Southern Health

Monash Medical Centre
246 Clayton Road
Clayton, 3168
Victoria

Postal Address
Locked Bag 29
Clayton South 3169
Victoria

Tel 03 95946666
Fax 03 9594 6111

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The Secretary
Senate Community Affairs Reference Committee
Suite S1 59
Parliament House
CANBERRA ACT 2600

Re: Senate Inquiry into Aged Care

Thank you for providing Southern Health with an opportunity to submit details of its program to systematically prevent or relocate young people with catastrophic brain injury from Aged Care nursing homes to community living with either their families or in supported residential living units. The following submission details the development of the Acquired Brain Injury, Slow to Recover program since 1996.

If you require more information, please contact Murray Gee, Manager ABI STR program, 229 Thomas Street, DANDENONG VIC 3175, Murray.Gee@southernhealth.org.au.

Yours sincerely

Robyn Trebilco
General Manager
Regional & Ambulatory Service
Monash Medical Centre
Clayton Road
CLAYTON VIC 3168

Email: robyn.trebilco@southernhealth.org.au

Submission to the Senate Inquiry Into Aged Care

Since the inception of the Commonwealth State & Territories Disability Agreement CSTDA) in the early 1990's, the Victorian State Government has made great strides to improve the living conditions of young people with disabilities. This includes closing all the large rundown institutions that were entrenched with corrupt, exploitative and in some cases abusive practices and relocating these people into community based housing in small groups, establishing day programs and work related activities to produce as normal a lifestyle as possible. As part of this focus, non government funded agency large institutions were also closed and redeveloped. The only major disability accommodation institution that still remains in Victoria is the Kew Accommodation units currently being redeveloped.

With the closure of these institutions and the improvement of living conditions for existing clients, the demand for twenty four hour care has increased markedly in time due to aging carers and medical technology able to keep people alive. The rate at which resources become available and for new accommodation projects has not met the pace of this demand therefore other accommodation options such as Aged Care nursing homes and Aged Supported Residential Services have been used for this purpose. These accommodation options are either socially inappropriate, do not provide the necessary required services and generally do not meet the needs of younger residents. In Victoria this situation has reached a crisis point where the Acute Hospitals are demanding placement of people in the community with more complex needs.

A Victorian research paper determined that approximately thirty percent of young people in Aged Care nursing homes had an acquired brain injury with many young people taking up valuable hospital beds as appropriate services were not available within the community. In a response to this issue, the Victorian State Government allocated $5.0 million dollars to develop a new service system for people with catastrophic brain injury. This submission provides details of the Acquired Brain Injury, Slow to Recover (ABI STR) the achievements that this program has made in developing a service system for some of the most disabled people within our community and the outstanding results made by being proactive instead of reactive to needs. Please find attached to this summary a detailed program review and summary 1996/1998.

The ABI STR program was established to relocate people with catastrophic brain injury from acute care and nursing homes to community care and was allocated at $1.0 million per year increasing by $1.0 million each year for four years to a total of $5.0 million budget. Resources were to provide service to at least 100 clients at an average cost of $50,000 per client. From the following summary of results as of January 2004 this estimated target was achieved with a doubling of the number of clients receiving services. This was achieved by integrating clients into existing generic services, providing timely and ongoing rehabilitation to meet their rate of recovery, by providing top up resources not provided from other programs to meet their special requirements and by navigating the service system for families.

Please accept this submission as a model of how to achieve better outcomes for young people with disabilities, make substantial savings within the acute sector and limit the demand on Aged Care nursing home beds for this target group.

ABI STR program summary data January 2004.

Client data

a) Total number of clients received or receiving services from the ABI STR Program from the 1/7/1996 till 1/1/2004= 193.

b) Of the 193 clients

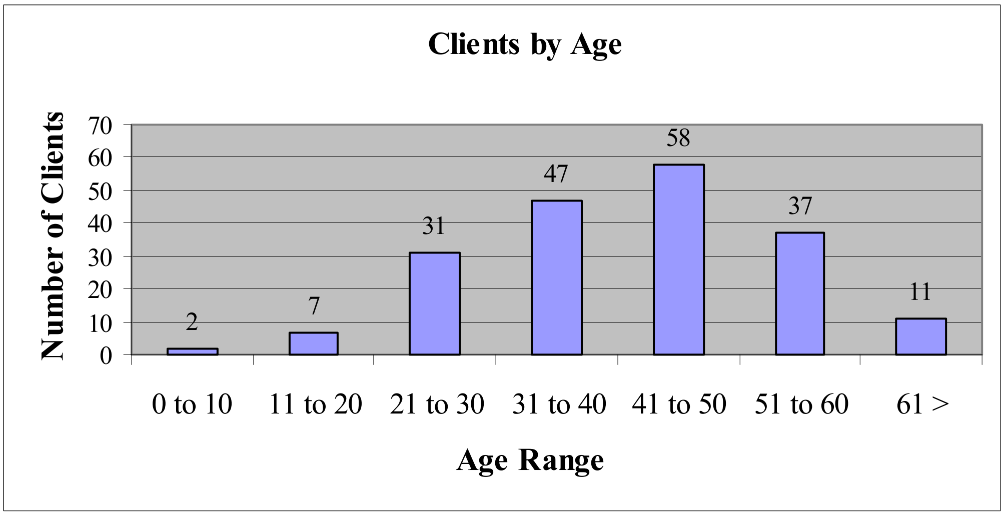
- **133 are currently receiving services**
- 37 have been discharged
- 21 deceased
- 2 having care plan produced (There are currently 11 clients on the waiting list.)

Client Gender

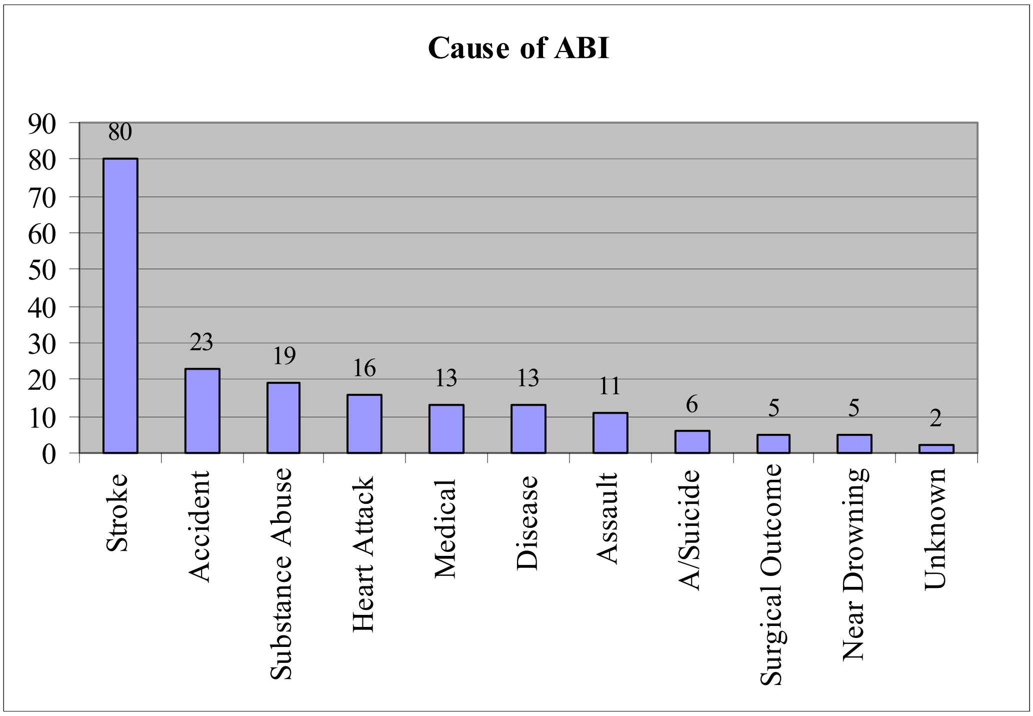
Male: 118(61%)
Female: 75(39%)

Client Age

- Average age = 41years
- Oldest = 64
- Youngest = 10

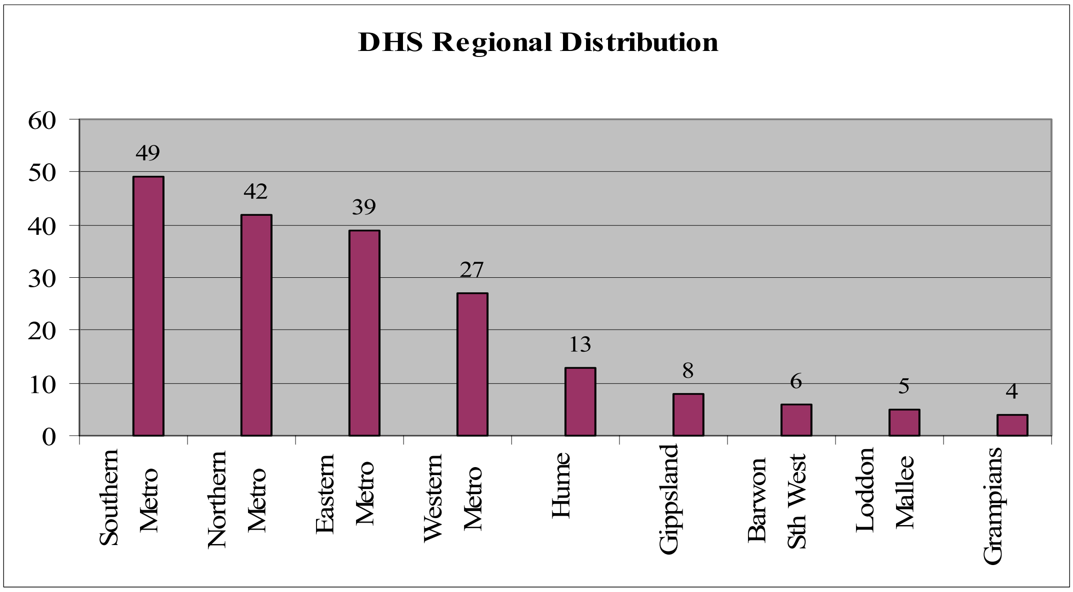


Cause of ABI

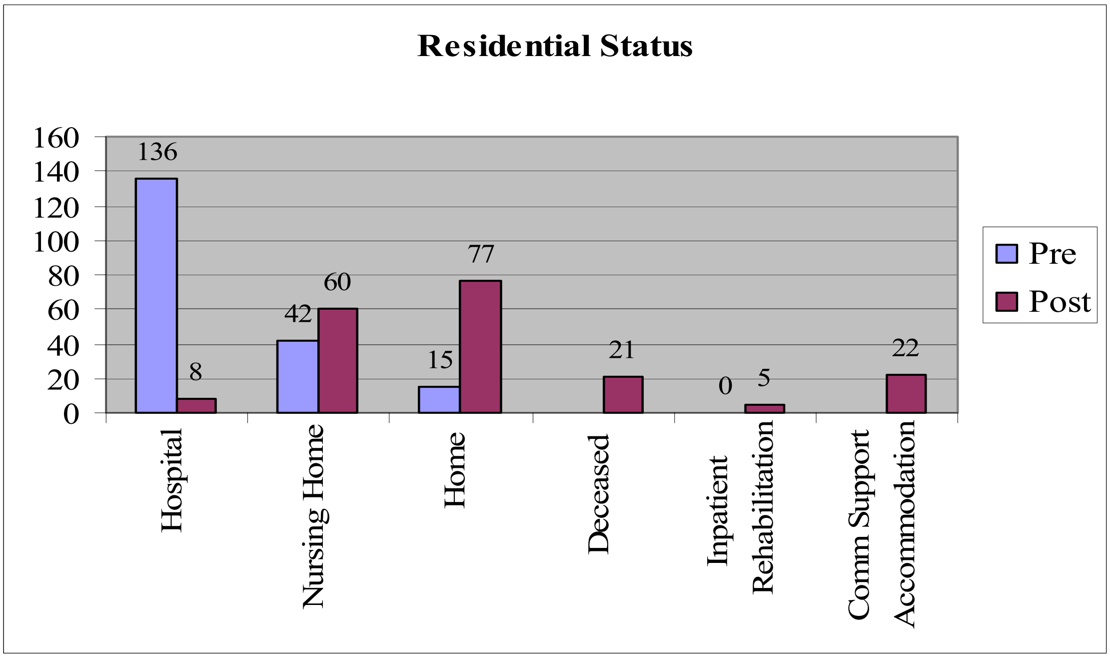


Disease = encephalitis, meningitis
Surgical = outcome of the result of surgery
Medical = brain tumour, anaphylactic reaction

Regional Distribution



Residential Status



The above graph identifies the change of accommodation following the introduction of ABI STR services. The greatest change is where clients are identified in hospital, through the provision of ABI STR services many will return home or into the community based accommodation. Prior to the development of the ABI STR program, very few of these people would have returned home but may have remained in Aged Care nursing homes.

Case Management

The ABI STR program has contracted a total of 6.74 Eft case managers which is sufficient to meet the client needs within the current program budget capacity. The level of case management service and the contract agencies are as follows.

Care Connect	2.0Eft
Melbourne Citymission	1.5Eft
ARBIAS	1.5Eft
Brian Foundation Victoria	1.0Eft
Bunurong Community Care	0.74 Eft

Acquired Brain Injury: Slow to Recover Program

Contents

Foreword

Rapid advances in medical technology and health services over recent years have enabled people who suffer catastrophic brain injury not only to survive their injury but to survive with the potential to recover levels of function not previously thought possible. The complex and highly individualised needs of this small but growing client group, however, together with their slow rate of recovery and their persisting long-term dependency and disability, have exceeded the current capacity of the health service system to respond adequately and appropriately.

The Acquired Brain Injury: Slow to Recover (ABI: STR) Program has been developed by the Department in conjunction with professionals in the field of acquired brain injury to remedy this situation. The Program is possibly unique in that it is designed as a compassionate and ethical rationing of limited resources to a highly specific group of clients. It has the potential to establish health service system benchmarks in achieving maximal integration of the resources of the mainstream health service system with a brokerage capacity to purchase particular and individually targeted services. It provides each client with a total package of care that is responsive to their immediate needs and capable of change over time, as they regain function and as they age, and it supports the families who provide long-term care.

The Ministerial Implementation Committee on Head Injury identified in 1993 the specific and different needs of people with ABI and high levels of dependency, and two specialist services were initiated: the ABI Case Management Service and the ABI Behavioural Consultancy Service, which contributed towards meeting those needs. The Department then commissioned a study by Health Solutions Pty Ltd with consultant rehabilitation physician Associate Professor John Olver, which led to the development of the pilot ABI: STR Program and its consolidation into a fully operational service. Following a competitive tendering process, the ABI: STR Program is now established as a permanent program under the auspices of the Southern Health Care Network.

The success of the Program over its first two years has exceeded expectations. Many of its profoundly disabled clients have achieved unanticipated levels of function, independence, and reintegration into their communities. A number have returned home to their families. With the recent tendering out of the Program, its operation within the mainstream health service system will now enable it to expand its influence on and integration with mainstream services.
I welcome this report which documents both the achievements to date and the standards for ongoing service delivery of the Program.

Rob Knowles
Minister for Health, Minister for Aged Care

Preface

The Acquired Brain Injury: Slow to Recover (ABI: STR) Program has been established to provide specific services to a small and generally younger group of people with catastrophic acquired brain injury (ABI) resulting in the most profound physical and cognitive disability and, in consequence, the most complex care needs. Until recent years, very few people with such severe injury survived, and the existing service system does not address their needs.

These people require specialist and sometimes lifelong medical, nursing and allied health care. Existing health and long-term care funding arrangements were insufficient for those without employment or road traffic compensation or coverage. The slow recovery and high dependency of these clients meant that inpatient and residential care services were unable to provide long-term clinical care and accommodation that was adequate and age-appropriate.

The ABI: STR Program has developed a unique model for the delivery of targeted and responsive rehabilitation and long-term maintenance services to people with severe ABI. It provides for brokerage of specific services for individual clients to enable the purchase, over time, of rehabilitation and long-term maintenance services which are clinically, socially and geographically appropriate.

