LIVING WELL

COMMUNITY LIVING SOLUTIONS FOR VICTORIANS WITH A DISABILITY WHO HAVE SIGNIFICANT HEALTH NEEDS

ATTENDANT CARE COALITION

JULY 1999

SECTION 1 - THE PROJECT

1.1 Background to the project

The past 15 years has seen a steady increase in the numbers of people with disabilities living in the community. The advent of attendant care programs and other community based support services has meant that many people have moved from institutional settings whilst others have been prevented from becoming institutionalised. State and Federal Governments through this period have supported these moves both at the policy level and through the funding of community based support services.

There is however still a significant number of people with disabilities who remain living in institutional settings because of high support needs associated with health issues. At the same time other people with disabilities end up in the acute health system when their needs could be better met in more community based settings.

1.2 Objectives of the project

The project sought to address these issues by:

- investigating the factors that contribute to the inappropriate hospitalisation and institutionalisation of people with high support needs in relation to their health care needs;
- developing alternative models of care, programs and support services that will enable these people to be supported outside of the acute health system;
- working with people with disabilities, service providers and policy makers to implement these alternative models.

1.3 Methodology

1.3.1 Reference group

The project was overseen by a reference group comprising people with disabilities and key people from the disability sector representing advocacy organisations, service providers and statutory bodies (see Appendix 1).

The role of the reference group was to identify issues, resource the workers through the provision of advice and information and to assist in developing the project recommendations.

The group met at intervals of six to eight weeks throughout the course of the project.

1.3.2 Drawing on previous work

The work of disability advocacy organisations in particular the Attendant Care Coalition (ACC), Headway Victoria, the Australian Ventilator Users Network (AVUN), Action Resource Network (ARN) and the Disability Resources Centre provided insight into health and support issues experienced by people with disabilities.

Research from previous projects provided useful information on particular aspects of the project. Some of these projects include:

- the Victorian Respiratory Support Service project on long term accommodation and support options for ventilator users (1998)
- Victorian Spinal Cord Service project on the treatment and recurrence of pressure ulcers amongst people with spinal cord injury (1998)
- a national research project examining the placement of younger people with a disability in nursing homes (1994-95).

1.3.3 Statistical/Quantitative Data Collection

Data was obtained from the Australian Bureau of Statistics (ABS) and other sources to document the number and location of younger people living in nursing homes in Victoria.

Sample admission data was obtained from the Austin and Repatriation Medical Centre (A&RMC) relating to common causes of acute admissions for people with disabilities.

Information was sought from the Royal District Nursing Service (RDNS) on common health problems experienced by people with disabilities using their service.

1.3.4 Examination of models

Consultations were conducted with personnel from a wide range of organisations including government departments, hospitals and community based services. Health and support issues and the existing models were identified and examined.

An Internet and literature search provided information on interstate and overseas models.

1.3.5 Input from people with disabilities

Input came from the seven people with a disability who served on the reference group. Some of these have high health related support needs as a result of their disability and provided the consumer perspective first hand. Other people with disabilities on the reference group had an insight and understanding gained from many years of disability advocacy.

In addition the project workers consulted with a number of individuals who have high support and/or complex care needs.

Further input from people with disabilities came from the work done previously by organisations controlled by people with disabilities (e.g. Housing Resource and Support Service, Attendant Care Action Group), other research projects and related consultations.

SECTION 2 - FINDINGS

2.1 Previous work

The Attendant Care Coalition has identified the inadequate resourcing of community based supports in Victoria, in particular the In Home Accommodation Support Program (IHAS) which provides a maximum of 34 hours of attendant care support per week to people with physical disabilities.

The lack of supports over this 34 hour limit has resulted in health problems for many people. Ill health has been caused by infrequency of fluid intake and toileting resulting in bladder and bowel infections. For many people the limitation on attendant care hours has resulted in infrequency of eating as there is not enough hours to support meal preparation or assistance with eating during day time hours. This again has caused ongoing health problems.

Many people whose needs exceed the IHAS limit of 34 hours per week are referred to inappropriate nursing home accommodation when their needs could more adequately be met through the implementation of additional community based support programs.

Other people with disabilities are permanently living in acute hospitals because their support needs cannot presently be met outside of these settings. For example some people with respiratory difficulties that require ventilation are living in acute hospitals while others are at risk of institutionalisation. The needs of these people are discussed in the 1998 report “Accommodation and Support Services for Long Term Ventilation Users” which was prepared for the Victorian Respiratory Support Service based at the Austin and Repatriation Medical Centre. This report recommended the development of a range of accommodation and support services, including a specialist accommodation facility for people with complex care needs related to long-term ventilator dependency, access to existing residential and respite facilities and the development of a flexible in-home support model.

The work of Headway Victoria and other organisations working with people with acquired brain injury indicates that some people with acquired brain injuries are remaining in inappropriate hospital settings such as locked wards in psychiatric facilities because there are insufficient community based supports.

Similarly many people with spinal injuries frequently return to acute hospital settings because of preventable health problems. For example pressure sores can result in months, and in some cases years, of hospitalisation. This issue is examined in the report prepared for the Austin and Repatriation Medical Centre, “*Mapping the management of pressure ulcers in the Spinal Unit*” (Wellard,1998).

2.2 Younger people with disabilities living in nursing homes

2.2.1 The scope of the problem

The following statistics indicate the scope of the problem:

- Department of Community Services and Health report, *Review of the National Attendant Care Scheme - June 1990*, states that in 1986 there were "over 2,000 persons aged 16-64 with a severe physical disability ...receiving Commonwealth-funded nursing home care in Australia ".

- Australian Institute of Health and Welfare report, *Demand for disability support services in Australia: size, cost and growth*, indicates that the 1993 figure for people with disabilities living in 'health establishments' including 'hospitals, nursing homes and other institutions' was 'some 19,000' (Australia wide).

- 1995 Commonwealth government report, *A National Research Project Examining the Placement of Younger People with a Disability in Nursing Homes for the Aged,* indicated 2231 younger people in nursing homes in Australia (302 of these in Victoria) at that time. This figure was obtained from a questionnaire circulated to 55 % of nursing homes in Australia with a response rate of 77%.

- More accurate information obtained from ABS - 1996 census data on people in nursing homes showing those enumerated by age by sex by statistical local area in Victoria gives a total figure in 0-64 age group of 1152. The Australia wide figure is 4649. (See Appendix 3 for detailed tables.)

2.2.2 Diagnostic categories of younger people admitted to nursing homes

The Aged Care Assessment Service (ACAS) Minimum Data Set does not provide an age/diagnostic breakdown of people recommended for nursing home placement. However information obtained from the Peter James Centre ACAS, which services the Eastern Metropolitan region of Melbourne, and other people in the disability field in Victoria indicates that the main diagnostic categories of younger people recommended for nursing home placement include:

- multiple sclerosis (MS)
- acquired brain injury (ABI)
- physical disabilities, including spinal cord injury, cerebral palsy
- stroke
- early dementia
- Huntington's chorea
- Down's syndrome
- uncontrolled epilepsy
- psychiatric disability, eg. schizophrenia.

2.3 Health problems experienced by people with disabilities

2.3.1 Conditions which necessitate hospitalisation

Information gained from discussions with personnel from the A&RMC Spinal Unit and Hospital in the Home and physicians at the Alfred Hospital and A&RMC indicate frequent causes of admissions associated with disability include:

- pressure ulcers - people with spinal cord injury (SCI)
- chest infections & pneumonia - people with multiple sclerosis (MS), motor neurone disease (MND) and other neurological disorders, cystic fibrosis and severe epilepsy.
- urinary tract & other infections- people with SCI, MS, people requiring dialysis.

