £4,000)

The grant was made for the evaluation of a scheme allowing recent amputees to spend five days in hostel accommodation in a hospital across the road from the limb fitting centre, thereby avoiding the necessity for repeated journeys from home and allowing for a period of concentrated physiotherapy and the opportunity to gain familiarity with the artificial limb.

A total of 68 individuals had taken part in the scheme by the time that it had to be (temporarily) halted. This was, however, never set up as a controlled experiment since those chosen to participate were selected precisely because of their ability to care for themselves unsupervised. The District Health Authority would take no responsibility for anyone staying overnight in a relatively isolated part of the hospital, more particularly since these people fell, at the outset of the scheme, under the DSA.

One aim was to discover whether delivery of the final limb was possible within 3 working days and if the speedy supply of the prosthesis would affect the time taken by someone to reach specified rehabilitation goals. Readjustments could be made on the spot, family could be on hand to help and the amputee would be staying in a setting like home.

The fortunate participants in the scheme underwent numerous detailed physiotherapy assessments both in the week in question and at follow-up sessions. All expressed satisfaction with the arrangements and apparently made speedy progress.

The double murder of doctors on Health Authority clinic premises elsewhere in the District led to the immediate review of security everywhere and the annexe was shut. It is hoped that the process can be eventually resumed on other premises. But the financial rearrangements consequent upon the transfer of responsibility for such people from the DSA to the District Health Authority has been a serious problem. Added to this is the fact that certain Leeds hospitals have applied for Trust status. And, in the course of reorganisation of responsibility for amputees, the person who originally acted as grant holder was moved to another job. All in all, the history of this modest scheme provides a fascinating vignette of the unexpected impact of fate and social change.

Category (v) Other Studies

■ Mr. B. Morrison, Assistant Director, Home and Leisure Safety Division, The Royal Society for the Prevention of Accidents (RoSPA), Birmingham

● Safety of Elderly People at Home - Training/Information Materials for Carers

▶ £25,000 in 1989

Included are contributions towards public and professional education concerning disability in young and old and from different causes, and grants awarded for special research or exceptional innovations.

The training and information materials were needed as part of a campaign one winter to promote the care and safety of frail elderly people at home.

The literature which the Society produced was of the highest quality, both in its content and presentation. It was produced after extensive consultation with appropriate specialists. The training video plus the excellent "trainers' notes" were most professional, with the mode of usage clearly indicated and the contexts defined. In addition there is a topic guide, Safety of Older People at Home, along with material specifically on avoiding falls and, finally, a simple checklist for anyone providing care.

The campaign literature was widely disseminated. All SSDs and District Health Authorities were told early about them. When the video was ready, 200 copies along with 15,000 checklists were prepared. All this material should continue to prove invaluable to many health professionals, teachers, students, police and carers.

■ **Dr. M. Floyd, Director,
Rehabilitation Resource
Centre, City University,
London**

● **Managing Physical Disability
at Work**

▶ **£20,000 for 1 year from
November 1988**

City University has a large business studies school and wanted to extend a programme of "disability awareness" training for the managers and supervisors of large employers. The grant was to fund the development and testing of training materials and publications.

This has been a successful venture. Help from Nuffield enabled the course teachers, two of whom are themselves disabled, to design resource materials for people attending short London courses, but also suitable for use by these same students in the places from which they came. Courses have been attended by disability officers of private firms, disability personnel in Government Departments, in the Equal Opportunities Commission and elsewhere. Thus the dissemination of information about the abilities, potential and rights of disabled people in the workplace has been like a "cascade", with its effects spreading from the University out to the periphery. The courses are now continuing independently.

■ **Mr. D. K. Seager and Sister
M. McNally, Marie Therese
House, St. Michael's Hospital,
Hayle, Cornwall**

● **Establishment of ENB Course
913: The Care and
Rehabilitation of Physically
Disabled People**

▶ **£19,505 over 1 year from
October 1988**

The money granted to enable this course to begin and run for one year has certainly been well spent. At the time it started there was only one other such course and it had a very different character from this one. The setting is ideal, in a purpose built unit for the care and rehabilitation of severely disabled young people. The teaching methodology is first rate, with well defined objectives, maximum student participation, opportunities for discussion, self learning, projects and in-course assessment. This excellent model for a course in the field of rehabilitation places due emphasis on the psychological and sociological dimensions of disability and on the needs of carers.