The Program aims to maximise clients' independence within the limits imposed by their injury, and to minimise their marginalisation. It respects the strongly held view of families that people with ABI neither want nor benefit from services that isolate them from the community. The Program enables its profoundly disabled clients to be integrated into mainstream services and, so far as possible, back into the community. Many of the Program's clients to date have, with appropriate support, been able to return home to their families.

The Program evolved out of a study commissioned by the Department from Health Solutions Pty Ltd. A pilot program was developed within the Disability Services Program, managed by Brian Hardy with Joan Snyder and Margaret Smyth, and then transferred to the Aged Care Program, where it was consolidated into an operational framework under the leadership of Rosemary Calder with Murray Gee and Jacinta de Souza. The Program development and operation has been guided by the ABI: STR Program Committee under my Chairmanship. Members of the Committee represented major service providers and consumer applicants. Following a competitive tendering process, the Program is now established as a permanent program under the auspices of the Southern Health Care Network.

Funded with a fixed total budget, the Program purchases individually tailored care packages to meet the widely differing needs of clients with severe ABI. Costs for a client may be high over the first two years to cover slow-stream rehabilitation and the provision of specialised equipment and home modifications. After this, generic services provide long-term accommodation support, with the Program providing any additional therapies and other assistance needed to maintain the client's level of independence.

Before the advent of the ABI: STR Program, many people with severe ABI remained, by default, for long periods in acute hospital beds. Younger adults were often moved into aged care nursing homes. Some were sent home with few supports, creating a heavy emotional and physical burden for their grief-stricken families. Few received even minimal rehabilitation services, despite the knowledge that appropriate therapy could achieve some gains in independence. Often the lack of appropriate care has meant that these people, far from improving, actually deteriorated unnecessarily, developing intractable but avoidable complications such as limb contractures and bed sores.

The ABI: STR Program is intended to prevent such situations from occurring again in Victoria.

The Program is highly cost-effective. In purchasing care that is appropriate, it avoids the significant inappropriate costs previously incurred in acute hospitals and other settings, including Commonwealth-funded residential care. Given the near-normal life expectancy of the predominantly young clients of this Program, even small improvements in function will have enormous cumulative benefits not only in quality of life for the client and carers, but also in the long-term care and support costs to the community.

This unique Program is also identifying and supporting evidence-based practice for the optimum management of clients with severe ABI, and extending the currently very limited knowledge of what is possible for these slow-to-recover clients. Already, Program outcomes are demonstrating that intervention at the earliest opportunity dramatically increases the potential for rehabilitation and gains in function, far beyond that expected on the basis of previous practice. A significant proportion of clients who would have previously required long-term nursing home care have, with the Program's support, been able to return home to their families and a vastly improved quality of life.

For the Program to continue and build on its successes to date, a number of issues demand attention. Growth and demand will need to be monitored, case management skills developed across the State, and professional education and awareness fostered to ensure prompt and appropriate referral. Most urgent, however, as more and more clients pass through the Program, and as family carers grow older, is the fast-expanding need for facilities providing appropriate respite care and long-term, age-appropriate supported community accommodation.

This document, written by Dr Angela Kirsner in conjunction with Ms Rosemary Calder, Mr Murray Gee and myself, charts the Program's development, defines its objectives, client group and structure, reports its considerable successes to date, and outlines its future directions.

Associate Professor John Olver
Chairman, ABI: STR Committee

Background

The Acquired Brain Injury: Slow to Recover (ABI: STR) Program has grown out of a number of Victorian government initiatives in the area of rehabilitation and ABI over the past decade and has been a priority and an early initiative towards development of a comprehensive and integrated statewide rehabilitation service system. The ABI: STR Program will form an integral part of that system as a discrete, specialist service, with additional responsibility for the long-term therapeutic maintenance of some clients.

Statement on Rehabilitation (1990)

In 1990, Health Department Victoria released a Position Statement on Rehabilitation articulating the Department's view of the health sector's responsibilities and involvement in rehabilitation for the 1990s. The report recognised the difficulty of establishing distinctions across the rehabilitation and disability services fields, compounded by the multiplicity of funding and regulatory agencies and considerable sharing of roles and responsibilities. It found that service development and funding responsibility and accountability arrangements were often unclear, not just between levels of government and between the government and non-government sectors, but also at the level of State Government agencies.

The report noted the importance of the Head Injury Impact Project underway at that time, and committed the Department to considering the Project's recommendations.

Surveys of younger nursing home residents

In 1991, the Aged Care Program within the Department conducted a survey to identify younger residents of nursing homes. Age and sex data were drawn from the Commonwealth data base, and a reported diagnosis for the younger clients identified was obtained through a telephone survey. The survey identified 282 nursing home residents under 60 years of age, of whom 86 (31%) had ABI. A further 35 people with ABI were identified as long-stay patients in acute hospitals.

These nursing home figures were confirmed in 1995 by *A National Research Project Examining the Placement of Younger People with a Disability in Nursing Homes for the Aged*, which identified 87 people aged under 60 years in Victorian nursing homes whose primary disability was attributed to ABI.

Head Injury Impact Project (1991)

The Head Injury Impact Project, undertaken in 1988 by Health Department Victoria and Community Services Victoria in conjunction with the Traffic Accident Commission (TAC) to look at the incidence and implications of head injury in Victoria, published its final report in 1991. Focussing on the population under 65 years of age, the project sought to identify the numbers of Victorians with ABI from head injury and their service needs, and to develop a strategy plan for service development. It found that:

- Each year, there were about 5000 public hospital admissions of people under 65 years with a head injury. Two thirds were under 25 years, nearly half under 15, and 71% male.
- In about 380 people each year, head injury resulted in moderate to severe disability, with about 70% of these eligible for compensation. About 11,000 to 12,000 Victorians aged under 65 years were estimated to have moderate or severe disability from head injury.
- There were about 4,700 Victorians under the age of 65 with ABI from stroke.

The Project reported shortfalls in almost all areas of service provision, including:

- inadequacies in diagnosis and staff training in acute services;
- barriers to rehabilitation, including inadequate services and poor access for clients without compensation;
- inadequate accommodation services and options, and shortage of appropriate respite care services;
- severe financial disadvantage for clients without compensation;
- inadequate community care and support and integration services (including poor provision of behavioural support services) to facilitate the return of people with ABI to daily life;
- low public awareness of ABI;
- inadequate support for carers of people with ABI, for country residents, and for people of non-English speaking background.

The report set out a comprehensive Head Injury Services Plan with the stated aim of bringing the entire system to a high standard and ensuring that, as far as possible, all people in need could receive the same high quality of service. The Head Injury Services Plan identified eight priority areas and made 41 recommendations, which are included in Appendix 0 of this document. In particular, it was recommended that:

- "… there be consolidation and further development of slow-stream facilities with an additional 10-12 beds for patients able to benefit from more than 6 months of rehabilitation; in the first instance, in a unit located in a metropolitan region but accepting patients from throughout Victoria." (Recommendation 1.5)
- "Legislative changes be sought to broaden eligibility for existing rehabilitation, disability and support services funded by compensation agencies set up by State legislation, so that those services can be made available to any person in need." (Recommendation 6.1)
- "Funding mechanisms be created to allow for relevant State government agencies to pay non-government service providers for provision of services to people with non-compensable injuries, where existing public facilities cannot provide the necessary services." (Recommendation 6.2)

It was estimated that implementation of the package of recommendations would cost up to $7 million capital (over three years) and $15 million recurrent (when fully implemented), with at least six (then) departments/agencies sharing responsibility for recurrent funding.

Ministerial Implementation Committee on Head Injury (MICHI) 1992-1993

The Ministers for Health, Community Services and Transport accepted these recommendations, and in 1992, MICHI – the Ministerial Implementation Committee on Head Injury – was set up under the chairmanship of Bishop Michael Challen and supported by the Brotherhood of St Laurence. MICHI's task was to implement the Head Injury Services Plan. After considerable debate, the decision was made that ABI services should be integrated into mainstream services, respecting the strongly held view of families that people with ABI neither wanted nor benefited from services that isolated them from the community. MICHI's overarching objective was, then, to provide leadership in this integration and ensure that people with ABI had access to all appropriate Government-funded services, both generic and specialist.

TAC agreed to provide $2 million in quarterly instalments over one year for services with specific outcomes for consumers, and MICHI allocated these funds to more than 20 projects addressing high priority recommendations and aimed at improving access to services. The non-recurrent nature of the funding meant that ongoing projects could not be established. Nearly half the funding – $915,000 over three years – was committed to the ABI Case Management Project (see below), to pilot case management services to people with ABI as a result of head injury. Other projects were concerned with appropriate accommodation for people with ABI, and with education, information and support for professionals and families of people with ABI (see Appendix 0 for a list of projects funded).

Convened for 12 months, MICHI had neither the resources nor the time to address all the Head Injury Services Plan recommendations. The committee focused on actions that met the greatest need or were best able to achieve change within the service system, and it identified a number of remaining issues that urgently needed to be addressed, including:

- inflexibility and inequity, particularly the serious discrepancies between services available to compensable and non-compensable clients;
- rehabilitation and support for people who are “slow to recover”;
- long-term accommodation and support options, particularly for those with high support needs and/or significant behaviour problems;
- respite and support for families.

The report noted that some patients with ABI had spent two years or more in acute hospital because of lack of a suitable discharge option; others had spent much longer periods in a psychiatric hospital; an estimated 200 younger people with high support needs were in geriatric nursing homes; and some were forced to live with families though this was not their preference and the families were ill-equipped to take on such complex care.

ABI Case Management Service

Given the decision that people with ABI should be treated within the mainstream health system, additional funding was needed to meet the specific needs of these clients and to provide individually packaged and coordinated services. The Case Management Project was therefore set up to target the post-acute care of clients with moderate to severe ABI, focussing initially on those not in receipt of compensation, to facilitate their smooth reintegration into the community.

Melbourne Citymission was invited to auspice the ABI Case Management Service and the project began early in 1993. The brief included education of the system, to ensure that people with an ABI were identified early and the case management team called in as part of discharge planning. Over its first three years, the ABI Case Management Service improved access to clients soon after admission and evaluation showed it to be highly successful in supporting clients following discharge from acute settings, but it lacked resources to create new options.

Points emphasised in the evaluation of the pilot service included the following:

- An important role of a case management service is to respond appropriately to referrals, to refer on where appropriate and to work intensively with those requiring the special expertise of the case manager.
- If at all possible, case management should be provided by a case manager who works near the residence of the client.
- The provision of good case management requires specialisation, with further specialisation required to work with people with ABI. The difficulties and demands of working with this client group should not be underestimated. Specialisation is also necessary to undertake the service development activities required to increase and support clients' access to mainstream service providers.

Focus on the needs of people with ABI who are slow to recover

The ABI Case Management Service continues to provide a referral and care planning service to meet the complex needs of clients with ABI. There remained, however, a small group of clients with severe brain injury who were very difficult to place, required prolonged high levels of clinical care, and fell outside the criteria of Disability Services and of Mental Health. These clients required funding beyond the means of existing programs. By default, they either remained in acute hospital beds or were discharged to a nursing home or in some cases a psychiatric institution.

To address this problem, the Department in 1994 contracted Health Solutions Pty Ltd, with rehabilitation physician Dr John Olver as consultant, to investigate the requirements for slow-stream rehabilitation and long-term maintenance services for younger Victorians with severe ABI. The study was commissioned by Mr Brian Hardy, Manager, Physical and Sensory Disabilities, within the Disability Services Program in the Department, who chaired the project steering committee.

The Health Solutions report was presented in June 1994. It outlined a model that involved individually tailored packages to support ongoing assessment and slow-stream rehabilitation over 6 to 18 months, with services targeted to meet the individual's needs while natural recovery continued. Over this time, it was anticipated that an optimum level of independence would be achieved (although experience on the Program to date suggests that a longer period of rehabilitation, up to two years or more, may be indicated for some clients). The client would then access alternative support services, such as long-term accommodation support or additional long-term services to maintain the level of function achieved and meet most of the ongoing support needs.

The model proposed that:

- funds to purchase specific services be allocated to individual clients and the resources be used to strengthen and enhance the capacity of existing mainstream services to meet the needs of people with ABI rather than developing a separate service infrastructure;
- regional "slow to recover assessment service teams" (STRAS teams) be established, made up of health professionals from different disciplines (eg. medical, nursing, therapy) who would purchase care and accommodation services and programs on behalf of the individual with ABI and provide life-long case management for the clients in their region;
- an agent from the STRAS team be the first point of contact for clients referred and, following assessment by the team, request funding from dollars held within the Department;

- a number of inpatient slow-stream rehabilitation units be established, as separate entities within existing rehabilitation hospitals, with no more than two such units in metropolitan Melbourne and up to four in country regions. The units would ideally be six beds, to provide sufficient economy of scale and ensure that staff are sufficiently experienced and skilled, and would provide the level of therapy needed to achieve functional improvement, prior to arranging for long-term accommodation and support needs.

In 1994, the Minister for Community Services gave a commitment to continuing support for people with ABI at the "Way Ahead Workshop". A Departmental ABI Working Party was established to ensure policy and program development for people with ABI across all Departmental divisions. Disability Services Division provided administrative support, to develop a strategic plan for ABI-related service development within the Department and to consolidate the work resulting from the MICHI process.

Challenges facing the Department at this stage included:

- the need, within acute care services, for a comprehensive and consistent approach to ABI identification, treatment and management, including rehabilitation, discharge planning and case management coordination;
- the need to guarantee ongoing provision of appropriate ABI case coordination and referral within acute care, community support, and long-term accommodation and nursing care services;
- the establishment of adequate Commonwealth and State funding sources to provide a viable range of medical, nursing and therapy services within residential care settings and in the community for people with high support needs.

ABI Behaviour Management Service

In March 1994, the Positive Approaches to Challenging Situations (PACS) Project began under the auspice of the Bouverie Family Therapy Centre. The project was funded by the Department for a period of two years, with an annual budget of $125,000, to provide consultancy to service providers working with people with ABI whose behaviour is challenging to others. Following a tender process, the auspice was transferred in October 1997 to Bethesda Hospital (now the Bethesda Rehabilitation Centre of Epworth Hospital), and the program became known as the ABI Behavioural Management Service.

Staff including neuropsychologists and clinical psychologists with appropriate expertise provide behavioural management services to clients with ABI, aged between 18 and 65 years, whose behaviour causes distress. This may include aggression, self-harming, inappropriate social behaviours or withdrawn behaviour. The service also supports families affected by the behavioural changes and staff working with the clients. Assistance may take the form of telephone or face-to-face contact, referral to appropriate agencies, training sessions for staff, families and carers, written information, and assistance in accessing scientific literature.

Development of the ABI: STR Program

In early 1996, the Minister for Health and for Aged Care, the Hon Rob Knowles, with the support of the Minister for Community Services, the Hon Denis Napthine, sought the approval of Cabinet for a discrete funding program to develop a service program targeting the needs of people who have severe brain injury, are difficult to place, require prolonged high levels of clinical care, and fall outside the criteria of Disability Services and of Mental Health. Cabinet approved funding to reach a total of $5 million per annum over 5 years.

This funding made possible the establishment of the ABI Slow to Recover Program, initially known as the ABI Slow-Stream Rehabilitation / Long-Term Maintenance Program. The aim was to develop, based on the Health Solutions proposal, a model of service delivery that would redress the difficulties faced by people with severe ABI in accessing the level and type of rehabilitation, equipment and support they required.

Following development of a pilot program within Disability Services, the Program was transferred in 1996/7 to the Aged, Community and Mental Health Division of the Department, which is responsible for extended care services including rehabilitation and long-term care. Design and implementation of the permanent Victorian wide ABI: STR Program was undertaken by the Aged Services Redevelopment Unit, with expert professional advice provided by Associate professor Dr John Olver together with members of the community health, medical rehabilitation and allied health fields. The Program has been fully implemented over its initial two years. On 26 October 1998 responsibility for the Program was transferred, as the result of a competitive tender process to, Southern Health, a major hospital and community health service in the South Eastern suburbs of Melbourne.