Statistical research

The statistical research was guided by the anecdotal information given by physicians. Data relating to inpatient episodes for patients with one or more specified disabilities and an admission diagnosis involving respiratory infections, pressure ulcers or urinary tract infections was obtained from patient admission records of the A&RMC. The data related to the 1997-98 financial year and was for patients aged between 0 and 64.

The extracted episodes were identified using the International Classification of Diseases (ICD) codes that are recorded for each inpatient episode to describe the diagnoses, complications and procedures related to the episode.

Costing data obtained from the A&RMC clinical costing system (Transition II) for each episode was used to determine the average bed day cost of treating each of the three specified conditions.

The primary findings are outlined below. Further information, including a breakdown of patient disabilities, appears in the tables in Appendix 4.

Respiratory Infections

There were 97 episodes involving respiratory infections. Of these respiratory infection was the principal cause of admission in 38 cases which accounted for 497 bed days. The average length of stay was 13 days with the range of stay being 1 to 55 days.

The average per day bed day cost of an episode with a principal diagnosis of respiratory infection was $756.

Urinary Tract Infections

Urinary tract infection was the principal cause of admission in 15 out of the 88 episodes recorded. These 15 cases accounted for 217 bed days with an average length of stay of 14.4 days and a range of stay from 2 to 63 days.

The average per day bed cost of an episode with a urinary tract infection as the principal cause of admission was $740.

Pressure Ulcers (Decubitus Ulcers)

Pressure ulcers were the principal cause of admission in 9 of the 26 episodes recorded. The 9 admissions for pressure ulcers accounted for 1126 bed days with an average length of stay of 125 days. The range of stay was 1 to 321 days.

The average per day bed cost for the 9 admissions caused by pressure ulcers was $595. The total cost for the resultant 1126 bed days was $669,970.

The majority of individuals with a principal diagnosis of pressure ulcer (6 out of 9) had a dual disability involving spinal cord injury.

Further insight into the role of pressure ulcers for people with spinal cord injury was obtained through examination of the research audit of admissions to the A&RMC's Spinal Unit.

In the audit period June 1992 to June 1997 there were 204 admissions for pressure ulcers with an average length of stay of 91 days. One hundred and forty individuals accounted for the 204 admissions with a range of admissions of 1-7 per person. The 204 admissions represented 15.8 % of the re-admissions to the unit (Wellard, 1998).

The data indicates that pressure ulcers frequently result in lengthy periods of hospitalisation. There can be no doubt this involves high cost in human terms for the individuals undergoing treatment.

In addition inpatient treatment for pressure ulcers results in considerable cost to the public hospital system. To illustrate this, the figures quoted from the Wellard audit of the spinal unit (above) are equivalent to at least ten acute beds being continuously occupied for the treatment of pressure ulcers for the five years of the audit period. Based on the A&RMC's current costings for the treatment of pressure ulcers this is effectively $2,171,750 per year for those five years.

2.3.2 Health problems in the community

Information obtained from discussions with RDNS field staff indicate that the main health issues for people living in the community are:

- skin problems including pressure ulcers
- bowel and bladder problems
    - infection (mainly related to catheterisation, fluid intake)
    - constipation (related to lack of mobility, fluid intake, diet).
- chest infections
- infections related to any invasive device (eg. catheter, gastrostomy, tracheostomy)
- nutrition problems (obesity, malnutrition)
- pain
- social and emotional problems, including depression.

As discussed in Section 2.1, the work of the ACC and other advocacy organisations indicates that the lack of appropriate and sufficient support programs is the predominant factor preventing people with disabilities from living in community based accommodation.

It also contributes to preventable health problems, often resulting in hospital admissions. This is supported by the sample data on hospital admissions and information obtained from RDNS discussed above.

The development and adequate resourcing of appropriate support programs will not only enable people with high support and complex care needs to live in the community but will also free beds in the acute hospital system.

2.4 Examination of existing models to address the problem

A range of approaches is used both in Australia and overseas to address the support needs of people with disabilities. This project highlighted a number of models or approaches to housing and support services that provide interesting insights for the development of services for people with high support and/or complex care needs in Victoria. The programs/models described below demonstrate some of the features of the supports needed by people with high support and/or complex care needs if they are to maintain a quality life in the community.

2.4.1 Co-ordination and brokerage

- ***Linkages Program***

Linkages programs cater for older people and younger people with disabilities who are at high risk of being inappropriately or prematurely admitted into residential care (hostel or nursing home). This may be due to a lack of services to assist them to continue to live in their own home or because they have complex care needs which cannot be met by existing Home and Community Care (HACC) services. Linkages programs develop individual care plans and broker funding to purchase required services from a range of service providers. This allows for more flexible service provision responsive to individual needs. However, as with the IHAS program, funding for Linkages does not keep pace with the need.

- ***Co-ordinated Care Trials***

The Co-ordinated Care Trials are a joint initiative by the Commonwealth and State governments aimed at improving delivery of health and community services to people with multiple service needs. They are intended to help people who require a complex mix of health and community services that are traditionally administered and allocated by different levels of government and different agencies within government. The trials mainly target older people however one trial in Sydney has explicitly included younger people with disabilities.

The main features of the trials are pooling of funds from Commonwealth and State funded programs and use of care co-ordinators to develop and monitor care plans.

Evaluation of the trials is still in progress, however the concept would seem to be worthy of investigation in relation to the development of appropriate community based health support services for people with high support and or complex care needs.

- ***Options Co-ordination Services, South Australia***

This is an example of comprehensive local client co-ordination. It consists of a statewide network of agencies working together to assist people with significant disabilities to access assistance, information and community services.

There are five Options Co-ordination agencies covering adults with acquired brain injury (ABI), children with a physical or neurological disability or ABI, adults with a physical or neurological disability, people with an intellectual disability, and people with a sensory disability.

The Options Co-ordination agencies are regionally based and co-located wherever possible to provide one local point of contact for consumers who may have a number of disabilities.

The Options Co-ordinators are case workers with a thorough knowledge of general and specific disabilities issues. They operate separately from service providers. This assists in making independent judgements about what services an individual needs and the best agency to provide the service.

Options Co-ordinators:

- provide consumers with information, counselling and support
- help consumers get what they want from the service system
- find or develop creative solutions to consumer needs
- help consumers enhance their personal and community networks
- provide access to assessment, resources and services
- purchase services on behalf of the consumer
- monitor and reviewing consumer needs

The Co-ordinator's role also includes:

- assessing the quality and responsiveness of services
- assisting in service planning and design
- participating in the development of service standards
- providing a contact point for the resolution of complaints.

- ***Extended Aged Care at Home (EACH) Packages***

These were established by the Commonwealth government to test whether it is possible to provide care in a person's own home at the level currently provided in a high care residential facility. Package providers have the role of ensuring that care recipients are provided with appropriate, flexible and co-ordinated support and assistance. Recipients must need care to a level that would be met only in a residential facility and must choose an EACH package over entry to a residential facility. Younger people are generally not considered eligible as support and accommodation of younger people with disabilities is a State responsibility.

The overall cost to the Commonwealth must be no different from that which would have been incurred if the recipient had been cared for in a high level care facility. The current rate in Victoria is $82.70 per day.

Operation of the packages is as follows:

1. The provider assigns a co-ordinator.
2. A documented care plan is drawn up. The provider can develop creative responses which may include the contracting of private individuals (with appropriate training and/or experience) or agencies.
3. On-going monitoring is provided.

