Services for brain injured adults – Report of a Working Group of the Research Committee of the Royal College of Psychiatrists, 1990

Membership: Ken Barrett, George Fenton, Alwyn Lishman, Roy McClelland, David Sumners, Andrew Zealley.

Advice was also received from Dr T. Craig, PRD Unit; Dr D. T. Wade, Rivermead Hospital; Professor J. Wing, Institute of Psychiatry; Professor N. Brookes, University of Glasgow.

Introduction

The remit of the group was to assess the service needs of brain injured adults and to propose minimum standards of care and provision. A substantial body of clinical research has demonstrated conclusively that brain injury in all but the mildest forms, and irrespective of cause, results in a wide variety of chronic impairments affecting many aspects of physical, psychological and social functioning. Indeed the later and more enduring disabilities are predominantly psychological in nature embracing cognitive deficits, emotional and behavioural difficulties. These can have a major impact on social and family life and return to work (Levin et al, 1979; Oddy & Humphrey, 1980; McKinlay et al, 1981; Brooks et al, 1986).

In spite of these generally recognised chronic and disabling problems for the brain injured adult and for his family, service provision in the UK remains poorly developed and in some situations absent (Gloag, 1984; Thomas, Bax & Smyth, 1989; MDS Report, 1988). Where services exist there is often poor uptake due to lack of co-ordination and integration (Livingstone, 1986).

Epidemiology

The reported incidence of traumatic brain injury varies considerably depending on availability of resources and cultural patterns of accidents (BMJ, 1984). One Scottish study found an incidence of 2% of the total population attending an accident department with head injury (Strang et al, 1978). About 20 per million each year are left with major disabilities (Bryden, 1989; London, 1967).

The most reliable prevalence estimates of people in need of rehabilitation services come from the community-based study of Bryden (1989). His esti-

mates of people moderately and severely brain injured ranged between 66 and 114 per hundred thousand.

The foregoing relates to traumatic brain injury only. The magnitude of the problem for all forms of brain injury would be much greater. While more accurate information is required on specific needs, there is ample evidence that a large number of young adults are presently in need of better organised and more comprehensive rehabilitation services. McCreadie (1983) has reported that almost one-third of the new long-stay, under 65 years of age, in Scottish psychiatric hospitals have "organic" diagnoses.

Definition and terms of reference

The clinical group under consideration has been defined as "brain injured adults". While the need for better services for brain injured children is stressed. these were considered to be outside the brief. The group under consideration therefore are adults under the age of 65 whose brain injuries are the result of trauma or disease. The term "injury" is preferred to "damage" as it is less stigmatising and more consistent with the positive approach appropriate for rehabilitation work. For the purposes of rehabilitation the different types of brain injury are best considered in terms of single incident brain injury (e.g. road traffic accident), repeat or recurrent injury (e.g. vascular or alcoholic brain damage) and progressive brain disease. Considering the latter group (e.g. Alzheimer's disease, AIDS), the emphasis must be on caring rather than on rehabilitation. While a similar network and organisation of services may often be required, the details of provision for such client groups will not be dealt with in this report. The fields of mental handicap and psychogeriatrics have likewise been excluded.

For the purposes of service provision a more appropriate classification can be based on severity of impairments.

(i) Mild and moderate injuries (e.g. head injury with PTA less than 24 hours). For this group of people the long-term prognosis is usually very good and the main requirement is

counselling and advice in the early postinjury period. Specific cognitive, emotional and physical impairments may need rehabilitation as appropriate.

- (ii) Those with significant physical or psychological impairments which are slow to resolve. This group of people require the services of a specialised neuro-rehabilitation unit. In addition to physical disabilities, cognitive and emotional impairments will usually exist becoming more prominent as improvements are obtained with physical disabilities.
- (iii) Those with severe behavioural problems with or without physical impairments. This group, although small, are the most demanding and often difficult to manage even within a specialised neuro-rehabilitation unit. High staffing with appropriately trained staff in a small behaviourally orientated unit are required. In addition their problems are often chronic and they may require long-term residential care.

For all groups the families of the brain injured should be considered from the outset. The stress and burden placed on this group of carers should be managed in proportion to need. The needs of spouses will usually be different from those of parents.

Service recommendations

In preparing these recommendations the working group have given careful consideration to their own varied experiences of neuro-rehabilitation, have consulted with other leaders of rehabilitation services and have taken account of current literature. The group would particularly endorse the 'principle recommendations' of a Working Party Report of the Medical Disability Society (1988) as indeed already endorsed by the Public Policy Committee of the Royal College of Psychiatrists (1989).