Concurrent developments

ABI Information and Training Strategy

The Non-Government Disability Training Unit was given responsibility, under a three-year Services Agreement with the Department, for coordinating training services to disability services funded by the Department. One project entailed developing a documented information and training strategy to enhance access and quality of services for people with ABI, and in November 1996 it released the report *ABI Information and Training Strategy*. The report identified 10 key principles for an integrated strategy; made 13 recommendations to improve the utilisation of existing information and training, and to fill identified gaps; and set out a model based on:

- a central reference point or network to facilitate access;
- an integrated, regionally delivered ABI consultancy/on-the-job training service;
- an integrated ABI information package;
- an integrated ABI awareness and information workshop package;
- an integrated general ABI short-course training package;
- ABI quality service training modules in each key competency development area;
- units in relevant accredited post-secondary training and education courses which focus on services to people with ABI and their carers, articulated with field-delivered training;
- pre-service training for disability workers to include provision of ABI information and awareness by means of consumer and ABI specialist provider speakers and provision of information kits.

Rehabilitation review

In 1996-7, the Department funded a working party of the Australasian Faculty of Rehabilitation Medicine (Victorian Branch) to conduct a review of rehabilitation services in Victoria and make recommendations for the future.

The Working Party's report, *Rehabilitation into the 21st Century: A Vision for Victoria*, proposed a model for service delivery across the State. It specifically identified the need for services for people with severe traumatic brain injury:

> Slow-stream rehabilitation is necessary for individuals with complex multiple conditions and those with significant traumatic injury requiring prolonged recovery in an inpatient or specialist nursing environment before active rehabilitation can be initiated. It comprises the same components as intensive rehabilitation but is of lower intensity and longer duration, with greater emphasis on specialised nursing care, establishing communication and basic living skills, maintaining joint range and minimising complications. Patients may improve to require more intensive rehabilitation or may be discharged to community housing or supported accommodation

> or remain in long-term care. All will require ongoing input to prevent complications and maintain function. (p.39)

The report emphasised the need for rehabilitation planning to:

- provide for preventive, review and maintenance services to provide long-term and possibly life-time follow-up and, where necessary, intermittent intervention, in addition to catering for immediate time-limited management of a presenting disability;
- ensure that rehabilitation takes place in the most appropriate setting/s over time for each individual, with options including inpatient, outpatient, community and home;
- provide for a range of age groups and social, cultural and linguistic needs.

The model proposed for rehabilitation services comprised:

- regionally-based rehabilitation consultancy and liaison services, to provide the point of access to rehabilitation services and to establish and maintain a continuum of care for people requiring or benefiting from rehabilitation services;
- regional/sub-regional broad-based expertise, providing locally accessible services for people with a wide range of disabilities; and
- highly specialised, condition-specific expertise on a cross-regional basis, providing post-acute and complex care on an inpatient or outpatient basis for complex conditions, including traumatic brain injury. These services should provide an outreach program to complement services in the local community by providing particular expertise in specific disciplines, case management, assessment, and additional training and support to local practitioners.

To ensure continuity and flexibility of care, the report recommended that funding for individuals needing rehabilitation should be based on a sequence of care, with the ability to purchase this care whenever it is needed (in contiguous or disconnected episodes) and wherever it is needed, including purchase of case-management services for a long-term client.

The report was launched in December 1997 by the Minister for Health, the Hon. Rob Knowles, who committed the government to implementing its recommendations. The Department has established an expert working party to steer this implementation.

National and Victorian Stroke Strategies

The first two years of operation of the ABI: STR Program have demonstrated that there is a significant shortfall in services available to meet the rehabilitation and long-term support needs of younger people with severe disability resulting from stroke. The National Stroke Strategy, released in August 1997, and the Victorian Stroke Strategy, released October 1997, should address these issues.

The National Stroke Strategy, developed by a taskforce that included medical and allied health professionals with expertise in stroke and funded by the National Health and Medical Research Council, aimed to respond to and support the needs of people with stroke through acute care, rehabilitation and community care, as well as addressing stroke prevention and the needs of carers.

In the area of rehabilitation and community care, the document highlighted the need for:

> regionally based, high quality and coordinated stroke rehabilitation services, and long-term support and maintenance for patients with stroke and their care givers [with] ready access to a seamless continuum of care, through acute care, rehabilitation, and community care.… delivered in appropriate setting/s for as long as is appropriate for each individual patient.

The document recognised that:

> Nursing home and hostel residents with stroke have particular needs, which should be recognised in their management. Education and awareness of nursing staff is of great importance. The level of independence and quality of life of many of these people, and the ease of nursing care, will be improved by some specific rehabilitation and ongoing maintenance therapy.

The goals and targets relevant to slow-to-recover clients included the provision of continuity of care for stroke patients throughout the continuum of stroke rehabilitation and care, and the establishment by acute stroke units, stroke rehabilitation units and primary care providers of a program of integrated care for long-term follow-up of all stroke patients, to ensure that patients' needs are being met and that they receive continuity of care. The Strategy also proposed that people with residual disabilities, including those in nursing homes and hostels, should have access to ongoing therapy to maintain independence, mobility, communication, cognitive functioning and quality of life.

The Victorian Stroke Strategy was compiled by a taskforce established by the National Stroke Foundation and the Department of Human Services to apply the national goals and recommendations to the Victorian situation. It noted the difficulty of accessing adequate rehabilitation services for "severely affected slow track patients", and the lack of rehabilitation services in nursing homes, which could have a significant place in improving mobility and quality of life. Recommendations included support for rehabilitation funding which would facilitate access for all patients to the full range of rehabilitation services appropriate to the needs of each, with the ability to move smoothly from one setting to another.

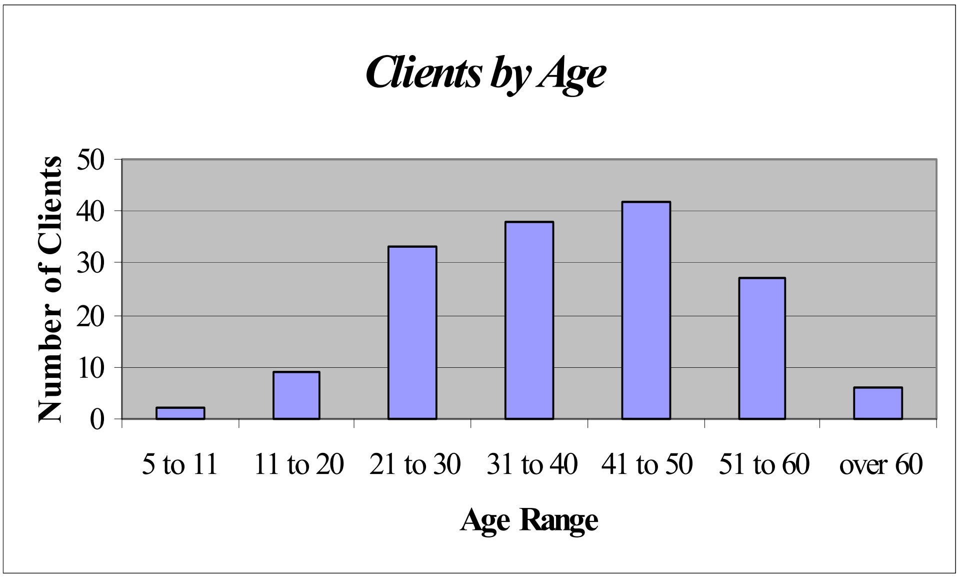
The Client Group

People with moderate ABI, who need rehabilitation for a few months to regain a level of independence that enables them to return to the community, are generally supported by mainstream acute and sub-acute rehabilitation services. The complex and long-term needs of ABI: STR Program clients place them beyond the capacity of these mainstream services.
The ABI: STR Program caters specifically for a small but significant group of recently brain-injured younger adults who are not eligible for compensation, and are distinguished by:

- the severity of their ABI;
- their slow recovery and persisting high dependency requiring prolonged rehabilitation and/or other therapies;
- the complexity of their care needs; and
- their inability to access, through any other means, services that are appropriate to their age, level of disability, and limited recovery potential.

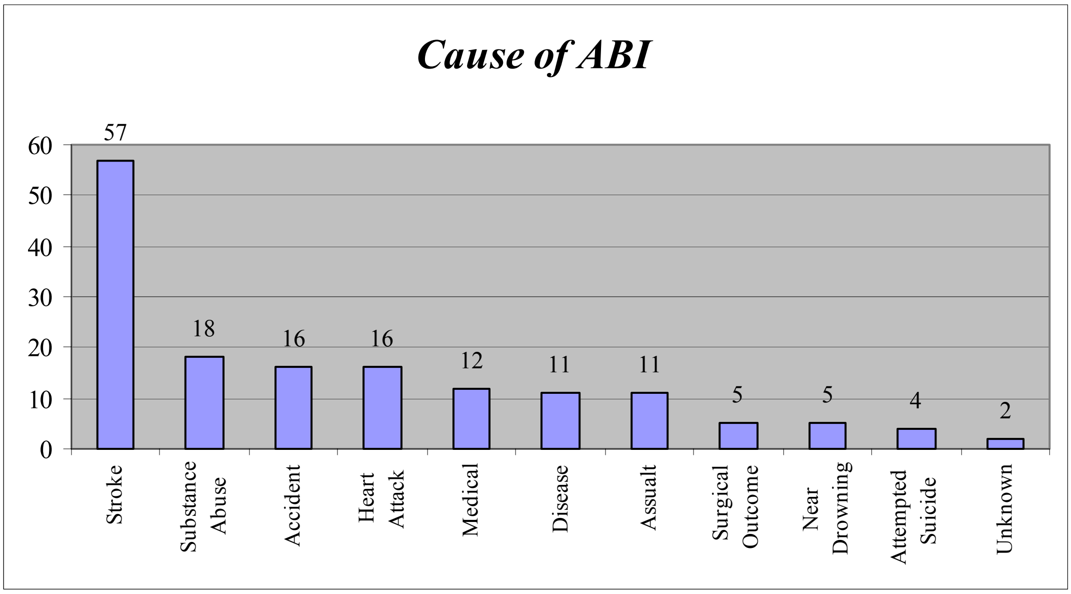
These clients require individual case management and care coordination over a prolonged period, involving a wide range of clinical, psycho-social, environmental, economic and family issues. By definition, no client is too severely brain injured or too disabled for the Program (although some may be unable to participate in active rehabilitation).
The Program targets clients in the younger age groups (excluding very young children lees than 5 years old), for whom age-appropriate services have previously been largely unavailable. Figure 1 shows the breakdown of clients by age group, to 1st September 2002.

Figure 1: Age by number of clients



While the Program was established to target people with recently acquired severe traumatic brain injury, it has become clear that it can also benefit some younger people with severe ABI from other causes, such as infection, lack of oxygen (eg. resulting from cardiac arrest, pulmonary embolus, near-drowning, hanging, drug overdose), and some younger people with severe stroke where mainstream services are inappropriate or inadequate. Figure 2 shows the breakdown of clients by cause of ABI, to 1st September 2002.

Figure 2: Causes of ABI



Disease = encephalitis, meningitis
Surgical = outcome as a result of surgery
Medical = brain tumour, anaphylactic reaction

ABI: STR Program eligibility criteria

To be eligible for funding through the Program, an applicant must satisfy *all* the following criteria:

- Medical:
  - has a diagnosis of severe ABI in relation to an acute health episode within the preceding two years
  - has a current primary diagnosis of ABI
  - is post-acute and medically stable or requiring limited medical intervention
- Age:
  - is at least 5 years of age
- Legal:
  - is non-compensable
  - has a legal guardian or advocate, if unable to give informed consent
- Social circumstances:
  - requires specific age-appropriate care and support, including individual psycho-social and familial assistance, which is not available through other programs. There may, for instance, be a need to purchase a specific environment because of the person's youth or because of family commitments and responsibilities (eg. a young family and parenting responsibilities)
- Management:
  - is not eligible for fast-stream rehabilitation or has not undertaken or completed sufficient rehabilitation
  - has been assessed as needing long-term nursing care and/or eligible for Commonwealth-funded nursing home services.

To be eligible for funding for long-term maintenance services, the client must:

- satisfy the above criteria *and*
- require clinical care or therapy *in addition to* that normally available in a nursing home or other care setting, to maintain muscle tone and the level of independence gained through slow-stream rehabilitation, and to prevent contractures and deterioration in health.

Access to the Program is also based on:
- the presence of other specific medical or social conditions that may indicate that mainstream services may be either more or less appropriate to meet the person's total care and personal support requirements;
- the availability of age-appropriate and clinically appropriate services in the area the person lives.

As the Program continues to develop, it will be possible to test and assess whether there is a capacity to extend some services to people who have the potential to benefit from the Program although they do not meet all the eligibility criteria (see page 45).

The Program is not appropriate for, and is not resourced to address the needs of, people with dementia or degenerative neurological diseases. Other services are available and appropriate for these people.

Effects of brain damage

While the effects of brain injury vary according to the part of the brain damaged and the severity of the damage, effects commonly include:
- medical problems, eg. epilepsy, dementia
- sensory changes, eg. changes in vision or hearing
- physical effects, eg. paralysis, abnormal fatigue
- swallowing difficulties
- cognitive change, eg. poor memory, difficulty concentrating, poor organisational skills
- communication problems, eg. speech, language and/or comprehension difficulties
- behavioural factors, eg. lack of inhibition, loss of initiative, repetitive behaviours
- emotional factors, eg. mood changes, depression, anger.

Once the initial stages of acute trauma have passed, people with ABI have a near-normal life expectancy.

Pattern of recovery and changing needs in people with severe ABI

Generally, recovery following brain injury is greatest over the early months after the injury, with rate of improvement then declining rapidly.

In people with severe ABI, improvement is very much slower than this and continues for considerably longer. There is a paucity of studies of the long-term outcomes and potential for these clients, and the ABI: STR Program is already contributing significantly to knowledge and evidence-based practice.

While the literature suggests that significant neurological improvement in these clients may continue for 18 months to 2 years, experience on the Program suggests that appropriate rehabilitation services may continue to achieve functional gains for some clients over longer periods of time, over and above the improvement that occurs naturally as the person adapts increasingly to their disabilities. In time, functional improvement plateaus and the person's daily activities are largely sufficient to maintain their level of function. This is the point at which therapy may be substantially reduced or discontinued, although some people will need a low level of ongoing therapy to prevent deterioration.

In the weeks or months after a severe ABI, the client may remain bedfast or dependent on total care before recovering to a level where active rehabilitation is possible. While some clients have multiple medical problems, many will be medically stable within a few weeks and do not need acute hospital care beyond this time. Often, physical, cognitive and possibly behavioural dysfunction limits the person’s ability to interact with their surroundings or participate in self-care or therapy. Clients at this interim stage need intensive nursing and often passive therapy to prevent deterioration, maintain physical functioning and maximise the potential for later recovery.

With support from the Program, this interim care may be provided in a nursing home. While mainstream facilities such as nursing homes cannot routinely provide the level of care needed, the Program can purchase additional care and ensure that the client’s progress is monitored so that active rehabilitation can be introduced when appropriate. The arrangement allows time for natural recovery to occur and for treatment teams to assess the client’s potential. For those clients for whom there seems to be little or no rehabilitation potential, it also provides relatives with time to adjust to the situation and plan for the future.

As natural recovery progresses, clients become increasingly able to interact with their environment and participate actively in physical and cognitive programs. The progression is similar to that experienced by most clients after brain damage, but the speed of change and the degree of persisting disability are very different. Clients on the Program progress slowly towards limited quality of life and independence. In the long term, some achieve independence in self-care and are able to live in the community with support. If the level and rate of recovery increase, the potential exists within the Program to transfer clients to faster-stream rehabilitation. Others require a substantial amount of attendant or nursing care after their natural recovery has plateaued, and some will need life-time care and support from the ABI: STR Program to complement funding from other State, Commonwealth, local government and non-government programs.

After the initial period of slow-stream rehabilitation, most clients will require therapy in the longer term, to maintain the level of function and independence gained or to maximise further potential for functional improvement. In some, recovery may plateau for an extended period, before recommencing slowly, possibly indicating the need for a further episode of targeted therapy and/or new drugs.

Program Structure

The ABI: STR Program has developed a unique model for the delivery of targeted and responsive rehabilitation and long-term maintenance services to clients with the most catastrophic ABI and the most complex and difficult care needs.

