An Investigation of Paediatric Rehabilitation Systems of Care in North America

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Executive Summary

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Project Description

An Investigation of Paediatric Rehabilitation Systems of Care in North America

A study of rehabilitation services and systems for children, in centres of excellence in North America, with special emphasis on models able to be adapted to the demographics of Australia and the unique needs of our young people.

Fellowship Highlights

In all centres, the observation of highly developed team processes for inpatient rehabilitation, especially goal setting, outcome measurement, family support and education, and interdisciplinary models of care.

The opportunity to observe Botulinum Toxin injections for spasticity (muscle tightness in cerebral palsy) given by different methods and within different models of care.

Superb services offered to individuals with cerebral palsy, including the Lifetime Specialty Care clinic for adults with cerebral palsy at Gillette Children’s Specialty Healthcare service, a program run by a specialist in paediatric rehabilitation and a doubly qualified specialist in internal medicine and paediatrics.

The Gait Laboratories at Alfred I. DuPont and Gillette Children’s, world leaders in this technology for the objective assessment of walking skills.

Orthotics and Seating outreach by Gillette Children’s Specialty Healthcare.

The Alfred I. duPont Hospital in Wilmington, Delaware, originally founded in 1940 as an orthopaedic facility and now a 180-bed hospital that offers all the specialties of
paediatric medicine, surgery, and dentistry, in effect a “general paediatric hospital” devoted to the welfare of children with disabilities, with a wonderful, family-centred approach.

Paediatric rehabilitation consultation and treatment occurring as multiple levels of care, across multiple sites using a variety of models, including tertiary hospital, peripheral hospital, home- and community-based. The paediatric rehabilitation specialist functioning as a member of many teams as required to meet their patients’ needs and to satisfy Insurers’ requirements.

The innovative Home and Community Rehabilitation at the Kennedy Krieger Institute in Baltimore, a program of short-term intensive rehabilitation in the community.

Continuum of care models for transition through a specialized school and therapy program to home, including Kennedy Krieger Institute’s Specialized Transition Program, the GF Strong Adolescent and Young Adult program in Vancouver and the Challenge Program at The Institute for Rehabilitation and Research in Houston.

Resources developed for families and referrers. The availability of print and internet resources for young patients and their families, and staff to manage resources and support family independence in this area. Highlights in this area included Sunny Hill Hospital, the Rehabilitation Institute of Chicago and the internet-based services (kidshealth.org) offered by the Alfred I. duPont Hospital. The program management system at Gillette Children’s Specialty Healthcare combines resource development with public relations and professional development.

Learning of the “Medical Home“ system.

The Shriners Hospitals System, which is quite unique in its approach, funding and philosophy, offering high quality pediatric rehabilitation, orthopaedic surgery, plastic, reconstructive and craniofacial surgery and spinal cord injury care with no charge to the patient, parent, or any third party.

High technology spasticity management programs including Intrathecal Baclofen Programs in every centre visited, and the Selective Dorsal Rhizotomy program at Gillette Children’s Specialty Healthcare, Minnesota.

Figure 1 Teaching Dolls at Shriners Hospital, Chicago
Major Lessons and Conclusions

The upper age limit of children and adolescents served by the rehabilitation institutions observed ranged from 17 to 21 years. Australian hospital and health services should consider the multiple advantages for young people in having access to a paediatric rehabilitation service, at least until school leaving.

In Toronto, the merging of a number of separate rehabilitation services has resulted in a single, well-organized service. This has occurred under the banner of “Ontario’s Promise”, a nonpartisan initiative uniting individuals and organizations from all sectors of society to work together for the children of Ontario. Unification of government and non-government sectors offering services to the same populations presents opportunities for development of the highest quality services.

Inpatient Rehabilitation Services must be able to provide resource-intensive therapy and support to children and adolescents suffering functional impairment and disability resulting from catastrophic injury or illness, for example traumatic brain injury, near drowning, spinal cord injury or disease, or multiple trauma. Demand for these services fluctuates and most of the conditions are of low incidence. Rehabilitation administrators have dealt with the “critical mass” issue in a variety of ways, but keeping the rehabilitation episode separate from the acute episode was a consistent feature.

In all services observed, therapists and other allied health staff had distinct rehabilitation caseload responsibilities. In addition, most staffing appeared to be program specific, with separate discipline structures to maintain discipline-specific training and support.