A pilot project has been operating in SA through a non-government agency, Aged Care and Housing (ACH), since 1993. Ten nursing home beds have been converted into EACH packages. Three pilot projects have recently been funded in Victoria. Discussions with the co-ordinator of the ACH program suggest that the package on its own would be insufficient for people with very high support needs, however the concept has value for the development of appropriate support packages for people with high support and/or complex care needs.

- ***Housing Resource and Support Service (HR&SS)***

HR&SS is a community managed organisation for people with physical disabilities who wish to live independently in the community. Their roles include:

- acting as a broker in the provision of In Home Accommodation Support (IHAS) (see 2.4.2. below).

- assisting individuals to identify and secure suitable long-term housing and support options.

- lobbying for adequately resourced housing and support options for people with disabilities.

- acting as a conduit between the Office of Housing in relation to housing needs and Disability Services in relation to case management and IHAS needs. HR&SS ensures that the accommodation matches the support package by appropriate negotiations and facilitation.

2.4.2 Basic support programs

- ***In-Home Accommodation Support (IHAS)***

The IHAS program funds on-going attendant care support to people with disabilities living in the community "to carry out daily living activities which they are unable to perform for themselves due to functional limitations" (Health and Community Services, 1993:2). Funding is allocated to individual people with a disability who can choose from a list of approved service providers. The funding is then administered by the chosen provider, however service users retain the right to change service providers. The maximum number

of hours available through the program is 34 hours per week. The service is provided free of charge to the service user.

In order to be eligible for the scheme the person with a disability must be able to manage with the maximum 34 hours attendant care per week and other community or voluntary support. The stated priority target groups for the service are people with disabilities living in inappropriate accommodation such as acute care/rehabilitation facilities or nursing homes and people with high support needs who are living in the community and whose "current care arrangements are at risk of breakdown and who are at risk of admission to institutional care" (Health and Community Services, 1994:8). In reality people who have permanent accommodation, however inappropriate, rarely gain access to the scheme, particularly people living in nursing homes which receive Commonwealth government funding.

The IHAS program provides a good model for provision of in-home support, with funding being tied to the individual thus enabling more control by individual service users. The program allows for flexibility in the use of support hours and choice of service provider. However the funding for the program is insufficient to cater for the number of people requiring the service and many applicants have been waiting for service for several years. In addition, the maximum number of hours available through IHAS (34 hours per week) is insufficient for people with very high support needs (see Section 2.1). An increase in the maximum hours is needed to allow for higher support and health related needs.

2.4.3 Combined housing and support models

- ***AIDS Housing Action Group (AHAG) In-Home Support Program***

Jointly funded by State and Commonwealth governments, this program provides housing and support (up to 28 hours per week allocated per unit) for people living with HIV/AIDS who require regular or intensive supervision and/or support as a result of HIV/AIDS related conditions. Evaluation of the program carried out in 1998 indicated a high degree of satisfaction amongst service users. Key factors in this satisfaction seem to relate to the high level of consumer choice, control and participation, the supportive role of the co-ordinator and flexibility in the use of hours. A high degree of flexibility and significant level of support by the co-ordinator was possible in the early stages of the program before all the places were allocated. Availability of the co-ordinator and degree of flexibility will be affected by expansion of the program.

- ***Supported Housing Development Foundation/Transport Accident Commission (TAC) Housing Project***

The Supported Housing Development Foundation (SHDF), in conjunction with the TAC, has recently developed a community based housing project in Melbourne for people with acquired brain injury (ABI). The project provides individual town houses/units on one site with access to 24 hour support. The housing project accommodates four residents who wish to live independently and require support services to do this. The project provides four separate 2 bedroom units on one block, with 2 units owned by individual residents and 2 units rented to Office of Housing eligible tenants with ABI. The residents are accommodated in their own units, with shared support provided on-site. A self-contained room has been allocated as an office for support agency staff.

The shared care service model is a "hybrid of residential care and attendant care.... It has a fixed component for shared overnight care and supervision, and a variable component for individual programs." Residents "can share individual hours and 'bank' unused hours." (Transport Accident Commission, 1998)

- ***Community Living Options Project***

The Community Living Options Project (CLOP) is a supported accommodation facility. Five men who have high support needs associated with their acquired brain injuries have their own self contained unit. These units are arranged around a communal living area. The facility is staffed 24 hours a day by attendant carers who assist the residents with daily living activities. One resident has high health needs and these are addressed by twice daily visits from RDNS. Before moving into CLOP the men had been long term residents of psychiatric and rehabilitation facilities. The CLOP facility was purpose built by the Office of Housing and the accommodation support is funded by Disability Services branch of the Department of Human Services.

2.4.4 Support programs related to health support and/or complex care needs

- ***Disability Health Care Support Service (DHCSS), South Australia***

The DHCSS has a consultative, educative, supervisory and advisory role within disability service provider agencies. Its model of care is based on the principles of The Disability Services Act 1986. The service aims to respond to client needs in creative ways to ensure that the individual's health support needs are met in the least restrictive manner.

Under the model specialist disability nurses consult with the client and relevant others to develop a Health Care Plan. Care workers are then trained and credentialed to undertake the tasks detailed in the individual's Health Care Plan. There is periodic reassessment of the health needs of the client and re-credentialing of the care worker.

DHCSS credentialed care workers provide support to people with varying needs including those with complex care needs. Examples of tasks undertaken include oral and tracheal suctioning, bowel care and catheterisation. Support is provided in a variety of settings including early childhood services, schools, respite and supported accommodation, in the home and attending community activities.

- ***Family Choices Program and Home Care Service - Royal Children's Hospital (RCH)***

These programs provide support to children with very complex care needs, including ventilator dependency, enabling them to live at home. Attendant carers, employed by a service provider agency, are trained by RCH specialist nurses to work with individual children. Program management staff report that the significant elements in these programs are:

- children using the programs must be medically stable/must not have a rapidly deteriorating condition

- detailed assessment is provided by RCH staff (usually by a nurse with access to specialist advice)

- attendants are given intensive training for attendants to work with individual children

- a detailed care manual is provided so that the attendant carer is not placed in the position of having to make significant decisions about care

- continuity of care is provided through having a small group of attendants for each child, carefully selected with the need for commitment stressed. All attendants look after the child on a regular basis so their skills are maintained.

- appropriate support for attendants is provided by the employing agency and RCH. Attendants can contact RCH whenever needed 24 hours a day.

- careful monitoring is provided. Attendants' skills are reviewed if the care plan changes and on a regular basis (at least every six months).

Legal/duty of care issues are covered by the involvement of appropriate health professionals, appropriate documentation, i.e. a detailed care manual and on-going monitoring and re-assessment of attendants' skills.

2.4.5 In-home medical treatment

- ***Hospital in the Home (HIH)***

HIH provides acute treatment at home with the patient remaining under the control of the hospital. There is a great variance in the way HIH units operate across the state. Some use only hospital staff while others purchase what is needed from community services such as attendant care (e.g. extra attendant care overnight, sleepovers), local GP, nursing, physiotherapy. HIH can provide care for people who live alone however this is more difficult both practically and legally. Examples of care include maintenance therapy for people with MS when they have exacerbation of symptoms, intravenous antibiotic treatment for chest and other infections, and complex wound care.

2.4.6 Highlights of overseas models of interest

- ***Canada***

Canada has a long history of debating and trialing individualised funding. The Roeher Institute, a Canadian 'think tank', has promoted the concept for twenty years. In practical terms the Individualised Funding-Service Brokerage model originated in British Columbia in the late 1970s amongst a group of parents of children with disabilities who were moving their children out of institutional care. A number of pilot programs have applied the model since then. The model "identifies on an individual basis what resources a person needs from society to achieve community living...using a service broker hired by the person" (Bain, 1999:9).