The Program enables these people to be integrated into mainstream services and, so far as possible, back into the community. It maximises their independence, within the limits of their injury, it minimises their marginalisation, and it achieves this in a manner which is highly cost-effective in the longer term.

Funds to purchase services are allocated to each client and these resources are used to strengthen and enhance the capacity of existing mainstream services to meet the needs of people with ABI rather than developing a separate service infrastructure.

Aims

The Program aims to:

- **provide individually targeted slow-stream rehabilitation services** to people with severe ABI who have the potential to achieve functional gains in their level of independence, and thereby to assist these people to achieve optimum levels of independent functioning;
- **monitor and provide passive rehabilitation** for clients not able to benefit from active rehabilitation in the early weeks or months post-ABI, while allowing time to assess realistically the person's potential for recovery and/or to await further neurological recovery that may enable the client to participate in more active rehabilitation;
- **ensure timely and appropriate discharge from acute care and reintegration into community care** by providing the necessary level of support and assistance not otherwise provided by mainstream programs for these clients;
- **ensure a maintenance level of rehabilitation and sufficient attendant care services** to prevent physical deterioration for those who have sustained major and irreversible brain injuries and who may require long-term or life-long support;
- **extend the currently very limited knowledge** of the process of recovery following severe ABI, and the place of rehabilitation services in maximising recovery and independence for these clients, to develop evidence-based guidelines for optimum management of ABI: STR clients.

The service delivery model developed by the Program to achieve these aims involves:

- **coordinating**, through case management, access to services funded by the Disability Services Division and the Aged, Community and Mental Health Division within the Victorian Department, to provide services such as accommodation and daily living support;
- **identifying** the rehabilitation and clinical care needs of individual clients that cannot be met through other program areas, and purchasing services to meet those needs, to ensure that clients can remain with extra support within generic and community-based services;
- **contract purchasing** of core services, including slow-stream inpatient rehabilitation (within existing rehabilitation hospitals), case management, and the management and provision of aids, equipment and home modifications. This ensures a baseline level of services that can be augmented as needed, provides ready access to services, and supports the development of specific expertise in working with ABI: STR clients.

Legislative framework

The legislative framework for the Program is provided under the *Commonwealth Health Act (1953)*, the *Commonwealth Aged Care Act (1997)* and the *Victorian Disability Services Act (1991)*.

Funding

The State Minister for Health and Minister for Aged Care has committed a total of $5 million recurrently to be allocated over five years. Funds are provided on a prospective annual basis, with end-of-year acquittal requirements.

It was estimated that the funding would cater for a minimum of 20 new clients per year over the five years, to provide continuing services to approximately 100 people with severe ABI. Efficiencies achieved in resource allocation and purchasing of services, without compromise to the quality of care and outcomes for clients, will enable the Program to cater for a larger number of clients and potentially to minimise demand for future growth in funds to meet the long-term maintenance needs of the growing number of Program clients.

Program management and administration

ABI: STR Committee

The ABI: STR Committee is concerned with broad policy and Program direction. It oversees the development and ongoing administration of the Program, including the development and implementation of guidelines and policy documents. The Committee meets twice yearly, or more often if a policy issue needs debate and determination. It comprises:

- the Chairman:
  – a sessional, paid appointment made on an annual calendar-year basis on the recommendation of the Committee. The position is filled by an independent medical rehabilitation practitioner and is funded through the Program;
- ABI advocacy representative;
- ABI community service provider representatives:
  – 2 members
- professionals in core health and allied health disciplines:
  – 4 members, who must have expertise in the rehabilitation and long-term maintenance of people with severe ABI. They must include a nurse and a physiotherapist, and may also include a rehabilitation physician (in addition to the Chairman), occupational therapist, speech pathologist or other relevant health professional;
- ABI: STR Equipment Coordinator:
  – the Program of Aids for Disabled People has provided this service. It is an essential part of the ABI: STR Program and is funded on an ongoing basis. Requirements for the position and the current arrangements are set out on page 27;
- Departmental representatives
  – participated in the Committee during the development of the Program to ensure that access to mainstream services was facilitated through regional Departmental offices. The ABI Services Coordination Unit in the Department will maintain representation;
- representative of the auspice organisation.

The Committee has been independent of the funding body and is to remain independent of the auspice organisation.

Program administration

Up to 26 October 1998, the Program was administered within the Aged, Community and Mental Health Division of the Department. Following a tender process, responsibility for the Program was transferred toSouthern Health. The terms of the contract require Southern Health, in addition to administering the Program, to review and update the care plan proforma, produce an annual Best Practice Report, review and refine the ABI: STR Program guidelines, and produce a client information kit for distribution.

Budget responsibility

Overall responsibility for purchase of services and management of the budget rests with the administrative management of the Program. This was originally the Executive Officer responsible for the Program within the Department and now is the Chief Executive Officer of the auspice organisation responsible for the Program (Southern Health). The Chairman of the ABI: STR Committee in conjunction with Southern Health is responsible for overseeing the administration of the budget and, with the Committee, for allocation of resources within the budget.

Individual client management

Case management

The ABI: STR Program contract purchases case management for clients from a number of case management services, purchasing extra case management as necessary from the service and/or from other case management services, as appropriate for individual clients.
The case manager for each client:

- identifies the potential eligibility status of the client;
- develops an individual care plan, in consultation with the family, regional Departmental staff and involved medical and allied health professionals;
- locates the required services from existing Departmental programs and/or applies for rehabilitation and support services from the ABI: STR Program;
- organises, or assists clients and families accepted by the Program in, the purchase of services approved by the ABI: STR Service Panel (see below);
- regularly reviews the client's progress and function, potentially for the rest of the client's life.

To provide consistency for client and family, ABI: STR clients remain, where possible, with the same case manager over at least the period of slow-stream rehabilitation. They may be transferred to a generic case management service after this if appropriate.

ABI: STR Service Panel

The ABI: STR Service Panel is responsible for allocating services and funds to individual clients. The Panel:

- decides on applicants' eligibility for ABI: STR Program support;
- considers applications to the Program, based on information provided in the care plan developed by the case manager and the available resources;
- approves the purchase of a range of services and equipment for eligible clients;
- regularly reviews resource allocation for each client through consideration of the up-dated care plan (see page 24).

The Panel comprises of at least:

- the Chairman:
  – this position is filled by the ABI: STR Committee Chairman;
- a representative from the ABI: STR auspice body:
  – to approve services and funding to be provided to individual applicants.

To enable efficiency and a speedier response to requests, decisions on service provision may be made by the ABI STR program manager relying on their past experience and guidance from the ABI STR program Chairman.

The Panel may also include other members invited by the Charirman. The Chairman may seek extra advice as needed regarding individual Program applicants.

Application, assessment and care plan

The first contact with the ABI: STR Program is usually via a contracted case management service. It may, however, come through any route, including other clinical services or personal contact. Potential clients are referred to an appropriate case management service for the development of a care plan, which is then submitted to the ABI: STR Service Panel (see Figure 3).

The care plan, particularly the goals set by each care professional, is of central importance. It provides the basis for the ABI: STR Service Panel's decisions regarding services, both initially and on review.

In developing the care plan, the case manager must discuss all STR applications with the relevant Regional Departmental of Human Services office to ensure that the client is accessing all relevant mainstream services and resources.

The care plan will include personal details, personal history, guardian or advocate details, a full medical history, and reports from specialists including a full neuropsychological evaluation and evaluations by physiotherapy, occupational therapy, speech pathology and others as required. It will indicate the potential for rehabilitation, specifying:

- well defined and measurable rehabilitation goals for each discipline or therapy;
- strategies to achieve these goals;
- expected time-frames to achieve goals; and
- the amount, type and cost of services to be provided.

The Panel assesses each care plan and may request further information, to determine whether the services and levels of service requested are reasonable and appropriate for the client and sustainable within the resources of the Program.

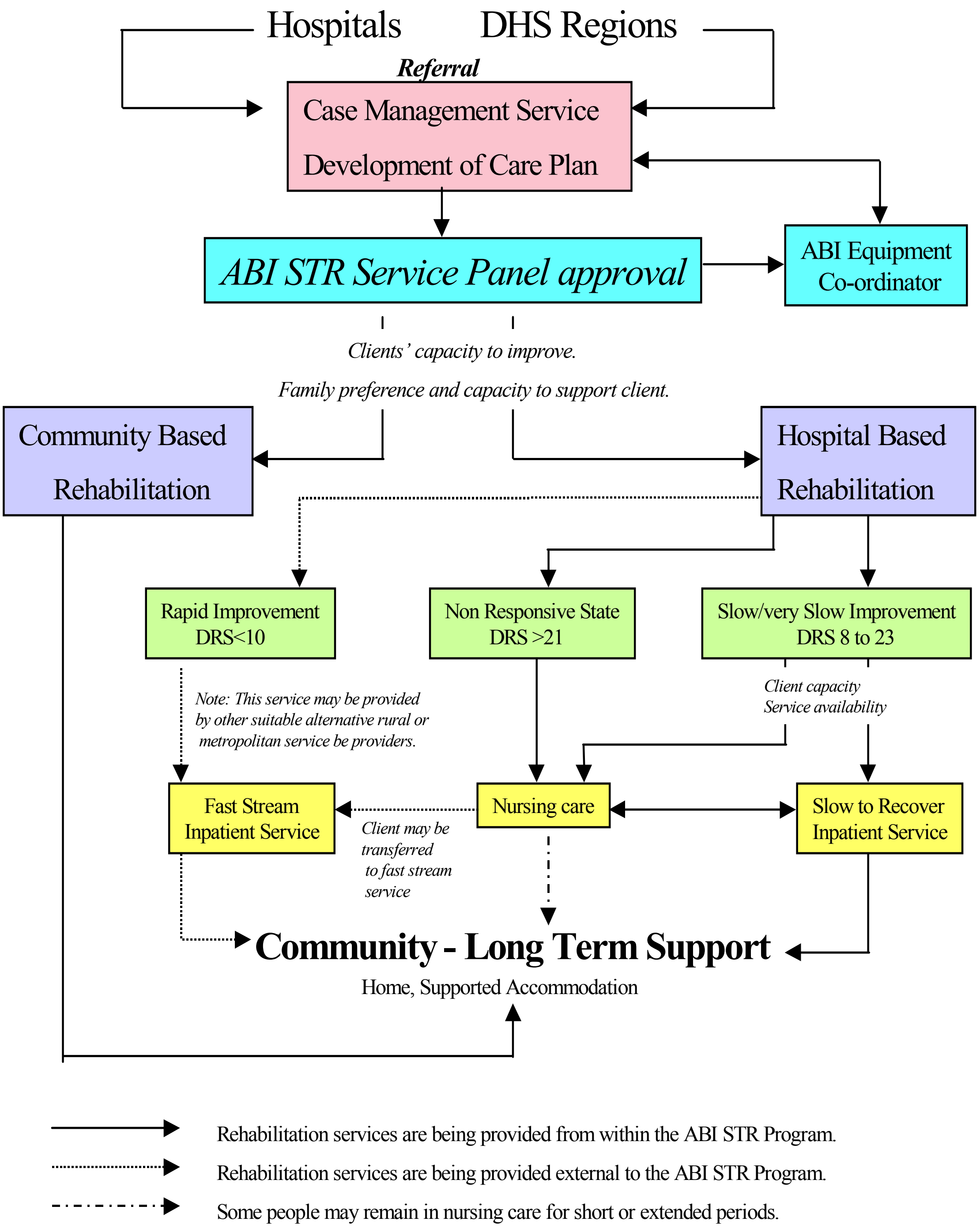
During the course of an agreed care plan, clinicians and the case manager may, in conjunction with the client and family, change or modify therapies or equipment so long as they remain within the agreed care plan budget. Changes that require additional resources or significantly alter the care plan goals or service costs are referred to the ABI: STR Service Panel for approval.

Guidelines used by the ABI: STR Service Panel to assess care needs will continue to be refined in the light of Program outcomes and research. Currently, the Disability Rating Scale (DRS) is being used in conjunction with clinical judgement to determine access to the ABI: STR inpatient service, and may also be used as a guide to the level of service required (see Figure 3). The aim is to differentiate reliably between:

- people for whom mainstream rehabilitation services are appropriate;

- those who require slow-stream rehabilitation services through the ABI: STR Program;
- those who are currently unable to participate in active rehabilitation (although they may be reassessed at a later stage), but require services to prevent contractures and maintain muscle tone. These clients are generally clinically non-responsive and may be supported in a nursing care facility.

Figure 3: Overview of the ABI: STR Program structure and assessment process



Client review

The ABI: STR Service Panel regularly reviews each client's progress and care plan. Reviews are usually every three to six months for clients receiving slow-stream rehabilitation or in the first year post-injury awaiting neurological recovery before active rehabilitation; and once a year for long-term maintenance. This, however, will depend on the circumstances of each particular client. There must always be the flexibility to review a client if:

- care-givers perceive a change in care or therapy needs;
- the client shows emerging potential for further recovery;
- the circumstances of the family care-givers change.

The review seeks to:

- determine whether the care plan goals have been met and are appropriate;
- ensure the care plan is adjusted, where necessary, to meet the client's changing needs or address changes in the care-giver's circumstances;
- identify when specific services are no longer required through the Program.

It is possible for people on long-term maintenance to receive episodes of more intensive rehabilitation services, if assessed by the Service Panel as needing such services. This may, for example, be to:

- address specific problems or co-morbidities
- maintain function
- take advantage of further emerging potential for functional improvement; or
- take advantage of a new treatment or drug (eg. Botulinum in association with short-term physiotherapy has enabled people with long-standing contractures to achieve significant functional gains and has reduced their care needs).

The review process is an integral part of the ongoing development of the Program and of the development of the evidence base for improving practice (see page 44). The inputs and outcomes for each client will feed into prospective planning for other clients on the Program.

Service delivery and location

The ABI: STR Program aims to provide services in the accommodation setting that is most appropriate, clinically and socially, for each client. This entails balancing, on the one hand, the advantages of locally delivered care, where family and friends have easy access but rehabilitation services may be less available or lacking specific expertise, and on the other hand, rehabilitation services delivered at a facility that offers expertise in treatment of ABI but may be geographically distant from family and friends.

The Program is maximising options for service delivery at the regional and local level by resourcing specialist inpatient settings which are able to provide specialist advice and consultancy to health professionals throughout the State (see page 26), and by providing resources and access to expertise for family, friends and communities caring for people with ABI.

Early care and monitoring

Clients who are non-responsive in the weeks or months following their ABI and need high dependency nursing care, passive therapy and monitoring, but not acute care, are usually assessed as eligible for, and most appropriately cared for in, a nursing home. The Program provides extra support to meet identified needs until the client recovers sufficiently to participate in active rehabilitation or it is possible to make an informed assessment of future needs.

Slow-stream rehabilitation

The Program enables the delivery of slow-stream rehabilitation services to clients:

- in the client’s own or family home;
- in a residential care facility, which may be a nursing home or other supported community accommodation setting;
- through outpatient services, same-day rehabilitation, day therapy centres, or non-government disability organisations and facilities;
- on an inpatient basis in extended care services or rehabilitation facilities.

Rehabilitation services are provided through the Program for as long as the client continues to make functional gains that will change the level of independence or the level of care required in the long term. When the Program was first established, the expectation, based largely on the limited literature available, was that rehabilitation services should be available for 18 months. As stated earlier, however, experience to date suggests that the potential for functional improvement may extend for considerably longer than this. The need for rehabilitation services is reassessed for each individual client and judged by the ABI: STR Service Panel based on information contained in the care plan, to ensure that each client has the greatest possible potential to make functional gains and that resources are being used efficiently.

Core rehabilitation services provided include physiotherapy, speech pathology and occupational therapy, with other therapies and treatments being considered by the ABI: STR Service Panel on a case-by-case basis. Interpreter services are purchased as necessary, usually through the telephone interpreter service, local government, or other mainstream interpreter services.

Specialised and expensive medical needs such as Baclofen delivered by an intrathecal pump or Botulinum Toxin may be approved for a client if not provided by Medicare and not covered under the Pharmaceutical Benefits Scheme. These costs are subject to individual assessment by medical practitioners and are considered by the ABI: STR Service Panel on the medical practitioner's recommendation.