Each course takes up to a dozen nurses and the training scheme now pays for itself. On their return to their own hospitals the students must be applying the lessons learnt here, to the benefit of both patients and colleagues.

■ **Mr. R. Lynham, British
Geriatric Society, London**

● **Nurse Study Grants in the Care
of the Elderly**

▶ **£10,000 over 2 years from
January 1989**

By July 1991 fifty-six nurses had participated in this scheme. It provided modest sums of money to allow those interested in geriatrics to attend conferences, seminars and meetings or to go and see units which featured innovative care programmes. The reports which they subsequently wrote are excellent. Lively and interesting, they revealed a great deal about the writers' expectations and how unusual it was for any of them to have such opportunities. The final report from the Society will be ready early in 1992.

■ **Mr. A. Billington, Winged
Fellowship, London**

● **Volunteer Training Officers**

▶ **£12,000 over one year from July
1990**

This was to fund the cost of three Recruitment and Training Officers to be based at three of the Winged Fellowship's five holiday centres.

The purpose of this grant has been amply fulfilled. It has ensured that the young volunteers who offer to act as personal assistants to severely disabled people on holiday at one of the Fellowship's homes receive a modicum of training before they begin. Since the grant became available there have been more offers of help from intending helpers than ever before. Part-time trainers at each centre have gone outside to various colleges and schools to recruit and give talks to volunteers and subsequently provide them with some basic practical instruction. The support given has been much appreciated by all the Centre Managers, who are in a good position to judge the success of the one year training scheme.

■ **Dr. R. W. Jones, Director,
Research Institute for the Care
of the Elderly, St. Martin's
Hospital, Bath**

▶ **£30,000 in 1988/89**

The money was given as a final contribution towards the maintenance of an Institute, originally funded by the Trust, as a contribution towards running costs and to help pay for a fund-raising scheme to put the place on a firmer financial footing.

The Director is a keen and able young scientist, fully engaged in running several projects whilst seeking support for others. His main research is in the following fields: dementia scales; measurements of functional capacity in the elderly; the safety of medicines, particularly multi-medication.

Academic dissemination of the work of the Institute is well underway, six papers have been published and more presented at conferences.

■ **Dr. E. T. Etheridge, Head of
Department of General Studies,
Royal National College for the
Blind, Hereford**

● **Further Education Unit Project
PICKUP**

▶ **£5,815 in 1990**

The money was for buying equipment necessary to proceed with a project on the commercial updating and training of employees who were experiencing handicapping loss of sight. The equipment involves synthetic speech technology and can transform the communication capacity of those who work with computers and word processors.

The project was completed at the end of August 1991 and a Report went to the Further Education Unit of the DES. Already, as a direct result of this project and of the Report, the College for the Blind is in the process of setting up a special unit to pursue this educational objective on a permanent basis and a PICKUP Development Officer has been appointed. This grant to the College for the Blind was clearly a case of money well spent.

■ **Mr. V. Henny, Chairman, Keep
Able Foundation, Brentford,
Middlesex**

● **Ability Workroom**

▶ **£50,000 in 1990/91**

This grant was to fund the first year running costs of an ability workroom, where an integrated range of new and conventional assistive devices would be available for trial on the spot by severely disabled people.

Having developed assistive devices for boats on the open sea, this highly imaginative former oil industry employee has transferred, in retirement, his considerable skills and boundless energy to the creation of assistive devices for the disabled. He has trawled many countries for ideas and appliances and, with the invaluable assistance of first rate computer programmers and technicians, has put together highly ingenious new, man-made interfaces linked to more familiar existing devices. Commercial robotics and electronics have been successfully cannibalised for the benefit of the disabled. The resultant equipment is available, for demonstration and practical trial, in a workroom on his commercial premises. The expensive workroom full of uniquely integrated tools has been made possible by multiple grants, to which the Trust has contributed one fifth.

The new equipment has, so far, been specifically intended for high lesion quadriplegics. Provided such individuals retain some movement, even if it is only the capacity to blink or blow, their intentions can be converted into purposive activity by sophisticated electronic devices. They can thus control lights, doors, bed angles, telephones and word processors, to mention only a few of the possibilities which open up. Assessment can take place by the severely disabled person attending the workroom along with a carer, or a selection of the equipment, on a trolley, can be sent along to a home or hospital.