(i) Service organisation

(a) District level services

A consultant psychiatrist and psychiatric team should be identified in each health district (Health Boards in Scotland and Republic of Ireland, Health and Social Services Boards in Northern Ireland) with responsibility for liaising with acute medical and surgical services for acutely brain injured patients. Liaison services would not need to be a full-time commitment and can provide a vital first filter for patients with emotional and behavioural problems in need of psychosocial rehabilitation. Many patients once medically stable can be managed more appropriately in the structured and supportive environment of a psychiatric unit. District level provision will usually ensure early and easy access to services.

The psychiatrist in such a service should have training and experience in neurology or neuropsychiatry.

Each district should also identify appropriate continuing care services for patients returning to the community either from acute services or from the Regional Rehabilitation Unit. The present developments in community-orientated psychiatric services are ideally placed to manage, with appropriate support, the longer term needs of this client group.

(b) Regional services

It is recommended that each region review its existing services and evaluate service requirements for brain injured people embracing short-term rehabilitation, community and residential care. Prevalence estimates of brain injured adults with major neurobehavioural impairments suggest a need in each region for a neurobehavioural unit. While precise needs will vary most will require a 20–30 bed inpatient unit with associated day and out-patient services. A spectrum of community and long-term care facilities appropriate for client needs is also required (see action iii).

Units must be staffed so as to provide an appropriate mix of rehabilitation skills to address the physical, psychological, social and family needs of this client group. Each region should identify a core rehabilitation team to staff the unit and to provide a consultation and support service to district teams.

Good team leadership is pivotal. The specific professional background is probably less essential than personal qualities and neuro-rehabilitation experience. Nevertheless, within the context of the present Resource Management Initiative, a medically qualified person of consultant status will probably provide the optimal management links with medical, surgical and local authority services.

A register should be maintained by the Regional Brain Injury Rehabilitation Unit of all patients referred to the service. This would provide an information base for service evaluation, follow-up studies of brain injured people and clinical audit.

(ii) Rehabilitation

Most patients with moderate or severe brain injury require rehabilitation. Early and easy access to the services of a specialist rehabilitation team are essential. Consultation and advice should be available on request to providers of acute services. This will ensure both early and appropriate referral to the Regional Brain Injury Rehabilitation Unit.

Developments in brain injury rehabilitation must take account of existing services. At the present time there are about six units in the UK providing early rehabilitation for brain injured people, mostly serving the needs of their regions. The late cognitive, emotional, behavioural and social sequelae of severe

head injury are inadequately met even by such rehabilitation services.

The following are considered important features of a high quality and effective service:

(a) Size

The optimal size for an in-patient brain-injury rehabilitation unit is about 20 beds. This should be regionally based and serving a population of about 2–3 million. In some settings a supra-regional service might be considered. Some regions may require more than one unit.

A small number of patients with severe behavioural problems require a separate facility. This might be part of the Regional Unit. Duration of stay for such a group will usually be much longer than for the other patients (2–3 years) and 10 beds should be identified for this group. Occasionally the services of the Regional Secure Unit may be required for patients with severely disruptive behaviour. Some patients will require long-term residential care (see section iii).

(b) Location

The Brain Injury Rehabilitation Unit should be placed as centrally as possible within the region to facilitate access and continuity of care for long-term management. Close proximity to a DGH ensures easy access to specialist investigation and support for staff. However, adequate space for rehabilitation activities must be provided. The opportunities provided by retraction on psychiatric hospital sites should therefore be considered.

(c) Staffing

Brain injury rehabilitation is a very demanding and labour intensive activity. An appropriate level of nursing and therapy staff must be provided for effective functioning of the service. Due account should be taken of the opportunity for day-patient and outpatient programmes. A typical staffing profile should be as follows.

Nursing: 30 staff with an appropriate mix of general and psychiatric training

Occupational therapy: 5 staff

Physiotherapy: 4 staff
Speech therapy: 2 staff
Clinical psychology: 1
Educational psychology: 1

Social worker: 1

Medical: 1 Consultant and 1 Trainee.

For those patients with severe behavioural problems special expertise in behavioural management is essential. This should be reflected in a greater balance of psychiatrically trained nurses and more clinical psychologists. Nursing staff should have training in the behavioural therapies. Social work services are essential for early assessments, work with families, resettlement and community support. Easy access to other medical specialties, particularly orthopaedic and physical medicine will also be important.