Long-term maintenance

The ABI: STR Program funds attendant care services at any stage, where these are necessary to supplement services available through mainstream service providers. In the long term, Program clients are assessed to access mainstream programs for accommodation and attendant care support. Where mainstream programs do not provide a sufficient level of service, the ABI: STR Program provides resources to purchase extra attendant care and/or ongoing maintenance therapy services as required to meet identified needs.
These services may be delivered in:

- the home;
- a nursing home, if the person requires continuous nursing care and medical supervision;
- a community-based shared accommodation facility. These facilities accommodate a number of people on the one site and foster the involvement of family, friends and the community;
- any other appropriate supported accommodation environment, such as supported residential services (ie. private residential facilities registered to provide personal care).

Some clients on long-term maintenance may require further episodes of more intensive therapy to maintain their level of function, address specific problems or co-morbidities, or take advantage of new treatment options or newly emerging potential for further improvement. This will be assessed by the ABI: STR Service Panel based on information in the care plan.

Development of inpatient and consultancy services

To ensure a firm basis for its rehabilitation services and the ready availability of these services, the Program is developing inpatient slow-stream rehabilitation units at major rehabilitation centres, through contract purchasing. This will both foster expertise and excellence in the management of ABI: STR clients and ensure that economies of scale maintain cost-effectiveness.

Units will be developed on a regional basis to ensure that specialist inpatient slow-stream rehabilitation is available to clients relatively close to their home and community. To provide the basis of an adequate service, two ABI: STR inpatient units located in the Melbourne metropolitan area are considered essential. Smaller units linked to one of these units are also required through appropriate sub-acute services in non-metropolitan areas.
Inpatient services are currently being purchased on an individual client basis in non-metropolitan facilities through the same service purchase arrangements. All inpatient services will be purchased on a bed day basis through a sub-contract arrangement established and maintained by the Program administration.

Additional funding in 1997/8 made it possible to develop the first of the slow-stream inpatient rehabilitation units in the metropolitan area, at the Royal Talbot Rehabilitation Centre. It started to deliver services under the ABI: STR Program early in 1998 and by July, four ABI: STR clients were using the service. The purchasing arrangement will enable at least five clients at a time to use the service. Development of the second unit, at Caulfield General Medical Centre, began in 1998.

The Program has set out to purchase services from the metropolitan units in a way that will support their development as centres of excellence, with specialised medical, allied health and nursing skills and a capacity to provide telephone, face-to-face and video consultancy services to professionals and care providers involved with ABI: STR clients. Cost-effective support for local care providers will entail the use of information and communication technology such as video conferencing.

The purchasing arrangements will enable each of the two metropolitan units to provide specialist consultancy services to half the State, each taking responsibility for supporting provincial centres and the regional rehabilitation consultancy and liaison services that match their catchments (see pages 12 and 43). Specialist training in these units will be expected to contribute to the development of the skills of medical, nursing and allied health therapists across the State in the care of this client group.

Community-based supported accommodation

Clients assessed as eligible for high dependency residential care may be able to live within the community if appropriate accommodation with care can be provided. While the ABI Westgarth Community Shared Accommodation Facility has been developed to provide such care to a small number of clients, there are very limited options for accessing such services. Departmental regional offices have established accommodation support waiting lists and ABI: STR Program clients for whom such care is clinically and socially appropriate will be included on these. Until such time as there are adequate services, other accommodation services or solutions will need to be developed for individual clients. The future development of accommodation options is discussed on page 43.

The Westgarth Facility provides long-term community-based accommodation for five people with severe ABI who require twenty-four hour care. As the first such purpose-built, community-based facility developed by the government within Victoria, it will serve as a model for further similar facilities. The design incorporates five self-contained units joined by a common area, and ensures that each resident has the greatest opportunity to learn activities of daily living and independence while providing a high level of individual privacy, support and security.

The Westgarth Facility was developed through co-operation between the Disability Services Division and Aged, Community and Mental Health Division of the Department. It was undertaken at the insistence of the families of young people with severe ABI who had no alternative to inappropriate institutional care (four of the current five residents had previously been accommodated in the now closed North Eastern Metropolitan Psychiatric Services institution).

Equipment and home modifications

The ABI: STR Service Panel approves in principle the purchase of equipment and home modifications if these items are not available through other programs (eg. Program of Aids for Disabled People, Office of Housing, Home Renovations Scheme).

To ensure a consistent and cost-effective approach, the ABI: STR Program has contracted the purchase of all equipment and home modifications through the St Vincent’s Hospital Program of Aids for Disabled People Co-ordinator, who also serves on the ABI: STR Committee as the ABI: STR Equipment Co-ordinator. The ABI: STR Program pays St Vincent’s Hospital 12.5% of the purchase price of each item to cover administration costs. The ABI: STR Equipment Coordinator is an essential part of the service and is to be funded on an ongoing basis. The coordinator must be a qualified occupational therapist with expertise in aids, equipment and home modifications for disabled people, including the application of these items, the relevant Australian Standards requirements, and a knowledge of suppliers and costs.

The cost of equipment and home modifications, including the administrative costs, is approximately 15% of the total allocated ABI STR budget, or $150,000 of every $1 million dollars spent on services.

Cultural considerations

The individualised purchasing arrangements of the ABI: STR Program mean that cultural issues are readily, sympathetically and appropriately accommodated. Experience on the Program confirms the experience of domiciliary rehabilitation teams working in various locations in Victoria, that for many people of non-English speaking background, rehabilitation is most acceptable and effective when it is delivered in the home.

The language needs of people from small minority communities, however, will always be a particular challenge, and interpreter services will need to be provided to ensure needs are met as effectively as possible.

Program Outcomes

The ABI: STR Program has been notably successful in achieving the aims set out on page 19:

- to provide individually targeted slow-stream rehabilitation services to people with severe ABI;
- to monitor and support those not yet able to benefit from active rehabilitation in the early stages post-injury;
- to ensure clients' appropriate discharge from acute care and reintegration into community care;
- to ensure a maintenance level of rehabilitation and sufficient attendant care services for clients in the long term; and
- to extend the currently very limited knowledge base and develop evidence-based guidelines for optimum management of ABI: STR clients.

The Program has enhanced the quality of life for individual clients and families, and demonstrated long-term cost-effectiveness. The client stories that comprise the next chapter illustrate that both these outcomes are optimised when the client is referred and intervention begins as early as possible.

Client numbers, placement, and expenditure have been systematically monitored. To date, however, while each client's case history charts the client's progress in detail, the Program has not defined an appropriate measure of functional gains that allows ready comparison between clients and clearly demonstrates functional gains in relation to interventions over time for each client. In the future, use of an appropriate measure of functional independence will be included in each client review to provide such information. In the meantime, the client stories in the next chapter provide strong evidence of the significant gains for clients and families.

Relocating clients to a more appropriate environment

The ABI: STR Program has been especially successful in assisting younger clients with recently acquired severe brain injury to move from acute hospital to appropriate rehabilitation and accommodation facilities, and in ensuring that the accommodation environment is appropriate to the client's age.

Of the 157 clients accepted to the Program up to 1st September 2002, 108 were in an acute hospital at the time they entered the Program, 38 in a nursing home, and 11 at home.

On 1st September 2002:

- 65 clients had returned home, supported by an individually tailored care package. It is likely that, without the Program, the majority of these would have been placed inappropriately in geriatric nursing home beds.
- While the number of clients in nursing homes had risen from 38 to 44, the group of clients had changed. In many cases, the nursing home provides interim accommodation, with some rehabilitation services provided under the Program, until a further assessment of rehabilitation and care needs is possible. For example:
  - On discharge from hospital, some clients may require an extended period of nursing care, with some rehabilitation services, until they are ready to move to an inpatient rehabilitation unit, or home, or to other community-based accommodation.
  - Interim placement may provide families with time to come to terms with the situation, and/or to organise home modifications and support options.

For clients requiring long-term placement in a nursing home, the facility is selected for its willingness and ability to cater for a younger disabled person on a long-term maintenance program, with family involvement in care.

- 19 clients are now living permanently in a community supported residential environment. The demand for this new service type is high, and the service is in urgent need of expansion.
- 10 clients are still in hospital awaiting discharge.
- 2 clients are in inpatient rehabilitation
- 17 clients have died.

About half the clients on the Program had moved from slow-stream rehabilitation to long-term care. Two clients had left the Program: one ("Zena", see page 36) reached a level at which she was able to be supported by mainstream services; the other had been receiving mainstream services before acceptance by the Program but required top-up funding from the Program for a single episode of specific services.

Integration into generic or community-based programs

The ABI: STR Program had, by 1st September 2002, integrated 30 clients totally into generic or community-based support programs such as:

- Disability Services, including in-home accommodation support, day programs, community supported accommodation;
- Home and Community Care (HACC), including assessment and care management, health care and support, home care and property maintenance, Linkages, personal care, respite, social support and service system resourcing, Adult Day Activity Support Service, community nursing services;
- supported accommodation within aged care programs, including nursing homes, hostels and supported residential services.

Before the ABI: STR Program, people with severe ABI may eventually have accessed such services, but it was usually too little and too late to take advantage of the window of recovery. The ABI: STR Program has, through the advocacy and discharge planning role of case management, enabled clients to access an appropriate range of services at an appropriate time. Top-up funding has ensured that the clients do not fall outside the resource capacity of the generic programs. In many instances this enables clients to be supported in the community rather than being placed in a nursing home.

Experience to date indicates that if the Program is to continue to provide the required specialist ongoing rehabilitation services, other program areas will need to provide greater access to their existing programs (see page 43).

Clients funded

The funding of $1 million in the first year of the ABI: STR Program (1996/7) was intended to support a minimum of 20 new clients, with an ongoing intake of at least 20 per year with each additional $1 million recurrent funding over the five years. At the end of this time, the Program would be providing continuing services to approximately 100 people with severe ABI.

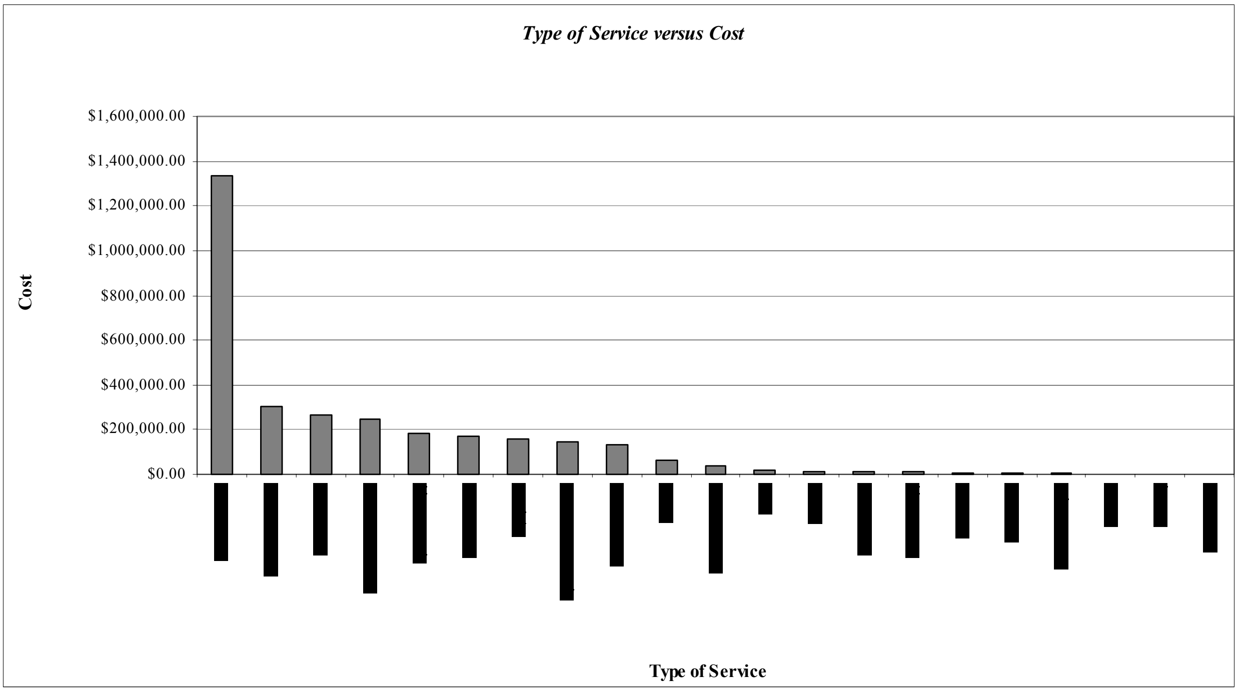
At the time the Program was launched, 15 clients were being funded by the Department under special arrangements, at a total cost of $600,000, and these were the Program's first clients. By April 1997, the Program had exceeded its target, with 25 clients funded (18 male, 7 female, aged 13 to 49 years) under the first year's funding of $1 million.

The $3 million allocated in 1997/8 was $1 million more than originally planned, and while $600,000 of this was directed to developing new ABI: STR inpatient services (see page 26), the funding for the year was not able to be fully utilised. There were two reasons for this: the inpatient development was delayed by administrative factors beyond the Program's control, and the uptake of services was limited by the availability of ABI case management services. Nevertheless, by 30 June 1998, 52 people were receiving or had received services from the Program (35 male, 17 female, aged 14 to 59 years), at a cost of $2 million, substantially exceeding the original target of 20 people for each $1 million allocated.

Breakdown of expenditure

Figure 4 shows the proportion of program expenditure by service type, to 30 June 1998.

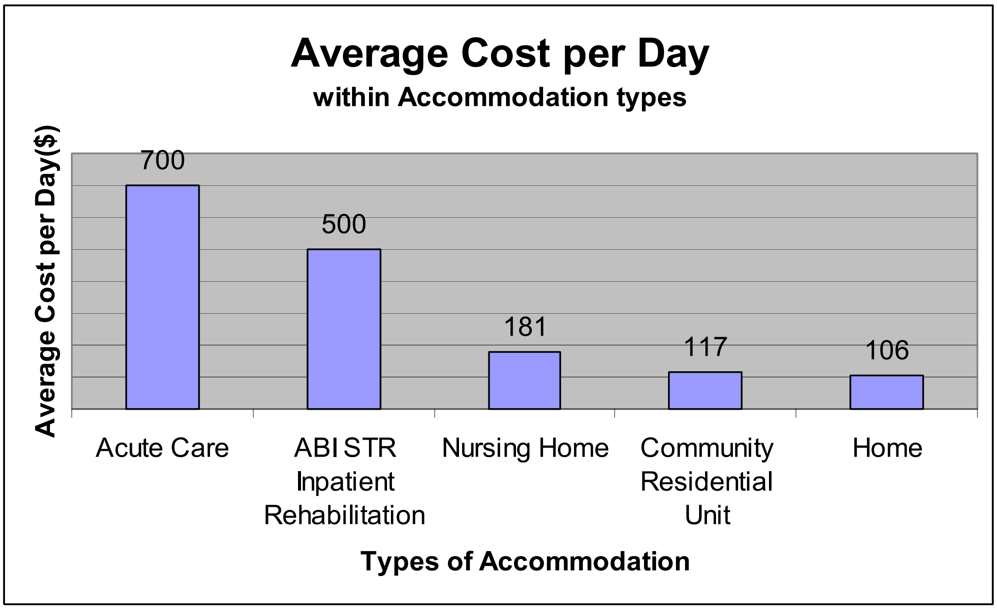
Figure 4: Funds committed ($) by service type



Supported accommodation includes up to 80-90% of the Program's expenditure on attendant care. The Program purchases community-based supported accommodation from non-government organisations.
Medical includes Botulinum Toxin and intrathecal Baclofen treatments. Average cost per patient for a Botulinum treatment is approximately $2,000 and for Baclofen, approximately $2000-$5000 per annum for the medication and $10,000 for the infusion pump.
Administration includes administration wages, Royal Talbot ABI inpatient service establishment, ABI: STR Service Panel Chairman's consultancy fee, additional case management, initial assessment by allied health professionals, and a small amount for publications etc.
Transport is provided to clients mostly in rural areas to attend allied health appointments. This is far more cost-efficient than paying travel costs for the allied health professionals.