Such a custom built and complicated system is inevitably expensive and its purchase to date has been dictated by the money available to some very severely disabled individuals, from compensation awards or charitable donations. However, since the system of integrated devices does restore to someone a remarkable degree of autonomy, it is certainly possible that

it might prove cost effective, in terms of saving the expense of paid attendants.

This is a case which the talented innovator would like made, although he himself is not personally equipped either for carrying out economic cost benefit assessments or for persuading service managers. There is another possible development from the original Henny set-up, namely its adaptation to fit the mental and physical abilities and requirements of elderly disabled people, a considerably larger group than the young quadriplegics, and proposals for diversifying are in hand.

■ Ms. N. Robertson, Director,
Prince of Wales Advisory
Group on Disability, London

● Conference on Independent
Living and Housing for
Physically Disabled People

▶ £7,000 during 1989/90

The funding paid for part of the costs of a conference organiser, the remaining costs coming from the Joseph Rowntree Foundation. It was organised jointly with Shelter.

The intention of the Nuffield Trust was to provide an opportunity for two groups of professionals, namely those concerned with housing and those in other "support services", to meet and increase mutual understanding of their contributions towards independent living for disabled people. It was hoped that the conference would concentrate on examples of good practice which were already offering increased choice and control to disabled people.

The perception of the organisers was significantly different from this. They conceived of it as also affording a chance for disabled persons themselves to voice their grievances about the very unsatisfactory housing many of them experienced and to make their demands for radical improvements known. Shelter worked closely with the British Council of Organisations of Disabled People, with the Community Living Development Team at the King's Fund Centre and with the Living Options Project. 240 delegates attended, 40% of whom were disabled, from local authorities, voluntary organisations and charities. As there was a strong emphasis upon the burgeoning "disability rights" perspective considerable time and effort went to finding a conference venue which could accommodate large numbers of wheelchair users.

From the point of view of the Nuffield Trust, the original objectives may not have been fulfilled, although the two day event did serve other functions.

■ Ms. S. Dalby, Huntingtons
Chorea Association
(COMBAT), London

● Preparation of a Training Video

▶ £2,200 in 1988/89

On account of many unanticipated difficulties, the intention of making a training video about this condition was not fulfilled until November 1991. At this time the assistance of a well wisher from Channel 4 television meant that the project could at last be completed and a copy was sent to Dr. Ashley-Miller. Apart, therefore, from the delay this limited project was evidently a success.

Theme conferences

(i) *The problems of obtaining and maintaining relevant current information about physically disabled persons.*

This was organised by Professor Cairns Aitken and held in Edinburgh in May 1990. The 38 participants were from Edinburgh University, Scottish Health Boards and Social Work Departments, English and Welsh Authorities and the voluntary sector.

It had originally been intended to focus on creating and maintaining registers, since these could provide estimates of the whole disabled population for purposes of epidemiology and would supposedly also

serve to lead service providers towards identified individuals in need. The cost and difficulty of maintaining such registers, however, and the availability of reliable estimates of prevalence from the OPCS survey caused a shift in the direction of the proceedings. Discussion of recently disclosed government intentions regarding community care, added to the need to devise assessment procedures and address case management, concentrated the minds of the participants remarkably and gave the ultimate conclusions of the conference a more topical relevance.

The Report, entitled *Assessment of a Disabled Person for Community Care Services*, was published in September 1990 and distributed to all Health Authorities and Social Service Departments. Only a special investigation could estimate the impact which this particular document had upon related service managers at the start of a time of great change.

(ii) *Problems of physically handicapped school leavers and ways of mitigating them.*

The stated aims of this conference, organised by Dr. Anthony Ward and held in Keele in April 1991, were:

- i* to demonstrate the need for specialised services for young people with physical disabilities;
- ii* to stress to managers and budget holders the role that such services play in improving the quality of life for both clients and carers;
- iii* to bring together people involved in planning and operating these services and demonstrate the variety of strategies and practices being developed in response to local needs.