In rehabilitation services across the USA, Intrathecal Baclofen (ITB) is widely considered to be the “standard of care” for individuals with severe spasticity. ITB, once established and successful, becomes a lifelong treatment, and patients need to remain in regular contact with a team knowledgeable about tone assessment, the interrelationships between tone and function, and trouble-shooting pump problems. Consideration needs to be given to setting up this program in Queensland, and a “lifetime” approach for patients, with paediatric and adult specialists pooling their knowledge and skills may be a useful model for Queensland.

Consideration should be given to starting a selective dorsal rhizotomy program for the treatment of cerebral palsy. This treatment is not currently available anywhere in Australia. In Queensland, we have the facilities for 3-dimensional gait analysis and the rehabilitation service to provide the very important postoperative therapy.

Botulinum toxin injections for treatment of focal spasticity are given under a variety of models in North America. A major lesson from this was for us to look at how this medication can be given across different settings, especially with a view to making this treatment more available to patients living in rural and remote locations.
Introduction

Paediatric rehabilitation is a new area of subspecialty medical care in Australia. The specialty is concerned with improving health and function, and maximizing quality of life, independence and participation for children with disabilities, especially physical disabilities. In Australia, paediatric rehabilitation specialists are involved mainly in the care of children with acquired brain injury, spinal cord injury and disease, congenital spinal cord dysfunction (spina bifida), cerebral palsy and limb loss or limb deficiency.

The Australasian Faculty of Rehabilitation Medicine was formed in 1993, but similar professional faculties have been existence in the USA since the 1940’s. Consequently, formalised rehabilitation systems are more advanced in the USA. In addition, the private health system in the USA expects hospitals to provide goal-directed treatment programs and discharge-focussed services for severely injured and otherwise incapacitated individuals. This task falls to the rehabilitation service, and with good reason, as a functional approach is an important skill of the rehabilitation medicine specialist.

At the time I applied for and was awarded my Churchill Fellowship, there were a mere 15 paediatric rehabilitation fellows comprising the paediatric division of the Australasian Faculty of Rehabilitation Medicine. One to two new paediatric fellows are admitted to the Faculty each year.

Meanwhile, the number of children (or their caregivers) seeking rehabilitation services continues to climb. The life expectancy of children with a number of disabilities, such as spina bifida, muscular dystrophy, conditions dependent on mechanical ventilatory (breathing) support and major multiple trauma, has increased due to advances in emergency services and acute medical care. Social advances have led to changes in the philosophy of the care of persons with disabilities. The focus is now on community living and away from institutional care. As we strive for inclusion, we must search for the least restrictive alternative for individuals with disabilities – in living arrangements, the provision of education, therapy and medical care.

I work as a paediatric rehabilitation specialist and the director of the Queensland Paediatric Rehabilitation Service, a service established in 1996, originally funded as a pilot project by the Motor Accident Insurance Commission of Queensland. The aim of my study tour was to learn from well-established centres of excellence in paediatric rehabilitation, with a particular emphasis on studying models and systems of care.

My systemic approach was based on the fact that the rehabilitation episode occurs within a complex medical, social and educational environment, and is quite different to a simple doctor - patient encounter. Current thinking in rehabilitation care and research is guided by use of the World Health Organization International Classification of Function (formerly the International Classification of Impairment, Disability and Handicap). This classification identifies health and disability issues as relating to body structure and function, activity (previously disability) and participation (previously called handicap). Under this structure, an individual’s rehabilitation is planned around their strengths and difficulties, in the context of their
family situation, societal roles and modifying factors in their environment. The patient and family are central to the planning and to the execution of care plans.

Thus, the clinical skills of the rehabilitation professional are put to use within a complex system. It is my belief that the planning and execution of the system is as important for the patients and clients of the service, and for rehabilitation outcomes, as the individual skills of practitioners working within the service.