- ***United Kingdom***

The Community Care (Direct Payments) Act of 1996 has given local authorities through their social services department the power to make cash payments to individuals instead of arranging community care services for them. This enables the person with a disability to arrange and manage the support services they need, for example to employ a personal assistant. Direct payments cannot be used to purchase residential care.

To qualify for direct payments the applicant has to be capable of managing the payments and arranging the services they require or have someone acting on their behalf who organises the services and handles the payments. Applicants are assessed against national eligibility criteria.

Direct payments do not effect eligibility for social security entitlements and recipients are also eligible for the Independent Living (1993) Fund. This fund works in partnership with Local Authorities to enable jointly funded packages of care aimed at providing the opportunity of independent living to people with severe disabilities who are at risk of requiring residential care. Payments from this fund are also made directly to the individual and are to help cover the cost of personal and/or domestic assistance.

- ***USA***

In the United States services vary greatly from state to state. There are a number of "self determination" projects in various states which are testing the principle of individualised funding. These are funded jointly by the State governments and the Robert Johnston Woods Foundation.

The results of some research indicates that self managed care is more cost efficient and maintains the individual's health better than agency provided personal care (Mattison, Prince, Manley and Whiteneck, 1995).

Medicaid Waivers

Medicaid is a state administered program funded jointly by the federal and state government which helps pay for medical services for eligible low income earners. Medicaid waivers allow states to forgo typical Medicaid eligibility criteria and to provide services.

The Model Medicaid Waiver can provide case management, respite care, in some cases home modifications and skilled nursing in the home to people who would otherwise require hospitalisation

The Home and Community Medicaid Waiver provides similar (and some additional) services but is limited to particular categories of people such as those with developmental disabilities and technology dependent.

- ***Sweden***

In Sweden the legislation *LASS 1994* guarantees funding to individuals (up to age 64) who require a minimum of 20 hours per week personal assistance. Payments are made either directly to the consumer or, if they prefer, to the service provider.

The Stockholm Co-operative for Independent Living (STIL) is a user co-operative that enables people to organise their own assistants. Membership of the co-operative is dependent on the individual attending a "supervisor's course". On completion the member can hire, train and manage all the aspects of using a personal assistant. "Buddies" are available to provide peer support to STIL's new members if required.

Many of STIL's members have an intellectual disability and where necessary a legal representative, often a family member acts as the "supervisor". Where this support is absent STIL will appoint, with the individual's consent, a member to act as a "deputy supervisor". In turn the deputy supervisor is supervised by STIL staff who are also users of personal assistants.

2.4.7 Key features of the models/programs

The programs described above demonstrate a number of features that are important in the development of appropriate services for people with high support and/or complex care needs.

- *Individualised services, choice and control*

The models used in the co-ordination and brokerage, support and housing/support programs allow for a more individualised approach, with support services tailored to meet individual needs. Services are provided in a place of the individual's choice and service users have a significant degree of control over their support services.

- *Shared resources*

Totally individualised services provide people with disabilities with the optimal choice and control over their own lives. This should ideally be the goal of all service provision.

However, in the light of limited resources, carefully planned sharing of resources may be necessary in some situations. It is essential that, if shared use of resources is being considered, models be developed around the needs of individuals. Individuals should not be 'slotted in' to pre-existing models that do not suit their needs. Planning should involve looking at people's choices, needs and all the possible ways of meeting their needs, in conjunction with consideration of the available resources.

The combined housing and support models described in 2.4.3 demonstrate ways of establishing housing and support options that allow for sharing of support services while still retaining individual space and a greater degree of choice about lifestyle than is possible in institutional settings or traditional group homes.

- *Community based complex care*

The Disability Health Care Support Service and the RCH Family Choices and Home Care programs demonstrate that complex care can be safely provided in community based settings by appropriately trained and supported non-medical staff. Hospital in the Home services illustrate that some acute medical care can also be provided appropriately at home thereby reducing the number and length of hospital admissions.

- *Co-operation between funding bodies*

The Aids Housing Action Group program, which is jointly funded by the Commonwealth and Victorian governments, and the Co-ordinated Care Trials, which pool resources from a number of different funding sources demonstrate the possibility of significant co-operation between the different levels of government. Such co-operation will be vital if younger people with disabilities who have high support and/or complex care needs are to be enabled to live in the community.

The work of the Housing Resource and Support Service demonstrates the importance of liaison and co-operation between intra-departmental sections/divisions. HR&SS acts as a conduit between the Office of Housing (in relation to housing needs) and Disability Services (in relation to case management and support needs) thereby ensuring that the accommodation matches the support package.

SECTION 3 - ADDRESSING THE NEEDS: A PACKAGE OF SUPPORT

As can be seen from the project findings discussed in Section 2, people with disabilities experience a range of health issues which result in differing support needs. There is clearly no single solution to meet these needs. A range of supports is required.

People with significant health and/or complex care needs require a package of support. Significant elements of such a package are discussed below. Different individuals will require different elements of the package to meet their particular support needs and their needs may change over time.

3.1 Elements of the Support Package

3.1.1 Co-ordination and brokerage

Locating, accessing and co-ordinating the range of services they need can be a difficult, time consuming and sometimes impossible task for people with high support needs. Co-ordination and brokerage services are required to assist people with complex care/health needs to locate and access the range of services they need to live in the community. The main functions of such a service would be:

- assessment of individuals' needs and available resources
- planning for an individualised service response
- linking individuals to services and supports
- brokerage of funds for services
- monitoring the provision of services.

3.1.2 Adequate support to meet basic daily needs

The IHAS program, described in Section 2.4.2, provides a good model for provision of in-home support, with funding being tied to the individual thus enabling more control by individual service users. The program allows for flexibility in the use of support hours and choice of service provider.

However there are very lengthy waiting periods to obtain IHAS services. Many people with significant health and/or complex care needs are either unable to obtain IHAS services or require more extensive support than is currently provided through IHAS or other in-home support programs. Often this 'short-fall' in support contributes to the health problems experienced or results in inappropriate placement in a nursing home or other institutional setting.

An urgent increase in the funds available to in-home support programs is required to enable:

- more people to access in-home support

- an increase in the maximum number of support hours available through in-home support programs such as IHAS to allow for higher support and health related needs.

3.1.3 Access to care 24 hours a day

As well as needing a higher number of support hours people with significant health and/or complex care needs are likely to require support across the full 24 hours of the day. While for most people this will not mean having active attention for 24 hours, it does mean that they require **access** to care throughout the day and night. This includes:

- planned regular out-of-hours care - e.g. night-time turning, assistance with toileting.

- unplanned out-of-hours care which requires attention although not an immediate response.

- emergency out-of-hours care which requires an immediate response.

Further research is needed to determine how the out of hours service can best be provided, however possible options suggested through the project include:

- roving night-time care teams covering a defined geographical area. Such teams could provide routine scheduled care and respond to unexpected urgent care needs. These could be developed through existing services such as attendant care service providers or RDNS.

  The preventative care possible through such teams could significantly decrease the number and duration of hospital admissions related to conditions such as pressure ulcers.

- use of existing 24 hour community services, e.g. contracting out an emergency response service for people with disabilities to the ambulance service.

3.1.4 Complex care provided by appropriately trained non-nursing staff

As the models described in Section 2.4.4 demonstrate it is possible to meet a significant proportion of complex care needs through appropriately trained and supported non-nursing staff. The Disability Health Support Service in South Australia provides a positive example of how such a service can enhance the opportunities for people with disabilities who have significant health needs to receive the support they need in community settings.