Figure 5 shows the *per diem* cost of various types of rehabilitation and accommodation support, ranging from acute care, the most expensive at an average of $500 per day, to home care, the least expensive at an average of $123 per day. While the cost to the ABI: STR Program is lowest for clients in extended care centres and nursing homes, the greater part of funding for these options comes through other funding sources.

Figure 5: Average cost per day in different types of accommodation



Client Stories and Outcomes

The success of the ABI: STR Program is most persuasively demonstrated in the individual histories of its clients. While the Program has not, to date, systematically evaluated gains in functional outcomes and quality of life, clients' stories clearly demonstrate the Program's value and efficacy. The stories presented here are a representative selection. Some clients achieved dramatic and unexpected improvement, others had more restricted potential, but even the most disabled – "Bill" – has made some gains and is now supported in an appropriate setting close to his family. The last story, that of "Doug", demonstrates vividly the situation before the advent of the Program: the lack of appropriate management and resources, the enormous wastage of inappropriate resources, and the hopeless situation facing families and clients.
Names and identifying details have been changed to protect client confidentiality.

"George"

George, an immigrant from Iran, was a 45-year-old widower when he suffered head wounds in a brawl at work. Four rehabilitation hospitals rejected him because of his limited potential for functional gain, the high demands on nursing staff and the lack of a clear discharge plan. Four months after his injury, he finally moved from acute hospital to an insurance-sponsored rehabilitation facility that caters for compensable clients. WorkCover subsequently rejected his claim, but he remained in their facility, sponsored by a public hospital, until other arrangements could be made.

Referral to the Program six months post injury

When George was referred to the ABI: STR Program, six months after his injury, he could walk about ten metres with the help of one person, but he was otherwise dependent on a wheelchair, which he could not propel himself. He needed help with balance and standing. He could neither shower nor toilet himself, with anxiety compounding his disabilities in these areas. His severe communication and cognitive deficits prevented him from accurately communicating even basic needs to his carers. He could not concentrate on any sort of assessment for more than thirty minutes.

The initial goals were to enable him to sit unsupported and transfer with minimal assistance, become more independent in showering and dressing, participate in simple tasks around the house, and communicate his basic needs.

The Program approved funding of $13,500 for three months to provide George with physiotherapy, occupational therapy, neuropsychology, speech therapy, social work and attendant care. The attendant care enabled George to return home to the care of his young adult children, and he attended a local rehabilitation centre as an outpatient.

After a year on the Program

Some thirteen months later (nineteen months after the injury), while George still needed a lot of help, he had made marked gains in a number of areas. The Program was providing 43 hours per week of attendant care plus one session each of physiotherapy and hydrotherapy, and a day centre program. His children were studying at university, and attendant care was provided at a level that ensured that this could continue.

He could now walk up to one hundred metres outdoors with supervision and a new ankle splint, and could walk short distances unsupervised. The aim was for him to walk further and in the community without supervision. He could transfer independently and stand alone for short periods, with therapy now attempting to extend this period. He was greeting people and could carry on some simple conversation.

George could concentrate for short periods, could plan and organise simple tasks, and could manage a range of personal care and everyday living tasks, but he carried these out only some of the time and a further aim of therapy was to make this more consistent. The poor motivation caused by his brain injury was a limiting factor: he needed much encouragement and prompting, and his family still tended to do too much for him. Nevertheless, he was initiating tasks such as turning up the heating system, going to toilet, or making a cup of tea.

Although the support George receives from the Program has not decreased in financial terms, remaining at around $54,000 per annum, the type of services purchased have changed. High levels of allied health services have been replaced by a lower level of therapy, with attendant care accounting for around $50,000. At his next six monthly review, he is likely to move towards a maintenance level of services.

Benefits of the Program

Without the support of the Program, George would have had a very much lesser quality of life. He would most likely have been placed in a nursing home a few months after his injury. Alternatively, his very devoted family may have taken him home, but he would have remained bed- or chair-ridden and totally dependent, and this would have been at enormous cost not only to George, but to the family socially, personally and in terms of their careers and work prospects.

"Bill"

Bill had been a highly successful young graduate working with a city firm when, at the age of 29 years, he was admitted to the intensive care ward of a Melbourne hospital with multi-organ failure. His problems included intracerebral haemorrhage, bilateral pneumothorax, aspiration pneumonia, respiratory failure, sepsis, infections at multiple sites, acute renal failure, rhabdomyolosis and hepatitis. The cause could not be identified, but he sustained severe hypoxic brain damage.

Referral to the Program five months post injury

Five months after his initial illness, Bill was referred to the ABI: STR Program. Like George, he was a "bed blocker", still in the acute hospital and rejected by various rehabilitation hospitals because his potential for functional gain was limited, there was no clear discharge plan, and his condition placed high demands on nursing staff. While he had been medically stable for some time, he had no active movement in his limbs, limited trunk control, and needed head support when sitting, though he had some active head movement when tracking and scanning. The case management assessment described him as being in a "twilight coma". He responded to familiar people, particularly parents, close friends, and some regular staff, and to pain.

Bill's long-term prognosis for neurological recovery was poor. At best, with extensive physiotherapy, it was considered that he might regain some semi-purposeful movement in his limbs and be able to utter a few words and communicate simple needs. It was clear that he would require long-term institutional care. Without therapy, there was the potential for further loss of joint range and muscle length due to increasing hypertonia.

It was agreed by all, including his parents, that Bill needed full time nursing care and he was admitted to a nursing home, with the Program purchasing extra attendant care to supplement the care provided by the nursing home, and therapies to assess his capacity for recovery. While his family lived in rural Victoria, they requested that he be cared for in Melbourne, where his friends could visit and become part of his therapy. His family have continued to visit him regularly.

The Program approved physiotherapy, speech therapy, occupational therapy, dietetics, music therapy, massage therapy and attendant care at a cost of $41,000 per annum, plus additional equipment at $8,500.

Three months later (eight months after the initial illness), the Program approved funding for Botulinum Toxin injections to loosen his spasticity, with additional physiotherapy and equipment to ensure the best outcome from the Botulinum Toxin. The recommendation for further equipment included hand splints, wheelchair, and a tilt table. The total cost additional was $24,000, with the Botulinum Toxin for nine months accounting for $8,000 of this.

After six months on the Program

A further three months on (eleven months since the initial illness) Bill had shown some clear signs of alertness and awareness of his environment and was consistently responding to instruction and when people spoke to him, although he had no speech himself. The Program approved an additional $800 for therapy to train him and his parents in the use of a communication device and switching devices.

Feeding had been a consistent problem. This had been via a gastrostomy tube throughout Bill's recovery, but chronic problems with reflux and vomiting caused aspiration pneumonia, which resulted in numerous readmissions to acute care. A different type of gastrostomy tube was inserted a year after the illness, and the Program funded a monthly review by a dietitian at $30 per hour.

Home stays

Despite his problems, by fifteen months after the illness Bill had returned to his family home to stay overnight and once for a weekend. In that environment, he appeared to be hearing and understanding almost everything, responding appropriately with smiling, laughing, crying, groaning, and using long blinks to indicate yes.

These home stays were also achieved with the support of the Program, which provided funding to equip a bus owned by the nursing home so that it could transport Bill, and for a nurse attendant for three trips over six months.

Long-term support in a nursing home

Now in the third year after his initial illness, Bill remains in the nursing home, with his parent as his care coordinator. Baclofen is being trialed to improve his spasticity, and the Program supports a trip home every six to eight weeks.

Bill will continue to need attendant care plus a low level of therapy in the long term to maintain his level of function. His swallowing is showing improvement and it is possible that, with further speech therapy, he may be able to eat orally again. He is being encouraged to participate actively in his movement program, which is focussing on developing rolling and sitting and controlled flexion and extension. Attendant care workers under the supervision of therapists are providing two hours of occupational therapy tasks and fourteen hours of physiotherapy tasks per week. Other ongoing costs are related to maintaining the equipment used in his therapy and care.

The goals continue to concentrate on improving his physical, nutritional, emotional, and cognitive well being and maximising potential for movement. In the area of communication, therapy is concentrating on developing his capacity to respond and interact with others using long blinks and smiling. In particular, it is hoped that he may achieve a consistent yes/no response through eye contact and head turning. Therapists have established a daily diary for all visitors and carers to develop a map of his daily patterns of response and awareness.

Benefits of the Program

Bill's improvement has been slow and the gains made, small. Without the Program, however, even these small gains would probably have been denied him. His nursing care needs would have increased as contractures developed, and he may have remained for years in acute hospital, unable to be managed by any nursing home.

The Program has clearly improved Bill's quality of life. While he will continue to require nursing home care, therapy has enabled him to move beyond his twilight coma, to develop elements of movement and independence, interact with his environment and sustain some social milieu. One evening, he was taken by friends (who have been regular visitors and part of therapy program) to the pub they had all frequented at university. They had a rollicking night out and reported that all his responses were totally appropriate. They even fed him some alcohol – by mouth.

The Program has also lessened the burden of Bill's illness on his parents, enabling them to participate actively in his limited improvement, to feel that all that could be done is being done, and minimising the impact on their own health status, particularly their mental health status.

"Zena"

Zena was skate-boarding when she lost control and crashed into a wall, sustaining serious head injuries. She was eleven years old at the time, a bright, outgoing girl about to enter grade 6 at school. The family was already under considerable stress, as Zena's mother had died suddenly about six months earlier, and her father was managing as the sole parent. Without compensation, Zena did not have access to the only paediatric rehabilitation unit in the State, which is part of a compensation-funded rehabilitation centre. Another rehabilitation hospital rejected her on the grounds that the environment, among young adults with brain injury, was highly unsuitable.

Referral to the Program four months post injury

Zena was accepted by the ABI: STR Program almost four months after the accident. At this stage, she was interacting with hospital staff as well as her father, and could read and process information. She carried out small personal tasks such as combing hair and brushing teeth, and asked to be changed when appropriate. She could move around bed and lift herself into sitting position and, with the help of two people, could stand to be moved from bed to wheelchair. She was becoming less self-focussed and more interested in those around her.

The Program approved the purchase of inpatient services within the rehabilitation centre to the cost of $91,000 for six months. The goal was to send Zena home, with the support of an attendant care program, and integrate her back into school.

A further three months on (seven months post-accident), she was able to walk between two staff, and there were plans for her to return to school in term four.

The rehabilitation centre set very specific goals for the next twelve months. They aimed to bring Zena's comprehension of and participation in everyday conversation to a functional level, helping her to know when communication failed and to repair the problem. They also aimed to improve her ability to follow information in the classroom, with the support of an integration aid, and to bring her reading skills to the level where she could read concrete novels, short stories, and newspaper articles.

In physical skills, the aims were for her to transfer independently and walk fifty metres independently on even surfaces, indoors and outdoors, using the wheelchair for longer distances and recreation. Her left arm had little movement, and she was also being helped to manage this

Return to home and school

About ten months after the accident, and after the first six months supported by the Program, another six month rehabilitation plan was approved for Zena at a cost of $12,000. The Youth and Family Services Program agreed to provide attendant care, at an annual cost of $35,000, home modifications were carried out, and Zena returned home to live with her father. She returned part time to school with outpatient therapy part time. After the summer holidays, she moved on to secondary school with her peer group.

When she moved home, she was able to walk short distances with supervision, though she remained largely dependent on a wheelchair and she had no active control of her left arm. She still had impaired problem solving and memory, and problems comprehending both speech and writing. She required help with personal and leisure activities, and she neglected her left side.

The Program approved another $16,000 for outpatient therapy, plus $1,700 to cover school integration for six months.

Transfer to generic services

Six months later, some seventeen months after the accident, Zena was discharged from the rehabilitation centre and from the ABI: STR Program, with Youth and Family Services responsible for her long-term support at home and in school.

Though still limited, she had made considerable progress. With a knee brace and supervision, but without help, she was walking safely over smooth surfaces, although she needed some help on uneven surfaces, stairs, and in busy environments and her self-monitoring was not reliable enough to ensure her safety in the community. While she still had no function in her left hand, she could move independently in and out of bed and chairs.

Zena’s communication and cognition had continued to improve. She was aware of environmental sounds but needed help understanding their meaning, and help to recognise when she was being spoken to. Her comprehension of brief, concrete information was good, though she had difficulty with abstract material. She needed frequent reminders to maintain the quality and expressiveness of her voice. Her knowledge of words and vocabulary had improved, and she could concentrate for 10 minutes and use a diary and a timetable, although she needed prompting when a task demanded problem-solving skills.

She was managing to groom, dry and dress herself independently, although she needed help with showering, and with buttons and shoelaces, and she could use the toilet independently. She was preparing simple snacks and completing basic domestic routines safely and with minimal help, and she could handle money in shops. She was participating in the classroom, with a full-time integration aid, and had started to look at appropriate leisure and recreation activity

Benefits of the Program

Without the ABI: STR Program, Zena would possibly have remained in the acute sector. Her age would have made transfer to an aged care nursing home difficult. It is unlikely that her father could have taken her home. Her early attention-seeking behaviour would probably have been reinforced by staff seeking to comfort her, and this would have seen her diverge significantly, in behavioural terms, from her peers and friends. She would have remained a highly dependent and institutionalised child.

Instead Zena, although disabled, is living at home and supported by a mainstream program in a normal school, with her peer group. The Program supported her in an age-appropriate environment while her father moved through a period of great grief and stress, with the recent death of his wife compounded by his daughter's injury. When he was able to cope, the Program together with Youth and Family Services was able to assist him to have Zena at home.

"Muni"

Muni, at the age of twenty-two, lived with her family in a small flat. Born in Lebanon, she spoke and understood only basic English. Her history provides an example of how the ABI: STR Program can intervene for a limited time to enable a client to attain a level of ability where they can access generic services.

The day after Muni's first child was born, she had a severe intracerebral haemorrhage – a stroke. She required acute care for three months, undergoing a number of medical and surgical procedures. She was then moved to an acute rehabilitation hospital, where she progressed slowly. Four months later, she was discharged home with an intensive domiciliary rehabilitation program offering physiotherapy, occupational therapy, speech therapy, medical supervision and case management. She was retained on this program for longer than the scheduled eight weeks to help her to develop the physical capacity to manage her baby. Her husband had given up work to care for the baby, and he became her primary carer when she returned home. He was committed to caring for her.

When the domiciliary program finished, she was admitted with her husband and baby to a public Mother and Baby Unit for intensive parenting education, to improve the interaction between mother and baby, develop a routine for the baby, and encourage Muni to take over some of parenting from her husband.

Referral to the Program

The stay in the Mother and Baby Unit exhausted Muni's mainstream therapy options. Yet she needed ongoing intensive therapy in the home to continue to make gains. She was referred to the ABI: STR Program almost a year after her stroke.

She was walking independently without an aid on even surfaces, inside and outside, for about two hundred metres. She was, however, very slow, she lacked confidence walking in unfamiliar environments, and her gait pattern was poor. She could transfer independently, but needed help to get up and down from floor to play with her baby. It was very difficult for her to push the pram.

She showered and dressed herself with some distant supervision and some help in adjusting the taps and getting in and out of the shower. She could groom and toilet herself, and could eat independently provided someone helped her to cut up her food. She was starting to do simple tasks in the kitchen and around the house.

It was difficult to assess her cognitive ability, as she had severe problems both understanding speech and expressing herself, compounded by her limited English. She could follow simple commands. She worked well with a communication book, but she and husband were not using this outside the treatment situation. It was difficult for her to initiate tasks and she was reluctant to tackle unfamiliar things. Planning, sequencing and thought processing were all impaired, so that she could not be left to care for the baby alone.

She learnt best in her home environment, and the ABI: STR Program approved $14,000 to purchase home-based physiotherapy, occupational therapy and speech therapy, with forty hours of attendant care a week to give her husband some respite and the chance to explore re-employment options. The funding covered three months of services, with review scheduled after that time.

Supporting mothering skills

Therapy aimed to improve her balance and considerably extend her walking; to enable her to manage a wider range of domestic tasks independently, including preparing formula and food for the baby; to increase her vocabulary and use of speech; and to help her to participate in social activity of her choice, such as a play group.