**Program**

<table>
<thead>
<tr>
<th>Facilities Visited</th>
<th>Key Programs Observed</th>
<th>Contact Person(s)</th>
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<tbody>
<tr>
<td>Bloorview MacMillan Children’s Centre</td>
<td>• Neurorehabilitation program and rounds&lt;br&gt;• Neurodevelopmental program&lt;br&gt;• Musculoskeletal program&lt;br&gt;• 24 hour client care&lt;br&gt;• Day hospital&lt;br&gt;• Respite program&lt;br&gt;• Botulinum toxin program&lt;br&gt;• Botulinum toxin injections under conscious sedation protocol&lt;br&gt;• Community Outreach Recreation and Education&lt;br&gt;• Family resource room&lt;br&gt;• Designated Assessment Centre for Third Party Insurance claims</td>
<td>Dr Golda Milo-Manson&lt;br&gt;Chief of Medical Staff</td>
</tr>
<tr>
<td>Toronto, Ontario, Canada&lt;br&gt;21 – 24 July 2002</td>
<td><a href="http://bloorviewmacmillan.on.ca">http://bloorviewmacmillan.on.ca</a></td>
<td></td>
</tr>
<tr>
<td>Spaulding Rehabilitation</td>
<td>• Inpatient rehabilitation&lt;br&gt;• Case Management&lt;br&gt;• Inpatient Group Programs&lt;br&gt;• Consultation – Liaison Psychiatry&lt;br&gt;• Home care program&lt;br&gt;• Botulinum Toxin Program&lt;br&gt;• Intrathecal Baclofen program&lt;br&gt;• Local outreach model</td>
<td>Dr Donna Nimec&lt;br&gt;Ms Sally Potts&lt;br&gt;Program Director&lt;br&gt;Child Adolescent Program</td>
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<tr>
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| Blythedale Children’s Hospital           | • Inpatient rehabilitation • Day Hospital • School with integrated therapy and education • Biofeedback • Botulinum Toxin Program • Electronic chart | Dr Patricia Lawrence  
Chief, Department Rehabilitation Medicine |
| New York, New York                       | 1 – 2 August 2002                                                                     |                                                                                 |
|                                          | www.blythedale.org                                                                    |                                                                                 |
| Alfred I. duPont Hospital for Children   | • Inpatient Rehabilitation • Day Hospital • Intrathecal Baclofen program • Spina Bifida clinic • Spasticity management clinic • Gait Laboratory • Electronic chart • Extended school | Dr Michael Alexander  
Chief, Physical Medicine and Rehabilitation |
| Wilmington, Delaware                     | 5 – 6 August                                                                           |                                                                                 |
|                                          | www.nemours.org/no/aidhc  
www.kidshealth.org                         |                                                                                 |
| Kennedy Krieger Institute                 | • Inpatient rehabilitation • Interdisciplinary rounds • Therapy Centre and interdisciplinary goal setting • Day treatment ward • Interdisciplinary feeding program • Neurobehavioural Unit • Botulinum Toxin Program • Brain Injury follow-up clinic • Continuum of Care • School – Specialized Transition Program - integrated therapy and education • Home and Community Rehabilitation Program • Osteogenesis Imperfecta program | Dr Frank Pidcock  
Associate Director of Rehabilitation  
Ms Delores Moore  
Rehabilitation Manager |
<p>| Kennedy School                           | 7 – 9 August 2002                                                                     |                                                                                 |
| Baltimore, Maryland                       | <a href="http://www.kennedykrieger.org">www.kennedykrieger.org</a>                                                                 |                                                                                 |</p>
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<tr>
<th>Facilities Visited</th>
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</thead>
</table>
| Rehabilitation Institute of Chicago (RIC)     | • Inpatient rehabilitation  
• Group therapy  
• Botulinum Toxin Program  
• Intrathecal Baclofen program  
• Day programs  
• Practice councils  
• Center for Clinical Excellence and Education and Training Centre  
• Life Centre  
• Health Resource Center for Women with Disabilities | Dr Charles Sisung  
Director, Pediatric Rehab Program  
Ms Eileen French  
Education Coordinator |
| Chicago, Illinois                             |                                                                                       |                                            |
| 12 – 16 August 2002                           |                                                                                       |                                            |
| [www.rehabchicago.org](http://www.rehabchicago.org) |                                                                                       |                                            |
| Shriners Hospital for Children                 | • Inpatient rehabilitation of spinal cord injuries  
• Spinal cord injury clinic  
• Spina bifida clinic  
• Computerised urodynamic testing  
• Amputee clinic  
• Educational resources | Dr. Larry Vogel  
Chief of Pediatrics |
| Chicago, Illinois                             |                                                                                       |                                            |
| 14 – 16 August 2002                           |                                                                                       |                                            |
| [www.shrinershq.org/shc/chicago](http://www.shrinershq.org/shc/chicago) |                                                                                       |                                            |
| Gillette Children’s Specialty Healthcare      | • Inpatient rehabilitation  
• Botulinum Toxin Program  
• Intrathecal Baclofen program  
• Selective Dorsal Rhizotomy Program  
• Motion Analysis Laboratory  
• Lifetime Specialty Care clinic for adults with cerebral palsy  
• Assistive Technology Department and Outreach Service  
• Family Resource Centre  
• Computerized scheduling | Dr Linda Krach  
Medical Director, Rehabilitation |
<p>| St Paul, Minnesota                            |                                                                                       |                                            |
| 19 – 22 August 2002                           |                                                                                       |                                            |
| <a href="http://www.gillettechildrens.org">www.gillettechildrens.org</a> |                                                                                       |                                            |</p>
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<tr>
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| The Institute for Rehabilitation and Research (TIRR)           | • Adult and paediatric inpatient rehabilitation  
| Houston, Texas                                                | • Family rounds  
| 26 – 30 August 2002                                           | • Pharmacy Rounds  
|                                                               | • Constraint Induced Therapy  
|                                                               | • Challenge Program  
|                                                               | • Acute Hospital consultation – liaison  
|                                                               | • Botulinum Toxin Program  
|                                                               | • Intrathecal Baclofen program  
|                                                               | • Groups and classes  
|                                                               | • Brachial plexus surgery at the Texas Children’s Hospital                           | Dr Cindy Ivanhoe  
|                                                               |                                                                       | Director, Brain Injury Program |
| Sunny Hill Health Centre for Children                         | • Neumotor program and Brain Injury Rehabilitation  
| Vancouver, BC, Canada                                         | • Developmental and Behavioural Program  
| 2 – 5 September                                               | • Transition Planning  
|                                                               | • Patient Review Meeting  
|                                                               | • Goal setting and family care notebook  
|                                                               | • Sexual Health Resource Centre  
|                                                               | • “Kids-In-Action” program                                                        | Dr George Hahn  
|                                                               |                                                                       | Medical Director |
|                                                               |                                                                       | Lori Roxborough  
|                                                               |                                                                       | Department Head,  
|                                                               |                                                                       | Therapy Dept. |
| GF Strong Rehab Centre                                        | • Adolescent and Young Adult Service  
| Vancouver, BC, Canada                                         | • Inpatient admission review  
| 2 – 5 September                                               | • Therapeutic Recreation  
|                                                               | • School  
|                                                               | • Early intervention for mild traumatic brain injury  
|                                                               | • Seating and assistive technology                                           | Dr George Hahn  
|                                                               |                                                                       | Medical Manager  
|                                                               |                                                                       | AYA Service |
| British Columbia Children’s Hospital                          | Spina Bifida Clinic                                                              | Dr Paul Thiessen  
| Vancouver, BC, Canada                                         |                                                                       | Medical Director |
| 5 September                                                   |                                                                       | Spina Bifida Program                 |
FINDINGS