(d) Leadership and management

Given the demands of the client group and the multidisciplinary nature of professional working, good leadership of the rehabilitation unit is paramount. Breadth of clinical knowledge and skills are required and an ability to maintain good links with other health and local authority services. While personal skills and experience are the essential criteria for a leader of rehabilitation services, there are several reasons for considering medical leadership. These include requirements to negotiate with medical peers and the present climate of resource management which expects a high medical profile. A suitably trained psychiatrist or neurologist is probably the most appropriate professional to facilitate all aspects of the rehabilitation process.

(e) Policy for in-patient rehabilitation unit

There should be early and easy access to the Unit. Patients would normally be admitted directly from neurosurgery or other acute units.

Assessment and reassessment are key elements of clinical work and require ready access to specialist investigation and professional skills (clinical psychology, EEG, occupational therapy, physiotherapy, rehabilitation nursing, speech therapy).

Multidisciplinary working and a team approach are central to effective rehabilitation. A problem orientated approach is recommended and work on specific problems should be prioritised in relation to the resettlement needs of individuals. A balance needs to be maintained between the physical, psychological and social dimensions of rehabilitation appropriate to the needs of each individual. Expertise in behavioural management methods is essential.

Family involvement must be a key feature of rehabilitation work, from referral through to community follow-up.

Voluntary agency involvement and support should be encouraged, particularly as they can play a major role in longer term asects of care and support. The work of the National Head Injuries Association (Headway) in many parts of the country is particularly recommended in this regard.

While staff recruited to a rehabilitation unit should have appropriate training, much necessary additional training can and should take place within the unit itself. There is ample opportunity for different professional groups to acquire the skills of colleagues from other disciplines and a blurring of professional roles and boundaries. Such an approach

can lead to greater flexibility in individual practice and team work.

(f) Monitoring and evaluation

The activity of each rehabilitation unit should be selfmonitored aimed at maximising the cost-effective use of resources. Both the process of care and outcome should be the subject of regular clinical audit. There is much opportunity and need for clinical research.

(iii) Transitional and community care

The overall objective of rehabilitation is to return people with brain injury to optimal functioning within their own community and family. It must also be recognised that the majority of brain injured live in the community and most spend only a relatively small period of time in the rehabilitation unit. A major task for rehabilitation is the generalisation of skills and behaviours acquired within the rehabilitation unit to the home, community and work situations. The role of day programmes and out-patient work will be important in this respect. Nevertheless a tension exists between a regional rehabilitation service and local community-based support. Many patients with severe brain injury and their families require ongoing support and care on a long-term basis.

There is much to be said for the application of "case management" to the continuing service needs of brain injured adults (Appendix 1). The present and developing network of community orientated psychiatric services is well placed to meet the needs of this group. However, the relationship between regional specialist services and local providers will be central to the success of this model. It is suggested that the director of the Brain Injury Rehabilitation Unit at Regional level should act as a service broker forming links with local psychiatric services as appropriate. This will only function successfully with adequate support from and ready access to specialist rehabilitation services.

A small number of patients with severe and chronic behavioural problems will require long-term residential care. Present estimates suggest that about 12 places per million are required for this severe and multiple disabled group. An appropriate, dedicated and suitably staffed facility should be identified. This client group cannot be properly managed as part of a broader client group within existing long-stay psychiatric care. It may be possible for regions to purchase such provision from voluntary or private agencies. Full use should also be made of services of local voluntary bodies such as Headway and Mind.

Again the on-going needs of the primary carers, the families of the brain injured, require careful consideration by both the regional team and local providers.

(iv) Education and training

All professional groups involved in rehabilitation require an appropriate generic and specialist training.

(a) Medical

Clinical psychiatry can make a major contribution to the rehabilitation of brain injured adults. However there is a need to target training, particularly higher professional training, more appropriately to the needs of this group. Trainees interested in pursuing a career in neuropsychiatry and neuro-rehabilitation should obtain appropriate experience in clinical neurology. Experience in rehabilitation and community care is also most appropriate for brain injury rehabilitation. Specialist neuro-rehabilitation experience is essential and a small number of senior registrar posts should be established for this purpose.

It is recommended that the continuing care of brain injured adults is provided within local community psychiatric services. Present evidence suggests that one-third of the new long-stay have organic brain disease with the accompanying disabilities and handicaps. With the present focus on community care, psychiatrists responsible for the services of people chronically disabled by mental disorder are likely to be caring for an increasing number of brain injured adults. The training of most general psychiatrists therefore should include teaching in the neurosciences and where possible experience in neurology and neuropsychiatry.