The 210 people attending this conference represented a wide range of disciplines. First they contemplated and deplored the prevailing lack of co-ordination between agencies, then they heard of examples of good practice and plans with regard to disabled school leavers. This was an opportunity for related projects supported by the Trust, in North Staffordshire, Leeds, Oxford (ODIP), Exeter and East Devon, Herefordshire and Gloucestershire to gain a wide audience and provide inspiration to others.

The report, *Developing Services for Physically Disabled School Leavers and Young Adults*, which came out shortly after the conference, is particularly well designed and informative. Both its content and the contacts and references it includes should prove most useful.

(iii) *The care, support and treatment of moderately severe head injured patients.*

This European conference, organised by Professor Anne Chamberlain and her colleagues, was held at Leeds University in September 1991. It was attended by 200 participants and mainly took the form of workshops. It was essentially practical, designed to help with the establishment of special services, the assessment of physical and behavioural sequelae to head injury and the measurement of outcomes of different therapeutic regimes. The full report, *New Initiatives in Traumatic Brain Injury Rehabilitation*, will be published in the spring of 1992.

Conclusions

For a number of reasons this programme is unique. In the first place the chosen area of study, namely disability, is one which had previously been sorely neglected and not designated as a separate field for research.

Secondly, the nature of the research plan was remarkable. Instead of waiting for requests for grants to arise spontaneously and without much control over their nature, the Trustees took the decision to approach directly individuals or Health Authorities with a known record of work in this field or special ideas they wanted to pursue and to make it possible for them to develop innovative proposals. There were, for instance, clear prior ideas about the necessity for better information services, for the co-ordination of services for people with disabilities and for the elaboration of provisions for those with specific disabilities. This still allowed plenty of scope for a range of original ways of extending awareness of special needs and proposals for meeting them. In addition, the programme as envisaged allowed for the inclusion or continuation of valuable work concerning the care of elderly people in the community.

From the outset the idea of a "matrix" was central to this imaginative scheme. This meant that the programme as originally conceived was designed to involve a wide variety of researchers, each of them bringing to the proposed projects their own particular kinds of expertise and proven skills. But they were also deliberately chosen to provide a geographical spread throughout the whole country. The effect was to generate a period of intense action research and exciting new modes of service delivery from Aberdeen in the north to the tip of Cornwall in the south west. Whilst the actual funding provided by the Trust was of necessity limited in amount and time, the intention was to stimulate developments up and down the country which would, hopefully, be continued once their feasibility and usefulness had been demonstrated. It was also unusual to choose Health Authorities in many instances as the recipients of grants, in addition to the more familiar bases of academic departments. And provision was made for involving a number of voluntary organisations as well as service providers and orthodox investigators.

A further notable feature of the Nuffield programme was the decision, at an early stage, to plan for four theme conferences where those concerned with a specific area of research or development could exchange ideas with one another and with a wider community of related investigators. Inevitably the first of these meetings, held in Edinburgh at an early stage in the programme, was more general in content than later conferences, which addressed for example the problems of school leavers with disabilities and the sequelae of head injury. At the time of writing this Report the final conference, on information services, had yet to take place. These conferences have all contributed to the coherence of a programme which was consciously designed to have the maximum impact in the field of British disability studies.

In terms of total size or cost the programme has been substantial. At the time the assessment visits ended, in the summer of 1991, it amounted to £1.5 million and it had exceeded £2 million by March 1992. This had gone to 44 grant holders, involved with 58 separate projects.

All in all, this programme can be adjudged a remarkable success. It has made research into disability a respectable area for the involvement of

academics, rehabilitation specialists, therapists, voluntary organisations and imaginative businessmen and has encouraged a number of committed Health Authority Managers to make significant progress towards the co-ordination of services for people with a disability in their Region or District. In the course of time the publications resulting from the programme and the papers given on the subject by grant holders and participants are bound to spread knowledge more widely about the different facets of the programme, allowing examples of good practice to be copied or compared. In an era of super-specialisms this is a highly desirable outcome and can only be beneficial for those whose daily lives have so far been limited by inadequate public and professional responses to disability and handicap. Already there is clear evidence that the Department of Health has taken note of certain projects, namely the Royal College of Physicians survey and the pioneering work on information systems by Oxford Regional Health Authority. Meanwhile the more gradual influence of the many local innovations and researches made possible by the Trust must permeate practice throughout the country.