Models of Rehabilitation Services

After visiting and observing the centres listed above, it seemed clear that there were four basic models in which inpatient rehabilitation services are offered to children and adolescents. This relates particularly to services that offer the full range of rehabilitation, including inpatient rehabilitation. A more diverse range of services may be offered at a community and school-based level.

Type I - Stand alone paediatric rehabilitation facility
Bloorview MacMillan, Toronto - part of single network of 19 rehabilitation centres, with one inpatient unit, a day hospital, schools and outpatient services.

Sunny Hill Hospital, Vancouver – a provincial facility offering specialized services to children and youth with developmental disabilities aged birth to 19.

Blythedale, New York – stand-alone, 92-bed non-profit children's hospital serving young people from birth through age 19 years, with inpatient unit, day hospital, and integrated school and therapy program.

Type II - Paediatric rehabilitation service within a general children's hospital
Alfred I. duPont Hospital for Children, Wilmington Delaware - inpatient unit, day hospital, outpatient therapy and clinics – a general hospital but it started as an orthopaedic and rehabilitation hospital and retains a special focus on, and compassion for, children with disabilities.

Gillette Children’s Specialty Healthcare – a separate specialty hospital (see below) but co-located with Regions Hospital, a full-service private hospital (including a general paediatric hospital).

Type III – Paediatric rehabilitation service within a specialty children’s hospital
Kennedy Krieger Institute – “dedicated to helping children and adolescents with disorders of the brain”.

Gillette Children’s Specialty Healthcare, founded by Dr. Arthur Gillette more than 100 years ago, offering services to children with physical and functional disabilities or complex medical needs, and now extended to provide lifetime care to adults with cerebral palsy.