(b) Nurse training

The nursing skills required for brain injury rehabilitation do not fall wholly into either the RGN (Registered General Nurse) or RMN (Registered Mental Nurse) schemes. Rather, the brain injury nurse needs to acquire specific skills and will benefit from aspects of training of both these categories. Experience in mental handicap will often be of value.

Learner training. Given that RGNs are involved in the early stages of treatment of the brain injured in general hospitals, their training becomes highly significant. They can help prevent the emergence of undesirable behaviours and to propagate understanding of the complexity of such cases among their colleagues. At this learner stage decisions on training are made on a district basis and to a large extent depend on the presence or absence of a local Brain Injury Rehabilitation Unit. However, RMN learners might usefully spend twelve weeks as a training option where a brain injury rehabilitation unit is available. RGNs spend three months in psychiatry as part of their course and it is recommended that four weeks of this is spent in a Brain Injury Rehabilitation Unit.

Postgraduate training. At this level, proposals would require to be agreed by the appropriate national

board. Nurse practitioners (grade D or E) could spend a six month placement on a Brain Injury Rehabilitation Unit. In addition, places might be made available for others including: nurses from neurosurgical, surgical, medical or orthopaedic wards, community head-injury co-ordinators and staff from psychiatric hospitals which had expressed an interest in providing long term care for the brain injured.

The six months rotation would include clinical practice, as well as preparation of a project and possible research. Allowance should be made for time in school. Teaching should include input from other professions including medical, psychology, occupational therapy, physiotherapy and social work. Successful completion of the course should be acknowledged by presentation of a certificate of experience in brain injury rehabilitation.

(c) Psychology

Neuropsychology has traditionally focused on assessment procedures. However, there is an important contribution to be made by this professional group to therapeutic intervention embracing the full spectrum of behavioural methods, cognitive therapies and retraining. It is essential for entrants to this field to gain appropriate exposure to a wide range of therapeutic interventions.

In-service training provides an important opportunity for developing and raising standards of practice for all professional groups. District Health Authorities should be encouraged to release staff to attend professional and multidisciplinary courses at local, regional and national level on a regular basis.

Research and audit

Given the embryonic state of neurorehabilitation services for brain injured adults there is much need for further research. The following areas require further investigation:

- (a) detailed epidemiological and follow-up studies.
- (b) evaluation of the full spectrum of therapeutic interventions including drug therapies
- (c) family studies including family interventions
- (d) outcome studies
- (e) investigation of prevention strategies.

Individual units must evaluate the effectiveness of their own strategies as part of professional practice and the White Paper requirement for medical audit. Audit in rehabilitation should be multidisciplinary in nature.

Appendix 1

The Working Group considered the principles and practice of case management as they have developed in relation to the service needs of people chronically disabled by mental illness. Several features of rel-

evance to the continuing care needs of brain injured adults were noted.

First, the more severely brain injured tend not to actively seek help and will often drift away from contact with services. They are often lacking in the motivation, persistence and skills to organise the material aspects of their lives without assistance. Help may therefore be needed to resolve a range of problems spanning the medical, psychological and social domains.

An organisational solution is required for this group of people for whom regularly updated accurate information on clinical and social functioning is necessary and for whom clear structure of planned and co-ordinated care is required.

It was agreed that the long-term needs could best be met within the framework of a case management system at local level. The prime function of the "Case Manager" is to co-ordinate the care of clients who require a multiplicity of services. "Case Management" involves having a single advocate or to the extent possible a team of persons responsible for maintaining a long-term supportive relationship with the client regardless of where he/she is and regardless of the number of agencies involved (National Institute of Mental Health, 1987). The Case Manager performs the following functions:

- identifying clients who need and desire case management services
- (ii) working with the client to develop a comprehensive service plan based on client needs and goals
- (iii) providing information to help the client make informed choices about opportunities and services
- (iv) assisting the client to obtain needed services, supports and entitlements
- (v) being available and accessible during and after working hours
- (vi) advocating at the systems level for needed systems improvements. The case management system also recognises that for some clients there should be an aggressive outreach function to build trust and engagement and prepare clients to receive needed services.

Approved by Council March 1991

References

BROOKS, N., CAMPSIE, L., SYMINGTON, C., BEATTIE, A. & MCKINLAY, W. C. (1986) The five year outcome of severe blunt head injury: a relative's view. *Journal of Neurology, Neurosurgery and Psychiatry*, 49, 764-770.