A number of aims were specifically related to her care of her baby: to enable her to get up and down off the floor so she could play with the baby, to help her communicate effectively with the baby, and to enable them to access community together.

This last aim generated the next request to the Program. The pram Muni had bought before her stroke, though fine for the baby, was impossible for Muni to manage. The Program approved finance, and mother, baby and the occupational therapist went shopping to buy a pram/pusher that supports Muni and enables her to walk her child without help.

Muni will probably continue to receive support from the Program until she is able to move on to mainstream support services or manage without these services. The Program has considerably enhanced her independence, increased her parenting ability, and enhanced the chances that her marriage will survive in the long term.

“Helen”

Helen lived on the family property with her husband, the two of them farming it in partnership. At the age of 45, a bee sting precipitated a severe anaphylactic shock reaction with marked anoxia, and Helen sustained severe brain damage.

Two months after the incident, she was admitted to a private rehabilitation unit. She was agitated, anxious and confused, grabbing at people’s wrists and clothing. She spoke rapidly in whispered words and short phrases which were largely unintelligible, and she soon became totally mute. She did not follow verbal commands. Her agitation prevented assessment of her swallowing, and she was fed by a gastrostomy tube. She initiated nothing and fatigued easily, being distractible, perseverative, and sometimes physically aggressive. She nevertheless recognised familiar people, particularly old friends, and had some recall of long-past events. She was bedfast, with her extreme physical rigidity making it impossible even for her to be sat out of bed.

After some time in the private rehabilitation hospital, WorkCover denied Helen’s claim; however the hospital found some special funding to support her for a limited time, in conjunction with the limited funding available through her private health insurance.

Referral to the Program nine months post injury

When this funding ceased, Helen was referred to the STR: ABI Program. By this stage, nine months after the initial incident, she was more responsive and could make simple requests, but still perseverated a lot and fatigued easily. Listeners needed to be patient and encourage her to repeat phrases when she could not be understood. Physically, she was dependent in all areas, confined to a wheelchair and needing help with showering, dressing, and transferring. She remained agitated and very difficult to manage.

Contractures affected her left side and Baclofen was recommended to address this. Private health insurance covered a Baclofen pump, at $10,000, but not the drug itself. This was funded by the Program at a cost of around $5,000 per year.

With the Baclofen and substantial other support from the Program, Helen returned home to her farm and family about twelve months after the initial brain injury. The Program provided 20 hours of attendant care per week, bathroom renovations, aids and equipment (standing frame, shower and commode chair, wheelchair, continence aids, recliner chair etc), and ongoing therapy at the outpatient department of the local base hospital. It was also necessary to provide transport to get her to the local hospital for therapy.

After seven months on the Program

Seven months later (seventeen months after the initial incident), Helen's gait was unsteady, but she could get out of a chair and walk across a room. Her speech was still perseverative, but she could answer questions and interact with her family. With the Baclofen loosening her legs, her contractures were being stretched out by the physiotherapist. She was feeding herself, was largely continent, and was taking an interest in the farm again.

Without the Program, Baclofen would have been entirely beyond reach and attendant care not available. Helen would have undoubtedly have been placed in a nursing home. Therapy under the Program is likely to continue for at least another six months and attendant care, probably for the rest of her life, will enable Helen to remain at home with her family.

"Mark"

Mark's case illustrates the dramatic and unexpected recovery that can sometimes occur despite catastrophic injury and a very pessimistic prognosis. A young man with some intellectual handicap, Mark was the victim of an assault. He was admitted to hospital with hypoxic brain damage.

A month later, he was grimacing in response to pain but did not respond to verbal commands, nor follow movement or orientate to sound. There was no active response to any stimuli. His prognosis was considered poor. He was rejected by two rehabilitation hospitals. His mother, however, a very strong advocate for him, was strongly opposed to having him placed in a nursing home.

Referral to the Program three months post injury

Three months after the injury, Mark was referred to the ABI: STR Program. He had made only minimal gains in swallowing and communication, and remained totally dependent. He could obey simple commands and indicate "yes" with head movement, but he was not speaking at all. He was starting to manage semi-solid food by mouth, under supervision, but most of his feeding was by gastrostomy tube. He was incontinent, with condom drainage, and he needed turning every half hour to prevent pressure areas.

He was moved into the rehabilitation ward within the acute hospital. The level of therapy needed, however, could not be met by the ward, and the Program provided top-up funding at a level of $64,000 per annum for rehabilitation and $5,000 per annum for specialist case coordination. This covered five hours of speech therapy, three hours of occupational therapy, and five hours of physiotherapy, with a physiotherapy aide for a further six hours per week.

After four months on the Program

Four months later (seven months post injury), the improvement was dramatic. Mark was using an electric wheelchair, communicating verbally with ease, and feeding himself independently using a normal knife and fork. He was making progress in all activities of daily living. He was continent, responding well to verbal cuing, motivated to participate in therapy, and learning to manage pivot transfers with the help of one person.

Return to his home town

He remained in the rehabilitation ward for a further nine months. Sixteen months after his initial injury, he was discharged and returned to temporary accommodation at a hostel in the area he had formerly lived, with attendant care and local case management support through the ABI: STR Program.

Old issues resurfaced. He began drinking and this led to mood swings and depression. Regular therapy has been difficult to organise, and Mark's abilities continue to fluctuate markedly depending on tiredness and substance abuse.

Benefits of the Program

Without the ABI STR Program, Mark would have been discharged from hospital to a nursing home, with no further therapy. The support of the Program has enabled him to return to his own community, to semi-independent living and a semblance of his former life, and to reach a level of independence such that he could make his own decisions and some lifestyle choices.

Before the ABI: STR Program: "Doug"

Doug's story illustrates the difficulties faced by people with severe brain injury and their families before the advent of the ABI: STR Program.

Doug was a teenager when a failed suicide attempt left him with severe anoxic brain damage. He was admitted to a large metropolitan hospital, where he remained. His need for acute care passed, but no nursing home would take him because they could not provide the level of care he required. No rehabilitation hospital would accept him because it appeared that few functional gains were possible and no discharge destination could be guaranteed. No other alternative could be found.

Whose responsibility?

Despite his family's constant agitation, Doug remained in the acute hospital for two and a half years before he came to the attention of the Department. He was now 20 years old. Twelve months of bureaucratic correspondence followed, in the attempt to resolve which service should take responsibility for Doug's long-term care. It was finally agreed that he could move to a rehabilitation hospital for assessment and development of a program of care, with the Acute Care Division of the Department covering the $480 per day cost. Disability Services agreed to pay $5,000 in one-off costs, including modifications to a wheelchair, to maximise Doug's level of independent functioning and therefore minimise long-term recurrent costs for the Department. He would then move to a community hospital near his home.

The community hospital in question had, in fact, expressed its willingness to accommodate Doug much earlier in this saga, provided that ongoing funds were guaranteed to cover the cost of the care he required. The hospital was already caring for another young head-injured patient, so had experience in the area. The outcome finally achieved included a Commonwealth agreement to provide the nursing home benefit to support this arrangement.

This left a gap of about $180 per day between the Commonwealth benefit and the estimated costs of Doug's care, including physiotherapy. It was agreed that top-up funding would be negotiated between the Acute Health and Disability Services divisions, and that Disability Services would develop a proposal for the long-term care and funding of patients with similar problems to Doug.

The move from acute hospital after three years

When Doug moved to the rehabilitation hospital, he had spent more than three years in an acute hospital bed. The rehabilitation hospital initiated some slow-stream rehabilitation, and Doug made minor gains before moving to nursing home care in the local community hospital. With this move, overall case responsibility for Doug was transferred to the Departmental staff in the local Region, and a service agreement was undertaken between the Regional Office and the community hospital. Achieving this involved twelve months of complex negotiations back and forth between Departmental Divisions responsible for particular services for which Doug was potentially eligible, the Commonwealth Government, the community hospital and his family. The agreement, in addition to covering the recurrent costs of care, needed to cover such things as the cost of a special bed and equipment such as boom hoists, weighing attachments, and body slings. It involved reams of paper and hundreds of hours of salaried time.

Transfer to the pilot ABI: STR Program

Doug's case provided one of the case studies which led to the establishment of the ABI: STR Program, and he became one of the Program's first clients. When the pilot Program was established, his service agreement was transferred back from the Region to Disability Services. At that stage, top-up payments were $240 per day.

He has now been in the care of the community hospital for some three years. The one marked change in his condition is that he is much more restful than when first admitted. The Program has funded intrathecal Baclofen, an ongoing program of twice-weekly physiotherapy and massage, a quarterly occupational therapy program, and 70 hours per week of specialist nursing attendant care. A pressure care bed has reduced the skin ulceration he experiences despite the extra nursing care. He does not speak, and is fed by gastrostomy tube. Doug is, however, living close to his family, in a stable, caring and appropriate environment.

This improved situation is also cost-effective. Where an acute hospital bed costs around $600-700 per day, the current costs are about $140 per day met by the Commonwealth, plus $240 per day met by the State.

Future Directions and Challenges

Coordination with broad rehabilitation service development

The continuing development of the ABI: STR Program will occur in the context of the implementation, currently underway, of the 1997 report *Rehabilitation into the 21st Century: A Vision for Victoria* (see page 12). The Program addresses the need identified in that document to develop highly specialised, condition-specific expertise on a cross-regional basis to provide post-acute and complex care for low-incidence complex conditions and an outreach program of support and consultation to local practitioners.

Rehabilitation into the 21st Century also identified the need for regionally-based rehabilitation consultancy and liaison services. It is envisaged that these services will be staffed by rehabilitation staff in acute and other facilities throughout the health region as part of their rehabilitation role. The services will:

- provide the point of initial access to rehabilitation services, and the point of long-term contact, review and re-entry to the system;
- integrate services across the health region; and
- ensure that referral to rehabilitation is timely and appropriate, and that all appropriate patients are referred.

The ABI: STR Program will need to work cooperatively with these rehabilitation consultancy and liaison services to ensure the support of ABI: STR clients in their own localities. The services will help to ensure the ongoing link between specialist service provision and the generic mainstream service system which is basic to the Program.

Coordination with mainstream programs

If the ABI: STR Program is to continue to provide the specialist ongoing rehabilitation services required by clients, mainstream program areas will need to provide greater access to their programs. For example, the most costly single service purchased by the ABI: STR Program is attendant care and supported accommodation. This service, currently limited in availability, is provided by other Departmental services for younger people with disabilities living in the community.

Development of community-based supported accommodation

The capacity to provide supported accommodation in local communities for clients with disability resulting from severe ABI will be critical to the long-term viability of the ABI: STR Program. As discussed above (see page 26), community-based accommodation options for clients with high support needs remain very limited. Without appropriate accommodation options, the Program will become blocked by the need to provide high-cost, individually provided accommodation for its clients.

In addition to providing 24-hour care, accommodation for Program clients must enable the therapy, behavioural and daily living requirements of these people to be met. Facilities of this type urgently need to be established through the metropolitan area and in some provincial centres to enable clients of the ABI: STR Program to be sustained in the community over the longer-term in a cost-effective manner. The Westgarth Facility provides appropriate community-based accommodation for five people with severe ABI, and it will serve as a model for further similar facilities.

ABI: STR Program clients do not need exclusive accommodation. Their care needs are not dissimilar from others requiring long-term accommodation as a result of injury or disability.

The Program will therefore not only have to act as advocate to the State department responsible for the provision of public housing, but will need to work closely with TAC, WorkCover, insurance companies and government to ensure that appropriate accommodation services are developed.

Furthermore, the Program's current success in enabling many younger clients with high levels of dependency to return home, usually to the care of parents, means that in the longer term there will be an increased need for supportive care for older clients whose parents have aged beyond the point at which they can provide that care. Currently 21 Program clients are living at home with parents or other family. It can be anticipated that a significant proportion of these will require permanent community accommodation within the next decade, as their carers age or other factors such as family stress or breakdown intervene. Counselling and transitional support services will be needed to enable both the adult child and the parents to manage this separation appropriately.

The numbers requiring permanent community accommodation will increase considerably as more clients move through the Program to the maintenance phase. While the Program does not currently record the age of primary carers, this would enable some projection of requirements for long-term specialised community-based accommodation.

Regular respite will be essential to support families caring for clients at home, if such care is to be sustained. The need for respite will increase as parents or other primary carers age. As well as providing breaks for carers, respite will help clients and their carers to adjust to the transition to community care when it becomes necessary. The State respite care program and the ABI: STR Program will need to develop specific services appropriate to each individual.

Development of case management

The take-up rate for services provided through the ABI: STR Program is directly related to the case management available to locate potential Program clients and develop care plans for them. This factor limited the Program's ability to provide services in 1997/98.

The Program will need to develop, support and resource case management capacity across the State, including:

- specific ABI case management services, whether the Program contract purchases such services or purchases them on an individual client and/or local area basis; and
- mainstream case management services. If the Program is, where possible, to devolve responsibility for its clients to the local area, it will need to ensure that these services are resourced and trained to take on ABI: STR Program clients requiring long-term maintenance.

Best practice standards

The ABI: STR Program has the capacity to become a world leader in the development of best practice standards for management of clients with severe ABI. The Program will work with the specialist inpatient units, and in particular the two metropolitan units, to:

- establish best practice clinical, long-term care, and administrative guidelines for people with severe ABI, and set quality assurance standards based on those pathways;
- ensure, through the Program's purchasing responsibility, that these guidelines are implemented throughout the service system and delivery of services is regularly reviewed against the quality standards.

The ABI: STR Program auspice organisation is required under its contract to produce, in consultation with the ABI: STR Committee, an annual Best Practice Report, to inform rehabilitation and case management practitioners about the types of rehabilitation programs and interventions that have improved client outcomes and have achieved this in a cost-effective manner. The report is required to:

- identify approaches and models of best practice that have resulted in improved outcomes for clients by evaluating the rehabilitation care plans developed for individual clients, comparing actual outcomes for clients with those identified in the original care plans; and
- undertake a cost analysis, identifying any reduction in long-term support costs that have resulted from the Program.

In implementing best practice guidelines, the Program will need to work with accreditation services such as CHASP (Community Health Accreditation Service Program) and EQuIP (the quality assurance program of the Australian Council for Health Care Standards), to ensure that accreditation services for hospitals, community health and other services providers take account of the requirements of the ABI: STR Program.

Education and awareness

Professional education and awareness must be a central focus of the ABI: STR Program.

To ensure that all eligible clients are referred as early as possible, the Program needs to establish and maintain a high profile within hospitals and relevant agencies across the State. The referral pathway must be clear and well known, and the clinical and economic effectiveness of early intervention understood.

The Program also needs to ensure that all those providing services to ABI: STR clients understand their clients' needs and are supported in addressing those needs. This will increasingly involve the use of teleconferencing, particularly in rural areas, and development of the Program will need to take account of this.

Monitoring growth and demand

As awareness and up-take of the ABI: STR Program increases, the Program will need to monitor growth in demand versus supply, taking note of changing patterns of epidemiology and health and medical services. It will need to identify areas where new service types, additional resources or new services arrangements may be appropriate and necessary.

It will become clear, as the Program continues to develop, whether there is a capacity within the existing budget and Program structure to extend some services to people who have the potential to benefit although they do not meet all the eligibility criteria (eg. people with pre-existing ABI for whom a newly emerging treatment may be of benefit).

Any argument for new services or increased resources will need to be firmly grounded in demonstrated cost-effectiveness. The Program will need to develop a partnership with the Department that allows for mutual monitoring of the Program's effectiveness, to ensure that future changes in the health care system take account of the needs of current and future ABI: STR Program clients, and that the Program is supported to remain effective.

Recommendations of the Head Injury Impact Project (1991)

The main issues addressed in the Head Injury Services Plan have been grouped into eight sections, with recommendations.

1. Early Intervention

This requires that people who have been head-injured should be thoroughly assessed and linked up with appropriate services from the early stages of recovery onwards.

Acute care of head injury in public hospitals should ensure high-quality management, review and follow-up for all patients. In order to improve linkage of clients and services, particularly on leaving hospital, case coordinators should be appointed for people with non-compensable injuries, to complement those already employed by the Transport Accident Commission and the Victorian Accident Rehabilitation Council.