The significant elements in this type of service are:

- detailed assessment by appropriate health professionals (usually by nurse with access to specialist advice).
- credentialing - intensive training provided for attendants by a disability nurse. Attendants are credentialed to work with specific individuals.
- detailed care manual provided so that the attendant is not placed in the position of having to make significant decisions about care.
- continuity of care.

- appropriate support from employing agency (attendant care service provider) and specialist training agency.
- monitoring - attendants' skills are reviewed if care changes and on regular basis (at least every six months).

Legal/duty of care issues are covered through:

- involvement of appropriate health professionals
- documentation i.e. detailed care manual
- on-going monitoring and re-assessment.

3.1.5. Routine nursing care where this level of expertise is required

There are a number of health related and/or complex care procedures traditionally considered nursing duties which can be safely carried out by appropriately trained and supervised non-nursing staff as discussed in 3.1.4 above. However many people with disabilities still require some nursing care to monitor their health, because of the instability of their condition or the degree of complexity of their care. As demonstrated by the South Australian Disability Health Support Service and the RCH Family Choices Program, the level of expertise required should be assessed on an individual basis rather than designating specific care tasks 'nursing' or 'non-nursing' duties.

Possible options for providing nursing care include:

- increased resources to RDNS
- a specialist disability health support service
- increased resources to existing specialist services eg Victorian Respiratory Support Service, Spinal Cord Injury Service.

3.1.6. Treatment for acute health episodes not requiring hospitalisation

As with the rest of the population, people with disabilities may experience acute health episodes that require hospitalisation. However there are some acute health episodes for which treatment could be provided safely and effectively in the community.

Alternatives to hospitalisation for acute care include:

- *Hospital in the Home (HIH)*

As outlined in Section 2.4.5, HIH provides acute treatment in the home with the patient remaining under the control of the hospital. HIH units across the state operate differently, with some providing their services solely from hospital staff, others purchasing what is needed from community services such as attendant care (e.g. extra attendant care overnight, sleepovers), local general practitioners, nursing, physiotherapy. Examples of care include maintenance therapy for people with MS when they have exacerbation of symptoms, intravenous antibiotic treatment for chest and other infections, and complex wound care.

- *Post-acute care*

Post-acute care is care provided at home in the transitional phase from acute illness to restored health. It provides treatment (e.g. physiotherapy), support (e.g. home help) and links to ongoing community support services.

Further research is required to establish the extent to which HIH and post-acute care services could be more effectively utilised to provide in-home medical treatment for people with disabilities thus preventing some acute hospital admissions. For example, it may be possible to treat some episodes of conditions such as respiratory and urinary tract infections (highlighted in Section 2.3) either partially or totally through HIH and/or post-acute care.

3.1.7. Aids and technology

Appropriate use of aids and technology can help to prevent health problems and provide more security, e.g. mattresses/beds that lessen the need for regular turning, personal alarm systems. In some cases appropriate use of aids and technology may reduce the need for 'people support'.

The IHAS program currently provides an example of linking provision of appropriate aids to funding for support services. When an applicant is accepted onto the program their service provider is allocated non-recurrent funds to, among other things, assist the consumer "to negotiate with their local PADP issuing centre to purchase adaptive equipment or organise minor house modifications which have been identified as part of their assessment" (Health and Community Services, 1993:12).

3.2 Possible funding models for implementing the package

3.2.1 Individualised funding

Individualised funding provides resources that are tailored to the needs and wishes of the individual and are attached to that person. This enables each individual to receive the supports and programs which suit them personally. Individualised funding is either paid directly to the person or goes through a broker.

"During the 1990's there has been growing interest in individualised funding and to a lesser extent service/support brokerage. Stakeholders from various worldwide disability movements believe that access to financial resources and independent planning assistance can empower people with disabilities to meet their needs in ways that reflect their unique strengths and personalities. Importantly, the onus is placed on services to respond to individuals, rather than expecting them to meet program criteria.

Individualised funding... is now recognised as a fundamental requirement for self determination and full citizenship. Proponents agree that individualised funding will enable people with disabilities to exercise real decision making and control in selecting required community services and supports, while at the same time ensuring that these same services and supports become more flexible, responsive and accountable."

The Attendant Care Coalition is currently developing a proposal for individualised funding. The following principles underpin that proposal:

Inclusion - individualised funding must work in conjunction with society changing and developing to include all people with disabilities into its activities.

Self determination - individualised funding is a means to the goal of self determination. It enables the person with a disability to make decisions about their own lives (or the people closest to them if it is not possible for the individual to do so).

Entitlement - each person with a disability receives the services and supports that they need.

Portability - individualised funding enables each person with a disability to allocate their funding to a service provider of their choice and to change their service provider should they desire to do so.

3.2.2 Sharing of resources

Individualised funding is the preferred option. In the light of limited resources we need to consider innovative ways to meet support needs. Strategies to make the best use of resources may involve some sharing or pooling of resources. However it is important that such strategies do not lead to the development of institutional facilities, services or practices. Creativity and innovation is needed in the design of buildings for shared residences, in the location and type/range of housing options and in the development of care models.

Some examples of or suggestions for sharing of resources encountered through this project include:

- roving night-time care teams, as discussed in Section 3.1.3. One study carried out in the UK indicated that mobile services can be provided as cost effectively as provision of the same services on one site (Bennett, Yates and Molyneux, 1996).

- use of existing community services infrastructure, such as the ambulance or fire brigade. One possible example of using existing infrastructures could be the contracting out of the provision of a roving night-time care service to the ambulance service, which has vehicles and personnel on duty 24 hours.

- housing and support co-operatives, with spot purchase of housing in a limited geographical area and pooling of support services to enable flexible use of resources (similar to the AHAG Housing and In-Home Support Service).

- town houses/units (no more than four) on one site with staff unit to enable 24 hour access to support. The community based housing project for people with acquired brain injury developed by the Supported Housing Development Foundation (SHDF), in conjunction with the TAC, provides an example of such sharing of resources (see Section 2.4.3).

- purpose built shared residence with a mixture of individual private space and some communal areas, e.g. the Community Living Options Program (see Section 2.4.3).

However it is important that any attempts to share or spread resources do not compromise people's quality of life. Key principles for the development of housing and support options were identified at the Disability Support and Housing Alliance forum, 'Living Independently: Access to Choice' held in February 1999. It was agreed at the forum that housing and support options for people with disabilities must:

- offer people with disabilities real choice about their housing type, where and with whom they live
- maximise flexibility to allow for changing needs related to life cycle and disability. This applies to both short-term and longer term life-style changes
- maximise control for the individual over the service/s they use
- ensure that supports are adequate and appropriate to meet the needs of each individual
- ensure dignity, privacy and confidentiality
- provide access to full participation in community life
- provide for separate administration of housing and support services in order to minimise control of service providers over people's lives and to minimise conflict of interest.

SECTION 4 – RECOMMENDATIONS

The following recommendations are made in line with the Objects, Principles and Objectives of the Disability Services Act 1991 (see Appendix 5).

In order to progress towards the development of the required package of supports, it is recommended:

1. That the ACC, in conjunction with the Disability Support and Housing Alliance, seek to work with DHS to further develop disability housing and support models for people with high support and/or complex care needs that:

- offer people with disabilities real choice about their housing type, where and with whom they live
- maximise flexibility and control for the individual
- ensure that supports are adequate and appropriate to meet the needs of each individual
- ensure dignity, privacy and confidentiality
- provide access to full participation in community life
- provide for separate administration of housing and support services in order to minimise control of service providers over people's lives and to minimise conflict of interest.