BRYDEN, J. (1989) How many head-injuries. In *Model of Brain Injuries* (Wood & Eames). London: Chapman & Hall.

EDITORIAL (1984) Guidelines after initial head injury in adults. British Medical Journal, 288, 983-985.

GLOAG, D. (1984) Unmet need in chronic disability. British Medical Journal, 289, 211-212.

LEVIN, H. S., GROSSMAN, R. G., ROSE, J. E. & TEASDALE, M. B. (1979) Long-term neuropsychological outcome of closed head injury. *Journal of Neurosurgery*, 50, 412-422.

LIVINGSTON, M. G. (1986) Assessment of need for coordinated approach in families with victims of head injury. British Medical Journal, 293, 742-744.

LONDON, P. S. (1967) Some observations on the course of events after severe injury of the head. *Annals of the Royal College of Surgeons*, 41, 460-479.

McCreadie, R. G., Oliver, A., Wilson, A. & Burton, L. L. (1983) The Scottish Survey of "New Chronic" inpatients. British Journal of Psychiatry, 143, 564-572.

McKinlay, W. W., Brook, D. N., Bond, M. R., Martinage, D. P. & Marshall, M. M. (1981) The short-term outcome of severe blunt head injury as reported by relatives of the head injured persons. *Journal*

of Neurology, Neurosurgery and Psychiatry, 44, 527-533.

MEDICAL DISABILITY SOCIETY (1988) The Management of Traumatic Brain Injury.

NATIONAL INSTITUTE OF MENTAL HEALTH (1987) Towards a Model Plan for a Comprehensive Community-based Mental Health System. Washington: NIMH.

ODDY, M. & HUMPHREY, M. (1980) Social recovery during the year following severe head injury. *Journal of Neurology*, Neurosurgery and Psychiatry, 43, 798-802.

ROYAL COLLEGE OF PSYCHIATRISTS (1989) Report from the Public Policy Committee. Services for the Young Brain Damaged.

STRANG, I., MACMILLAN, R. & JENNETT, B. (1978) Scottish head injury management study. *Injury*, 10, 154–159.

THOMAS, A. P., BAX, M. C. O. & SMITH, D. P. L. (1989) The health and social needs of young adults with physical disabilities. *Clinical Development Needs*, 106.

Special Interest Groups

In June 1987 Council approved the establishment of 'Special Interest Groups'.

Procedure for establishing a Special Interest Group:

- Any Member wishing to establish a Special Interest Group shall write to the Registrar with relevant details.
- (2) The Registrar shall forward the application to Council.
- (3) If Council approves the principal of establishing such a Special Interest Group then it will direct the Registrar to place a notice in the Bulletin or its equivalent, asking Members of the College to write in support of such a Group and expressing willingness to participate in its activities.
- (4) If more than 50 Members reply to this notice, then Council shall formally approve the establishment of the Special Interest Group.

(5) The administrative support provided will be similar to that enjoyed by College Divisions. It should be noted therefore, that the college will maintain the list of members, prepare and distribute notice of meetings but will not provide staff to attend meetings, organise conferences etc.

In accordance with this procedure, Council has approved the establishment of a Management Special Interest Group. Members are invited to write in support of this Group and express willingness to participate in its activities. Members should write to Mrs Jean Wales at the College. If 50 members reply to this notice for the Group, then Council shall formally approve the establishment of this Special Interest Group.

Dr A. GATH Registrar

Lundbeck Teaching Fellowship

Fellows and Members of the Royal College of Psychiatrists, working overseas, are invited to apply for a Teaching Fellow from the UK to come to their country to provide a course of teaching in a designated specialist psychiatric subject. Overseas Fellows and Members may suggest a named teacher, but more importance will be given to the topic of their choice than to any individual.

A sum of £5,000 per year has been provided by Lundbeck Limited to cover the travel, living and incidental expenses of the Teaching Fellow who, it is envisaged, will complete the course over a period of 3-4 weeks. The host centre overseas will not be expected to provide any financial support.

Applications for 1992 should be sent to the Dean, The Royal College of Psychiatrists, 17 Belgrave Square, London SW1X 8PG. The Teaching Fellow will be selected by the Overseas Liaison Committee and his/her appointment ratified by the Court of Electors.

Dr FIONA CALDICOTT

Dean June 1991

The College Library

The Library will be closed from 3-12 August. During this period we regret that it will not be possible for

members to have access to the Library. Books may be returned to the College reception desk.