Rehabilitation should be accessible to all in need, with added provision for country and children's services. Slow-stream facilities should be expanded, and the Office of Psychiatric Services should maintain its current ABD service commitments.

It is recommended that:

1.1 Within 1 year, Health Department Victoria (HDV) encourage the organisation of specialised acute care head injury services in major metropolitan public hospitals with neurosurgical units, so that all patients of these hospitals with head injury will be reviewed by a head injury team.

1.2 Within 2 years, major metropolitan and regional base hospitals provide for all other hospitals case consultancy and assistance with development and acceptance of protocols for acute head injury management and follow-up.

1.3 Within 2 years, head injury rehabilitation services be available to each HDV region from existing agencies; agencies to be designated within 1 year.

1.4 Within 1 year, there be expansion of and improved access to paediatric neuro-rehabilitation services in two metropolitan centres, with catchments extending east and west to the state borders and including clients with compensable and non-compensable injuries.

1.5 Within 18 months, there be consolidation and further development of slow-stream facilities with an additional 10-12 beds for patients able to benefit from more than 6 months of rehabilitation; in the first instance, in a unit located in a metropolitan region but accepting patients from throughout Victoria.

1.6 The Office of Psychiatric Services preserve and continue to develop existing services for people with brain trauma and mental illness (especially where there are related behavioural problems), including inpatient and outpatient services, counselling and secondary consultancy to staff of other agencies throughout the state.

1.7 Within 1 year, five positions of case coordinator be funded through appropriate agencies, with the role of

- *locating people with non-compensable head injury while they are public hospital patients;*
- *liaising with all parties to ensure that services are arranged in accordance with clients' requirements;*
- *following through post-hospital to ensure the client is linked up with appropriate community services; and*
- *remaining in contact with clients for as long as necessary to facilitate individual service planning.*

2. Access

People with ABD should not continue to be excluded from appropriate services, and government funding should be made conditional on this. In addition, linkage projects can help to reintegrate people with ABD into the community. The special needs of country residents deserve more recognition.

Community awareness of ABD must be raised, and information made more readily available to various groups. People from ethnic communities need particular help to obtain services and information.

Transport is frequently problematic for people with ABD and their families, especially in country areas. Some assistance is available but improvements are needed.

It is recommended that:

2.1 *All contractual agreements with government-funded generic and specialist service delivery agencies should ensure access for people with ABD to appropriate programs.*

2.2 *Information packages be produced over 3 years for*
  - people (children and adults) with ABD,
  - their families and carers,
  - service providers including teachers; and
  - the general public;
  and be translated into community languages other than English.

2.3 *Information on ABD issues and services be available on a statewide basis through the Disabled Persons Information Bureau.*

2.4 *Headway Victoria continue to be funded as an information service and for advocacy on behalf of people with unmet needs.*

2.5 *A media campaign be conducted over 2 years to raise awareness of ABD in the community.*

2.6 *Community Services Victoria (CSV) fund projects to assist people with ABD to participate in the community by establishing links with individuals, organisations and general community services.*

2.7 *The recommendations contained in the transport report, "An Action Plan for Victoria" be addressed - particularly those concerning country residents.*

2.8 *HDV upgrade assistance with travel for health care and associated costs by country patients with ABD and their families.*

2.9 *A joint Action on Disability in Ethnic Communities (ADEC), Headway Victoria pilot project be undertaken to provide brokerage, advocacy and information for people from non-English speaking backgrounds with ABD, and their families, to assist their integration into mainstream services.*

2.10 *Health and welfare staff use interpreters more frequently and effectively with people from non English-speaking backgrounds.*

2.11 *HDV regional offices develop and apply a strategy to ease the problem of recruiting specialised rehabilitation staff or country positions.*

3. **Training**

Better staff training in ABD is an essential part of the strategy for making services more available, accessible and of better quality. Basic courses for service providers, in-service training for a wide range of staff, and continuing education for general practitioners, should all give attention to ABD.

It is recommended that:

3.1 *Within 2 years, curricula of basic training courses for workers in the health and community services fields include an ABD component, especially for nursing and medical undergraduates, social workers and recreation workers.*

3.2 *Tertiary institutions develop and publicise courses in ABD, targeted particularly at teachers, Office of Corrections staff, recreation workers, personnel managers and other types of service provider.*

3.3 *Specialist service delivery agencies be recognised and funded as appropriate to provide in-service training for a wide range of staff (including accommodation, respite and personal care workers) in the management of clients with ABD and their families.*

3.4 *Within 1 year, selected tertiary institutions offer more extended training in counselling of people with ABD and their families.*

3.5 *Continuing education of general medical practitioners include recognition, management and appropriate referral of the diversity of problems of people with ABD in the community.*

3.6 *Within 6 months, relevant government departments and other agencies designate a member of staff as a key contact point on head injury issues, including the co-ordination of training of staff within their organisation.*

4. Accommodation and Support Services

This emerged as a crucial area for improvement. Recommendations are designed to give people with ABD access to more community-based accommodation options, including existing public housing program and the accommodation program of CSV-funded agencies. Access to respite care needs expansion through extra Commonwealth funding and CSV-funded agencies.

Home-based care and support for carers should be expanded. Aids, equipment and home modifications are an integral part of such services. Also, clients with ABD and their families may require counselling.

It is recommended that:

4.1 *Community-based accommodation options be developed by establishing people with ABD as a target group in housing programs – particularly CSV's Supported Accommodation Assistance Program (SAAF) and the Department of Planning and Housing (DPH)'s Group Housing Program and Rooming House Program.*

4.2 *DPH ensure access of people with ABD to public housing stock through all its services.*

4.3 *Within 1 year, a small-scale supported living arrangement for dependent young adults with ABD be piloted and evaluated.*

4.4 *CSV and the Commonwealth Department of Community Services and Health negotiate with appropriate funded agencies to include people with ABD in existing accommodation and respite programs.*

4.5 *Additional funding be provided for short-term and emergency respite care in Commonwealth-funded accommodation.*

4.6 *CSV improve the funding and supply of aids, equipment and home modifications to people with ABD, especially children.*

4.7 *The Home and Community Care (HACC) program be expanded to provide in-home respite care, personal care and other in-home support for people with ABD and their carers*

4.8 *Existing agencies improve the availability and quality of counselling services for people with ABD - with special attention given to family members during the acute stage, including when the patient is in coma, and to both client and family when the client has returned to the community.*

5. Daily Activity and Learning

Assistance with return to work is required by many people who have had a head injury. Vocational rehabilitation agencies should offer training, counselling, work trials and on-the-job support, as well as follow-up.

Education staff should be involved in service planning for individual students, thus improving co-ordination of education and other service sectors. The need for more resources for students with ABD within the Integration Program should be reviewed.

Recreation services are emerging as very important for people with ABD, both during rehabilitation and, especially for the more severely disabled, in the longer term. This should be acknowledged through well-planned programs with trained staff, and through funding.

It is recommended that:

5.1 *Vocational rehabilitation agencies, including the Commonwealth Rehabilitation Service, improve access and develop services for ABD clients, viz.*
  - *specialised skill training programs;*
  - *vocational counselling and training;*
  - *co-ordination of work trials (in previous job) and work experience (in new job) to assist gradual return to work; and*
  - *vocational attendants;*

and follow up employees after placement.

5.2 *Support be provided by vocational rehabilitation agencies to employers and fellow employees to assist people with ABD remain in employment.*

5.3 *The Ministry of Education and Training review the adequacy of resources for students with ABD at primary and post-primary levels through its integration program, and at post-secondary level through TAFE provisions for students with disabilities.*

5.4 *Education staff participate in service planning for children and young adults who are clients of specialist rehabilitation and support agencies.*

5.5 *Rehabilitation agencies recognise recreation as an integral part of the client's rehabilitation program.*

5.6 *Recreation programs be supported by funding agencies, and provided by appropriately trained staff.*

6. Equity

One third of people with more severe brain injury are non-compensable and have restricted access to rehabilitation, accommodation and long-term support services. To overcome these disadvantages, eligibility for state-based rehabilitation and support services should be widened, by legislation where necessary. Funding also will be required for purchase of services not otherwise available to non-compensable clients in the public sector.

It is recommended that:

6.1 *Legislative changes be sought to broaden eligibility for existing rehabilitation, disability and support services funded by compensation agencies set up by State legislation, so that those services can be made available to any person in need.*

6.2 *Funding mechanisms be created to allow for relevant state government agencies to pay non-government service providers for provision of services to people with non-compensable injuries, where existing public facilities cannot provide the necessary services.*

7. **Community Protection**

Behavioural problems can be associated with brain injury. A minority of ABD clients exhibit violent or aggressive behaviour, and workers who encounter this in the course of service provision or caring should have access to specialist consultancy and support services.

An effective system is required to ensure that the driving licence is revoked in all cases where the person with ABD is no longer able to drive a motor vehicle safely.

It is recommended that:

7.1 *Service providers and carers encountering people with brain injury who behave violently or aggressively be provided with specialist support services in planning appropriate management strategies.*

72 *Roads Corporation investigate ways (including legislative) of ensuring that people who have sustained a head injury are assessed for fitness to drive before resuming, and that the licence to drive is revoked in all cases of unfitness.*

8. **Planning, Implementation and Monitoring**

A number of recommendations in the report may take some time to implement; others could be actioned quite readily, including some at little or no additional cost. Some recommendations anticipate further planning and development by the responsible agencies. Overall progress should be monitored by an implementation Task Force involving representatives of relevant government departments/agencies, service providers and consumers. Access to data on ABD needs to be improved.

It is recommended that:

8.1 *An Implementation Task Force, comprising key government departments/agencies and including service provider and consumer representation, be established for:*

- *oversight of immediate implementation;*
- *co-ordination of planning and service development in the main agencies, and*
- *evaluation of progress,*

and that it report to the Ministers for Health and Community Services within 12 months of the adoption of this report.

8.2 *Within 6 months, a working party be set up to identify standardised recording and classification of injuries and disabilities, including their severity.*

8.3 *Within 1 year, a working party be set up to further investigate ethical and legal constraints on access to case records and statistical data in health and related fields for bonafide research purposes.*

8.4 *A data base be created to collect and collate information in an ongoing prospective survey of ABD.*

8.5 *Agencies and programs which are the subject of recommendations in this report produce annual statistics showing (a) the numbers of people who have received their services, according to either diagnosis or disability type (sufficient to identify clients with head injury or ABD, and (b) the costs generated by the provision of such services.*

Projects Funded under MICHI (1992-1993)

Project: **Counselling Course in ABD**
Organisation: **Bouverie Family Therapy Centre**
Bouverie Family Therapy Centre was funded to design and conduct a counselling course in ABD, targeted to a broad range of workers including general practitioners, hospital social workers and generic community services workers with particular priority being given to lone and rural worker and those whose clients came from a non-English speaking background. The course was to run over a 25 week period for a half day per week and aimed to broaden the community base and availability of ABD counselling skills across the State. It was envisaged that these trained counsellors would assist sufferers and families to come to terms with the injury, thus supporting family unity, and provide services with understanding and strategies for dealing with challenging behaviour, thereby increasing access of the head injured to appropriate and effective services.

MICHI support - $59,421 over 3 years.

Project: **Consultancy re Accommodation Documentation Project**
Organisation: **MICHI/Brotherhood of St Laurence**
The aim of this project was to gain an appreciation of the processes involved in establishing small-scale accommodation services for young people with ABD thus enabling the development of future like services to be streamlined and the responsibilities of the various players clarified. A consultant was employed to document the establishment of 4 selected units – 3 ABD specified and 1 mixed – and her report was to be distributed to funding bodies and form the basis of a manual to assist others in appropriate service development.
MICHI support - $15,000

Project: **Consultancy re Accommodation Options for People with ABD**
with **Intensive Support Needs**
Organisation: **MICHI/Brotherhood of St Laurence**
MICHI identified a number of people with severe and multiple disabilities in Victorian hospitals who were medically stable and no longer require an acute bed at the cost of approximately $150,000 pa, and who could remain inappropriately in acute beds for years, given that existing care options such as geriatric nursing homes and attendant care services with a ceiling of 34 hours per week were not funded to provide the intensive support required. This consultancy aimed to develop a systematic response in programmatic terms to the accommodation/care needs of this small but expensive target group and to devise a standardised assessment tool.
MICHI support - $25,000

Project: **Information Packages on ABD**
Organisation: **Headway Victoria**
This one-year project concerned developing a comprehensive range of appropriate written information about management issues and service options, targeting carers, the head injured, and generic service providers. Publications described what a head injury is, how it affects the individual's and carer's life and what services are available from the post-acute stage. The project included an assessment of display and distribution points.
MICHI support - up to $165,000

Project: **Training Strategy and Educational Modules**
Organisation: **Social Biology Resource Centre**
The project aimed to facilitate understanding of head injury issues and skills in management of people with head injuries by professionals and other workers in a wide variety of generic services. A core training unit was developed for general use, and supplemented for selected professional and generic workers to cater for the needs of people from different organisations coming into contact with people with head injuries at different times in their working lives for different reasons, and having varying roles and responsibilities in regard to these people. It was seen as important that issues raised by head injury be made as relevant as possible for people in different occupational roles.
MICHI support - $130,000

Project: **Educational Video**
Organisation: **Social Biology Resource Centre**
This project produced an educational video on the psychosocial impact of head injury on those with a head injury and their carers/family. It aimed to facilitate understanding of the support and management needs of people with head injuries and their families as they adapt to the immediate and long-term effects of head injury on their lives. The video could be used in a variety of settings, to support the training program discussed above, provide focus for sessions in tertiary and in-service training and raise the awareness of the family and friends of a sufferer.

MICHI support - $20,000 for script development only

Project: **Directory of Accommodation with Support**
Organisation: **ARBIAS**
This project enabled the production and distribution of a directory of accommodation services for people with ABD where support is provided. The directory included contact names and addresses of the key agencies in the ABD field.
MICHI support - $8,500

Project: **Case Management**
A three-year pilot post-acute case management service involving five case coordinator positions was established. A project officer was employed to design and document the service and ensure an evaluation strategy was in place.
MICHI support - In principle $915,000

Project: **Minor Head Injury Research Proposal**
This three-year project involved Western Hospital and Geelong Hospital in the identification of a sub-population of people with minor head injury who should be offered review at a later date.

ABI: STR Program Performance Indicators

1. Total budget for the financial year
2. Total committed funds for the financial year
3. Total spent funds to date
4. Total surplus/deficit funds for the previous financial year
5. Number of clients received or receiving services from the ABI: STR Program
6. Number of clients currently receiving funding from the ABI: STR Program
7. Average age of clients currently receiving services
8. Age spread of current clients receiving services, including the age of the youngest and the oldest
9. Percentage of clients currently receiving services who have a current care plan
10. Numbers of clients receiving services at:

    a) home
    b) aged care nursing homes/extended care centre
    c) community-based shared accommodation
    d) hospital
11. Clients' residence when their ABI: STR Program support began, and their current residence
12. Types of services being provided, including the total budget commitment for each service and the percentage of the total budget
13. Average cost of services per client
14. Location of each client by area name and postcode

Equipment Expenditure

15. Total funds transferred to the ABI: STR Equipment Co-ordinator for the financial year
16. Total committed funds to purchase equipment through the ABI Equipment Co-ordinator for the financial year
17. Total surplus/deficit funds for previous the financial year

Documents developed by the ABI: STR Program

The following Program guideline, policy and Program development documents have been produced:

- The ABI Slow to Recover (Slow-Stream Rehabilitation / Long-Term Maintenance Guidelines) (To be revised and updated by new auspice agency)
- Guidelines on the purchase of specialised equipment for people with moderate to severe ABI through St Vincent's Hospital PADP Program
- Care Plan Proforma
- Application and Consent form
- Declaration of Compensation form
- Fees Policy for private medical and allied health ABI specialists.

Future document of the Program will include:

- the Annual Report of the Program documenting numbers of clients, types of injury, services purchased, trends, an analysis of outcomes for Program clients, and data on expenditure
- an annual Best Practice Report, to inform rehabilitation and case management practitioners working with clients with severe ABI about the types of rehabilitation programs and interventions that have resulted in improved client outcomes achieved in a cost-effective manner.