2. That the ACC, as a matter of priority, examine the possibility of working with appropriate agencies in one region to develop a proposal for an individualised funding/co-ordinated care trial. Funding from a number of sources would be pooled and individual plans developed and implemented for people taking part in the trial. Localised sharing of resources in order to make the most effective use of available resources could also be trialed, e.g. roving night-time care team. The possibility of linking this in to a Primary Health and Community Support (PHACS) demonstration project should be explored.

3. That the ACC work with the Victorian Spinal Cord Injury Development Group, the Victorian Respiratory Support Service and the Austin & Repatriation Medical Centre Hospital in the Home to trial the treatment of acute health episodes through Hospital in the Home, where appropriate assessment and consultation with the patient deem this suitable. It is further recommended that referral to Hospital in the Home be available not only through hospital admission, but also through the hospital outpatient system and directly from the community.

4. That DHS increase resources to in-home support and accommodation services to enable:
- more people to access the services thus addressing the urgent unmet needs, and;
- an increase in the maximum level of support available to allow for high support and complex care needs.

5. That DHS establish a specialist co-ordination and health support service for people with disabilities who have high support and/or complex care needs. Such a service would combine the co-ordination and brokerage roles as demonstrated in the South Australian Options Co-ordination service and the care planning and training roles as demonstrated

in the South Australian Disability Health Support Service (see Section 2.4.5).

6. That DHS develop and resource a range of urgently needed community based support services to enable people reliant on ventilatory support to live in the community. The services should include enhanced in-home support and respite, supported community based accommodation and respite. These options should be developed with ventilator users in an inclusive process and the resultant services should operate in line with the principles of the Disability Services Act 1991 and those listed in recommendation 1(above).

7. That the Commonwealth and State governments, as a matter of urgency, jointly investigate alternative options for younger people with disabilities living in nursing homes and develop a pilot project as recommended for Phase 2 of the National Research Project Examining the Placement of Younger People with a Disability in Nursing Homes for the Aged (see Section 1.3.2).

Conclusion

In the foreword to 'Acquired Brain Injury: Slow to Recover Program' the Minister for Health, Minister for Aged Care, Rob Knowles, describes the Acquired Brain Injury: Slow to Recover (ABI:STR) Program 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.....and it supports the families who provide long-term care" (Kirsner et al, 1999:iii).

These words could well apply to the package of supports sought for people with disabilities who have high support and/or complex care needs. Such a package is urgently required to ensure a quality of life for people with high support and/or complex care needs commensurate with that of other Victorian citizens.

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APPENDICES

Appendix 1

REFERENCE GROUP

Geoff Bell	Attendant Care Coalition (Management Committee)
Alan Blackwood	Transport Accident Commission
Victoria Chipperfield	Headway Victoria
Stephen Gianni	Office of the Public Advocate
Inez Gray	Attendant Care Coalition (Management Committee)
Lesley Hall	Attendant Care Coalition (Advocate)
Kath Hassall	Melbourne Citymission ABI Case Management Service
Greg Kidd	Paraquad Bridging the Gaps
Mary Lyttle	Residential Care Rights
John McInerny/ Elizabeth Watts	Supported Housing Development Foundation
Gillian Meldrum	Action Resource Network
Margaret Morrow	Attendant Care Coalition (Management Committee)
Phillip Ripper	Attendant Care Coalition (Executive Officer)
Joan Tierney *	Medical Practitioner
Natalie Tomas	Housing Resource and Support Service

* *Was unable to attend meetings but provided useful input and advice*

Appendix 2

ORGANISATIONS AND INDIVIDUALS CONTACTED IN RELATION TO THE RESEARCH

- ACT Disability, Aged and Care Advocacy Service (ADACAS). Australian Capital Territory
- Aged Care Assessment Service, Eastern Region
- Aged Care & Housing Service, South Australia
- Alfred Hospital
  Senior Physician
- Austin & Repatriation Medical Centre
  Casemix Co-ordinators, Health Infomation System
  Director,Clinical Services
  Director, Victorian Respiratory Support Service
  Consultant Physician
  Manager, Client Management Information System
  Manager, Perfomance Review & Evaluation
  Manager, Hospital in the Home
  Manager, Spinal Unit
- Australian Bureau of Statistics
- Australian Council on Rehabilitation of the Disabled (ACROD)
- Australian Institute of Health Welfare
- Australian Ventilator Users Network (AVUN)
- Commonwealth Department of Health and Aged Care (formerly the Dept. of Health and Family Services
- Community Services & Health Industry Training Board
- Department of Human Services
  In Home Accommodation Support Program
- Dr Joe Toscano, general practitioner who specialises in spinal cord injury
- Health Issues Centre
- Housing Resource & Support Service

- Health Services Commissioner
- International Ventilator Users Network
- La Trobe University (Lincoln Gerontology Centre)
- Linked Care – Hornsby Ku-ring-gai Coordinated Care Trial, NSW
- Melbourne Citymission
- Dr Jenny Morris, researcher, trainer and consultant on disability issues, United Kingdom
- National Association of Nursing Homes and Private Hospitals
- National Disability Advisory Council
- Paraplegic and Quadriplegic Association
  Community Nurse
- Dr Michael Montalto,Research Fellow, Centre for Health Program Evaluation/Director Hospital in the Home Unit Frankston Hospital
- Royal Children's Hospital
  Family Choices Program and Home Care Service
- Royal District Nursing Service
  Community & Disability Nurses
  Researcher
- Spastic Society of Victoria
  Health Educator
- St Vincent's Hospital
  Social Work Department
- Transport Accident Commission (TAC)
- WiN Support Services.

Appendix 3

STATISTICS - YOUNGER PEOPLE IN NURSING HOMES

Compiled from ABS data -1996 Census of Population and Housing

Table 1- Persons enumerated in Nursing Homes by State/Territory Age 0-64

State/Territory	Age 0-64
New South Wales	1766
Victoria	1152
Queensland	657
Western Australia	504
South Australia	337
Tasmania	151
Northern Territory	46
Australian Capitol Territory	36
Total	**4649**

Table 2- Persons enumerated in Nursing Homes by age by sex, Victoria.

Age	Male	Female	Persons
0-19	7	43	50
20-34	48	69	117
35-49	101	139	240
50-64	352	380	732
Total	**508**	**631**	**1139**