Problems of Programme Evaluation

The programme of the Trust had been deliberately designed as a “cohesive matrix of grants” awarded to a variety of projects, all sharing the common theme of physical disability, primarily affecting younger people, but including the frail elderly. Many applications arose from Health Authorities which had already manifested special concern with the field or they came from academics and consultants with comparable interests, but the range was catholic. As categorised by the Trust, the grants fell into five broad groups, namely: information; co-ordination between services, agencies and others; mobilising resources for individuals; developing services for particular disabled groups; and, finally, other innovations, from new training courses to the construction of special data systems and the imaginative use of new technology.

However, many projects fell into or crossed several categories. For example, the development of an experimental mode of service delivery was often combined with the intention to demonstrate the effectiveness of this new procedure or style of management. New computer programmes for data collection were devised in the service of better methods of helping disabled young people at home or for keeping in regular touch with stroke patients, and so on. Information services could be the theme which brought together very large groups of people in some places to pool their ideas and make recommendations, their assembly in itself manifesting the real possibility of co-operation in a common cause. A number of investigators considered that they were engaged upon “action research”. They were not carrying out controlled trials on randomised samples of disabled people but rather they were trying out new approaches and were unashamedly modifying their original plans in the light of experience. A number of grants were awarded for one-off exercises, to permit a new idea or approach to be developed to the point where its continued funding might be adopted by a service or agency. Indeed the hope of dissemination of successful experiments lay behind the entire venture. The programme was meant to show that many new ways of improving the quality of life of disabled people were feasible and had been tried throughout the country.

Only a proportion of the grants went towards what could be regarded as strictly “scientific” investigations. This has made the application of criteria devised to grade research less than useful or satisfactory for the programme as a whole. One such set of categories are those used by the ESRC, which ranks projects across thirteen parameters.

ESRC Categories for Grading Research Projects

- Contribution to Theory*
- Contribution to Practice*
- Contribution to Methodology*
- Contribution to Knowledge*
- Quality of Analysis*
- Collection/Organization of Data*
- Dissemination to Other Scholars*
- Dissemination to Practitioners*
- Dissemination to Policy Makers*
- Value for Money*
- Met Objectives*
- Overall Management*
- Overall Quality*

It will be noted that a number of these categories simply do not apply to some projects in the Trust's programme, precisely because these exercises in health service development were not set up as dispassionate, controlled research. Others were still incomplete at the time of visiting or of requesting follow-up information. In some cases there had been applications for grant extensions. One was incomplete because it had been interrupted.

However, when an attempt was made to apply the ESRC criteria and categories to the relevant projects in this extensive programme, ninety per cent came out as very good or adequate. One third were of the highest quality. This can be regarded as a very satisfactory result.

Judgements regarding the dissemination of results and the impact of utilisation of findings are bound to depend on a number of factors. In some instances the object of the entire exercise was the production of a substantial report, a book or training materials, in which case there was little problem about spreading the results. Work emanating from university departments could reliably be expected to result in academic articles and conference papers and this did turn out to be the case. In respect of three projects, Government statements or decisions have indicated that Trust supported research and developments have already had an impact (RCP survey, ODIP, Project PICKUP). Some projects were locally funded expressions of wider movements, such as Living Options, Lifestyles and the disability section within Shelter.

There can be little doubt that the three designated Theme Conferences have been an excellent component of the programme as regards dissemination, since they ensured that workers in the same field met and heard of one another's activities. It is harder to judge the impact, beyond a particular Health Authority, of attempts at co-operation and co-ordination in one specific setting, especially since in a number of respects public policies may now be actually in the process of undermining admirable local initiatives. However, the local impact of a project has sometimes been clearly demonstrable, by the decision, for instance, of an authority to continue the funding for a new post, or where a training scheme has begun to pay for itself. Another example of dissemination of the programme will occur when the next Royal College of Physicians report on disability is published in the summer of 1992 and will mention what has been achieved by the Trust.

One way of finding out the impact or dissemination of project results might be by a special questionnaire, once sufficient time had elapsed, distributed among grant holders, asking exactly what has been done to spread the news and eliciting their awareness of other components of the programme. Such research is by no means simple although, in this case, grant holders were at one stage supplied with an annotated outline of the programme. For the present assessment, however, reliance has had to be put on what grant holders said at the time of interview about the dissemination of their findings.