Table 3- Persons Enumerated in Nursing Homes - Age by Local Area, Victoria

Local area of Enumeration	Age 0-19	20-34	35-49	50-64	65 +	Total
Alpine (S)	0	0	0	0	17	17
Ararat (RC)	0	3	0	0	39	42
Ballarat (C)	0	0	8	27	534	569
Banyule (C)	0	0	3	27	449	479
Bass Coast (S)	0	0	3	3	77	83
Baw Baw (S)	0	0	0	3	73	76
Bayside (C)	3	3	0	15	569	590
Booroondara (C)	4	3	13	40	1189	1249
Brimbank (C)	0	0	3	20	324	347
Buloke (S)	0	0	0	0	18	18
Campaspe (S)	0	0	6	0	104	110
Cardinia (S)	0	0	7	9	80	96
Casey (C)	0	0	3	13	187	203
Central Goldfields (S)	0	0	0	0	39	39
Colac-Otway (S)	0	0	0	3	69	72
Corangamite (S)	0	3	3	0	66	72
Darebin (C)	0	3	6	21	540	570
Delatite (S)	0	3	0	0	84	87
East Gippsland (S)	0	3	0	11	147	161
Frankston (C)	0	3	16	18	238	275
Gannawarra (S)	3	0	0	3	44	50
Glen Eira (C)	0	0	3	18	495	516
Glenelg (S)	0	0	0	0	115	115
Golden Plains (S)	0	0	0	0	0	0
Greater Bendigo (C)	0	0	3	17	285	305
Greater Dandenong (C)	0	3	9	25	364	401
Greater Geelong (C)	3	0	11	29	822	865
Greater Shepparton (C)	0	0	6	11	163	180
Hepburn (S)	3	0	3	17	59	82
Hindmarsh (S)	0	0	0	0	40	40
Hobsons Bay (C)	0	0	0	9	214	223
Horsham (RC)	26	39	16	12	150	243
Hume (C)	0	0	3	6	67	76
Indigo (S)	0	0	4	19	171	194
Kingston (C)	0	3	4	29	674	710
Knox (C)	0	3	0	8	390	401
La Trobe (S)	0	3	3	4	151	161
Loddon (S)	0	0	0	0	0	0
Macedon Ranges (S)	0	0	0	0	56	56
Manningham (C)	0	0	0	8	182	190
Maribyrnong (C)	0	0	5	7	179	191
Maroondah (C)	0	6	19	31	402	458
Melbourne (C)			8	22	408	441

Melton (S)	0	0	0	0	30	30
Mildura (RC)	0	0	0	3	194	197
Mitchell (S)	0	0	0	0	59	59
Moira (S)	0	0	0	4	44	48
Monash (C)	0	6	11	25	459	501
Moonee Valley (C)	0	0	7	23	304	334
Moorabool (S)	0	3	0	0	28	31
Moreland (C)	0	3	7	27	536	573
Mornington Peninsula (S)	0	3	3	10	463	479
Mount Alexander (S)	0	0	0	7	99	106
Moyne (S)	0	0	0	0	61	61
Murrindindi (S)	0	0	0	0	40	40
Nillumbik (S)	0	0	3	3	56	62
Northern Grampians (S)	0	0	0	0	29	29
Port Phillip (C)	0	0	12	29	718	759
Pyrenees (S)	0	0	0	0	38	38
Queenscliffe (B)	5	0	0	3	56	64
South Gippsland (S)	0	0	0	6	134	140
Southern Grampians (S)	0	0	0	3	86	89
Stonnington (C)	3	3	10	24	412	452
Strathbogie (S)	0	0	0	6	63	69
Surf Coast (S)	0	0	0	0	23	23
Swan Hill (RC)	0	0	3	0	29	32
Towong (S)	0	0	0	0	0	0
Wangaratta (RC)	0	0	0	0	95	95
Warnambool (C)	0	0	3	0	41	44
Wellington (S)	0	0	0	10	102	112
West Wimmera (S)	0	0	0	0	10	10
Whitehorse (C)	0	3	3	22	659	687
Whittlesea (C)	0	3	0	10	183	196
Wodonga (RC)	0	0	0	0	58	58
Wyndham (C)	0	0	0	6	102	108
Yarra (C)	0	0	0	16	132	148
Yarra Ranges (S)	0	9	10	10	251	280
Yarriambiack (S)	0	0	0	0	37	37
TOTAL	50	117	240	732	15905	17044

Appendix 4

STATISTICS – AUSTIN & REPATRIATION MEDICAL CENTRE ACUTE ADMISSIONS

Episodes for patients with specified disabilities and specified conditions

The following tables show episodes for patients aged 0-64 with specified disabilities and specified conditions separated between 1 July 1997 and 30 June 1998.

Disability - refers to any of the specified disabilities recorded for a patient episiode. The specified disabilities were; Acquired Brain Injury (ABI), Cerebral Palsy (CP), Diabetes (DIAB) Epilepsy (EP), Intellectual Disability (ID), Muscular Dystrophy(MD) Poliomyelitis (POLIO), Psychiatric Disability (PSYCH), Spinal Cord Injury (SCI)

LOS - Length of stay

DRG - Diagnosis Related Grouping. Inpatient episodes are grouped into clinically similar groups based on the patient's diagnoses and/or procedures. DRGs form the basis of the inpatient casemix funding scheme.

Table 1 - Episodes where Decubitus Ulcers were the principal cause of admission

Disability	Age	LOS	DRG
SCI/PSYCH	60	143	019 Non-Acute Quadriplegia/Paraplegia, W or W/O O.R. Procedure
SCI/PSYCH	47	321	019 Non-Acute Quadriplegia/Paraplegia, W or W/O O.R. Procedure
SCI/EP	52	269	019 Non-Acute Quadriplegia/Paraplegia, W or W/O O.R. Procedure
MS	42	87	019 Non-Acute Quadriplegia/Paraplegia, W or W/O O.R. Procedure
SCI/PSYCH	41	61	019 Non-Acute Quadriplegia/Paraplegia, W or W/O O.R. Procedure
SCI/PSYCH	36	64	019 Non-Acute Quadriplegia/Paraplegia, W or W/O O.R. Procedure
ABI	41	1	507 Skin Ulcers Age<65
MS	49	54	019 Non-Acute Quadriplegia/Paraplegia, W or W/O O.R. Procedure
SCI/DIAB	60	126	502 Lower Limb W Other O.R. Procedure W Ulcer/Cellulitis

Table 2 - Episodes where Urinary Tract Infections were the principal cause of admission

Disability	Age	LOS	DRG
DIAB	59	8	576 Kidney & Urinary Tract Infections (Age<70 W CC) or (Age>69 W/O CC)
MS	42	11	576 Kidney & Urinary Tract Infections (Age<70 W CC) or (Age>69 W/O CC)
PSYCH	40	7	577 Kidney & Urinary Tract Infections Age<70 W/O CC
MS	44	8	019 Non-Acute Quadriplegia/Paraplegia, W or W/O O.R. Procedure
MS	44	15	556 Minor Bladder Procedures W CC
SCI/PSYCH	45	36	019 Non-Acute Quadriplegia/Paraplegia, W or W/O O.R. Procedure
MS	46	33	576 Kidney & Urinary Tract Infections (Age<70 W CC) or (Age>69 W/O CC)
PSYCH	27	8	577 Kidney & Urinary Tract Infections Age<70 W/O CC
MS	23	3	576 Kidney & Urinary Tract Infections (Age<70 W CC) or (Age>69 W/O CC)
EP/MS	23	6	576 Kidney & Urinary Tract Infections (Age<70 W CC) or (Age>69 W/O CC)
SCI/PSYCH	34	63	019 Non-Acute Quadriplegia/Paraplegia, W or W/O O.R. Procedure
PSYCH	45	2	577 Kidney & Urinary Tract Infections Age<70 W/O CC
EP	1	4	577 Kidney & Urinary Tract Infections Age<70 W/O CC
MS	59	10	576 Kidney & Urinary Tract Infections (Age<70 W CC) or (Age>69 W/O CC)
PSYCH	38	3	577 Kidney & Urinary Tract Infections Age<70 W/O CC

Table 3 - Episodes where Respiratory Infections were the principal cause of admission

Disability	Age	LOS	DRG
ABI/SCI/PSYCH	52	42	019 Non-Acute Quadriplegia/Paraplegia, W or W/O O.R. Procedure
ABI/CP	41	5	200 Other Respiratory Syst Diags (Age>64 W/O CC) or (Age<65 W CC)
PSYCH	58	6	133 Otitis Media & Uri Age>9 W CC
ABI/CP	31	4	134 Otitis Media & Uri Age>9 W/O CC
PSYCH	47	7	172 Respiratory Infections/Inflamns Age<55 W/O CC
MS	42	19	200 Other Respiratory Syst Diags (Age>64 W/O CC) or (Age<65 W CC)
MS	57	31	019 Non-Acute Quadriplegia/Paraplegia, W or W/O O.R. Procedure
MS	57	9	170 Respiratory Infections/Inflamns Age>54 W CC
ABI/CP	30	4	171 Respiratory Infections/Inflamns (Age>54 W/O CC) or (Age<55 W CC)
EP/ID	49	55	171 Respiratory Infections/Inflamns (Age>54 W/O CC) or (Age<55 W CC)
PSYCH	32	7	172 Respiratory Infections/Inflamns Age<55 W/O CC
EP/ID	24	34	200 Other Respiratory Syst Diags (Age>64 W/O CC) or (Age<65 W CC)
MS	52	17	171 Respiratory Infections/Inflamns (Age>54 W/O CC) or (Age<55 W CC)
ID/EP/DIAB	44	6	171 Respiratory Infections/Inflamns (Age>54 W/O CC) or (Age<55 W CC)
PSYCH	61	17	170 Respiratory Infections/Inflamns Age>54 W CC
ABI	56	11	003 Tracheostomy Except for Mouth, Larynx or Pharynx Disorder Age>15
PSYCH	57	2	166 Respiratory System Diagnosis W Ventilator Support
MS	58	14	019 Non-Acute Quadriplegia/Paraplegia, W or W/O O.R. Procedure
ID	36	4	134 Otitis Media & Uri Age>9 W/O CC
ABI/CP	5	8	201 Other Respiratory Syst Diags Age<65 W/O CC
ABI/CP	5	7	201 Other Respiratory Syst Diags Age<65 W/O CC
ABI/CP	5	2	201 Other Respiratory Syst Diags Age<65 W/O CC
ABI/CP	5	19	201 Other Respiratory Syst Diags Age<65 W/O CC
ID/PSYCH	48	1	171 Respiratory Infections/Inflamns (Age>54 W/O CC) or (Age<55 W CC)
ID/PSYCH	59	11	170 Respiratory Infections/Inflamns Age>54 W CC
CP/EP	45	10	171 Respiratory Infections/Inflamns (Age>54 W/O CC) or (Age<55 W CC)
PSYCH	26	7	171 Respiratory Infections/Inflamns (Age>54 W/O CC) or (Age<55 W CC)
PSYCH	59	7	170 Respiratory Infections/Inflamns Age>54 W CC
ABI/CP	0	4	172 Respiratory Infections/Inflamns Age<55 W/O CC
PSYCH	59	21	003 Tracheostomy Except for Mouth, Larynx or Pharynx Disorder Age>15
MS	47	9	171 Respiratory Infections/Inflamns (Age>54 W/O CC) or (Age<55 W CC)
ID	45	10	171 Respiratory Infections/Inflamns (Age>54 W/O CC) or (Age<55 W CC)
ABI/CP/EP	4	1	172 Respiratory Infections/Inflamns Age<55 W/O CC
MS	53	12	171 Respiratory Infections/Inflamns (Age>54 W/O CC) or (Age<55 W CC)
PSYCH	40	9	171 Respiratory Infections/Inflamns (Age>54 W/O CC) or (Age<55 W CC)
MD	36	51	200 Other Respiratory Syst Diags (Age>64 W/O CC) or (Age<65 W CC)
EP	56	8	170 Respiratory Infections/Inflamns Age>54 W CC
MS	46	6	200 Other Respiratory Syst Diags (Age>64 W/O CC) or (Age<65 W CC)

Appendix 5

DISABILITY SERVICES ACT 1992

SCHEDULE ONE

OBJECTS

The objects to the furthering of which the Minister for Health or Minister must have regard are—
(a) to ensure that persons with disabilities receive the services necessary to enable them to achieve their maximum potential as members of the community;
(b) to ensure that services provided to persons with disabilities—
(i) further the integration of persons with disabilities in the community, and complement services available generally to persons in the community;
(ii) enable persons with disabilities to achieve positive outcomes, such as increased independence, employment opportunities and integration in the community; and
(iii) are provided in ways that promote in the community a positive image of persons with disabilities and enhance their self-esteem;
(c) to ensure that the outcomes achieved by persons with disabilities by the provision of services for them are taken into account;
(d) to encourage innovation in the provision of services for persons with disabilities.

SCHEDULE TWO

PRINCIPLES

The principles which are to be furthered with respect to persons with disabilities are that—
(a) persons with disabilities are individuals who have the inherent right to respect for their human worth and dignity; and
(b) persons with disabilities, whatever the origin, nature, type and degree of disability, have the same basic human rights as other members of Australian society; and
(c) persons with disabilities have the same rights as other members of Australian society to realise their individual capacities for physical, social, emotional and intellectual development; and
(d) persons with disabilities have the same right as other members of Australian society to services which will support their attaining a reasonable quality of life; and
(e) persons with disabilities have the same right as other members of Australian society to participate in decisions which affect their lives; and
(f) persons with disabilities receiving services have the same right as other members of Australian society to receive those services in a

manner which results in the least restriction of their rights and opportunities; and
(g) persons with disabilities have the same right of pursuit of any grievance in relation to services as have other members of Australian society.

SCHEDULE THREE

OBJECTIVES

The objectives for providers of services or researchers are that—
(a) the services should have as their focus, the achievement of positive outcomes for people with disabilities, such as increased independence, employment opportunities and integration into the community; and
(b) the services should contribute to ensuring that the conditions of the every-day life of people with disabilities are the same as, or as close as possible to, norms and patterns which are valued in the general community; and
(c) the services should be provided as part of local co-ordinated service systems and be integrated with services generally available to members of the community, wherever possible; and
(d) the services should be tailored to meet the individual needs and goals of the people with disabilities receiving those services; and
(e) the program or the services should be designed and administered so as to meet the needs of people with disabilities who experience a double disadvantage as a result of their gender, ethnic origin, or Aboriginality; and
(f) the program or the services should be designed and administered so as to promote recognition of the competence of, and enhance the image of, people with disabilities; and
(g) the program or the services should be designed and administered so as to promote the participation of people with disabilities in the life of the local community through maximum physical and social integration in that community; and
(h) the program or the services should be designed and administered so as to ensure that no single organisation providing services exercises control over all or most aspects of the life of a person with disabilities; and
(i) the organisations or persons providing services to persons with disabilities, whether those services are provided specifically to persons with disabilities or generally to members of the community, should be accountable to those persons with disabilities who use their services, advocates of those persons, the State and the community generally for the provision of information from which the quality of their services can be judged; and
(j) the program or the services should be designed and administered so as to provide opportunities for people with disabilities to reach goals and enjoy lifestyles which are valued by the community generally and are appropriate to their chronological age; and Disability Services Act 1991
(k) the services should be designed and administered so as to ensure that persons with disabilities have access to advocacy support where

necessary to ensure adequate participation in decision-making about the services they receive; and
(l) the program or the services should be designed and administered so as to ensure that appropriate avenues exist for people with disabilities to raise and have resolved any grievances about services; and
(m) the program or the services should be designed and administered so as to provide people with disabilities with, and encourage them to make use of, avenues for participating in the planning and operation of services which they receive and the State and organisations should provide opportunities for consultation in relation to the development of major policy and program changes; and
(n) the program or the services should be designed and administered so as to respect the rights of people with disabilities to privacy and confidentiality; and
(o) the activities of the provider of services which relate to persons with disabilities should be conducted in accordance with the Principles set out in Schedule Two.