So how, apart from attempts at grading, should a multifarious programme of innovations be assessed? It is helpful to contrast evaluation in theory with the situations encountered in the real world. Theoretically, the basic requirements of evaluation or audit are:

1. *Clear definitions*
2. *Clear and specific*
 - i *aims*
 - ii *objectives*
 - iii *outcome measures*
3. *A monitoring system*

4. Regular reviews of progress

5. Analysis of results

6. Feedback of findings

Then the whole process is repeated and rolls on, informing and improving practice. Essentially, evaluation should be built in, not added on. It ought to be carefully planned in advance of the new intervention or mode of therapy and its importance understood by all concerned.

However, there are often considerable problems in the way of evaluating projects. They can be listed as follows:

1. A project may involve many people and professionals whose definitions and ideas about disability itself may vary considerably or even conflict. Multidisciplinary endeavours are notoriously difficult to bring about.
2. Aims, objectives and, particularly, outcome measures are seldom precisely specified. (The matter of outcomes in relation to disability services is highly debateable and very urgent since it can be central to the purchaser provider relationships which now prevail.)
3. A project may require the retrospective analysis of previous ways of delivering services. This can depend upon people's memories, or upon records which were devised for another purpose altogether.
4. The personalities and staff initially associated with a project or a grant application may change in the course of its development. This happened in several instances with the present programme, leading to uncertainties and a degree of discontinuity.
5. Totally unexpected events and accidents may interrupt a project. The most striking example of this was in Leeds, where a double murder on Health Authority premises in the District brought the amputees experiment to a halt. Less dramatic delays are common.
6. Changes in the local organisation of health services can interfere with the orderly implementation of change. In Frenchay Hospital, Bristol, for example, plans were cast into some doubt by the unexpected merging of Health Districts which began while a project relating to one District was underway. The decision of hospitals elsewhere to go for Trust status contributed to a situation where future implementation of sensible recommendations regarding district or community services became uncertain or irrelevant.
7. Finally, between the stage when this far-sighted disability programme was planned and its assessment, in 1991, major changes in public policy occurred. Community care legislation was introduced, based in part upon Griffiths' Report but differing significantly from his recommendations. The implementation of community care policies was itself delayed and the financial implications left unclear. A new general practitioner contract was introduced. Meanwhile, many local authorities, supposedly to bear a major responsibility for the disabled in the community, were subjected to "charge capping", enforcing restrictions upon the very services which would require to be sustained and strengthened. Newcastle-upon-Tyne is one notable example from within this programme. A model for the quality of its services and for inter-agency co-operation, it is faced with regrettable cutbacks and dislocation.

It was considerations such as these which brought about the decision to confront "evaluation in the real world" and make a virtue out of necessity. Raymond Illsley, in the Rock Carling monograph of 1980, writing on the evaluation of health services, said,

"In discussions of project design and data, instead of RCTs and unequivocal measurements of a single outcome, one meets non-

equivalent group design (with or without controls) interrupted time-series designs and triangulation (the simultaneous use of several sets of partial observations or perspectives focussed upon a common problem). And the data-collection methods are as variable as those used in general sociological research – historical evidence, index numbers, documents, records and files, interview and survey and simple participant observation . . . health policy and health services research deals overwhelmingly with 'open systems' similar in kind to those involving political and social action."

In other words, there is no disgrace in describing social events as they actually happened. Accordingly, in assembling the material for this assessment, the participants were taken into account, their personal styles and professional backgrounds, their perceptions and priorities, and their degree of commitment to the task in hand. In each place a careful history was obtained of the development of the project, with all its vicissitudes, flaws and fluctuations. An attempt was made to decide how far the originally expressed objectives and intentions were being fulfilled. The influence of the innovation was broadly considered, locally, further afield and nationally. The matter of dissemination of the findings or of the new approach was the final consideration. This wide-ranging method of enquiry is familiar in the social and political sciences and is legitimate in the present instance. Hence the foregoing report has taken the form of a series of vignettes or descriptions of innovative approaches to disability, rather than sets of tables and percentages.

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