The Chicago Shriners Hospital is a short term, 60-bed facility providing high quality paediatric rehabilitation, orthopaedic surgery, plastic, reconstructive and craniofacial surgery and spinal cord injury care, combined with education and research.
Type IV - Paediatric rehabilitation service within a general rehabilitation service

Spaulding Rehabilitation, Boston

Rehabilitation Institute of Chicago

The Institute for Rehabilitation and Research (Houston)

GF Strong Rehab Centre – Adolescent and Young Adult Service

All of these services offered paediatric rehabilitation as part of a full spectrum of rehabilitation services. Most had programs for adult traumatic brain injury, spinal cord injury, amputee, orthopaedic and geriatric rehabilitation, offered in inpatient, day hospital and outpatient settings. Spaulding was a little different to the others as the paediatric unit was organizationally part of Spaulding but in a separate location at the Massachusetts Eye and Ear Hospital, therefore also separate to the general children’s facility.

It is difficult to compare the different models and there is no “best model”. All are centres of excellence. What is helpful is to study what makes them excellent and try to draw those principles into our practice here. Below, I have attempted to draw out some of the common and unique features of the different places I visited, and explore those features in more detail.

Features of Rehabilitation Services of Excellence – Inpatient Care

Program Model

Inpatient Rehabilitation Services must be able to provide resource intensive therapy and support to children and adolescents suffering functional impairment and disability resulting from catastrophic injury or illness, for example traumatic brain injury, near drowning, spinal cord injury or disease, or multiple trauma. These conditions, which require intensive, inpatient rehabilitation therapy, are fortunately of low incidence in childhood. In the USA, despite the larger population compared to Australia, there are still relatively low numbers of patients requiring such inpatient rehabilitation.

For example, The Shriners Hospital of Chicago, a 60-bed facility, has 6 beds dedicated for children with spinal cord injury. These beds would accommodate most children and adolescents requiring this highly specialised service to the State of Illinois and surrounding states (although other rehabilitation services may also provide this service).

As well as being low incidence, these conditions also fluctuate in their occurrence in an unpredictable way, are resource-intensive and require therapists, nurses and medical staff to have highly specialized skills and access to specialized and expensive equipment.

In all services observed, therapists and other allied health staff had distinct rehabilitation caseload responsibilities. The services were separate to acute hospital
services. In addition, most staffing appeared to be program specific (with separate discipline structures to maintain discipline-specific training and support). This allowed all services to provide services of the highest quality.

The challenge then, for rehabilitation service administrators, is how to have the expert resources available when needed but still cope with the inevitable fluctuations without inefficiencies or waste. In other words, how to achieve the "critical mass" needed to provide an efficient service. In the models presented above, this problem is dealt with differently in each scenario.

- Stand-alone paediatric facilities tended to combine the neurorehabilitation caseload with developmental disorders, postoperative orthopaedic rehabilitation, complex medical conditions, especially ventilator-dependent children, and other chronic low incidence conditions requiring hospitalization.
- The paediatric hospital model (duPont) combined neurorehabilitation with postoperative orthopaedic and complex medical (including ventilator-dependent) caseloads.
- The specialty paediatric hospitals tended to have a strong relationship between rehabilitation, orthopaedics and neurosurgery, neurology and genetics.
- The full-service adult rehabilitation hospital generally combined paediatric and adult rehabilitation on one ward, with therapists having a mixed-age but like-diagnosis caseload. Spaulding was an exception, being located separately to both the adult rehabilitation service and the general children’s facility. They appeared to cope with this issue by having a larger number of patients on their Fragile Infant program (neonatal abstinence and chronic lung disease) and chronic pain treatment programs. In G.F. Strong, the adolescents shared a ward with adults but had a separate lounge, separate therapists and a separate therapy area.

Our service In Queensland, the Queensland Paediatric Rehabilitation Service, has dealt with this same issue by combining inpatient rehabilitation caseloads with outreach and outpatients, creating internal staffing flexibility.

**Goal Setting and Outcome Measurement**

In the privately funded health systems of the United States of America, the accreditation bodies’ and insurers’ requirements have led to excellent systems of care pathways, resource development and family participation. In particular, I noted a focus on measuring satisfaction of the young person and family, and on awareness and measurement of pain, falls risk and prevention of complications. These are protocol-driven and appear to be faithfully implemented. On the down side, some negative outcomes of these systems included the insistence on seven day inpatient therapy by some payers, whether or not this was deemed a useful rehabilitation strategy by the treating rehabilitation specialists (see below).

All institutions used the weeFIM as an outcome measure. This is an age-normed, generic outcome measure, which in essence measures burden of care. Most services
used additional outcome measures, particularly goal attainment scaling or measures
developed by their own institutions, to make up for identified deficiencies in the
weeFIM.

**Ages of Young People Served**

The upper age limit of children and adolescents served by the rehabilitation
institutions observed ranged from 17 to 21 years. Some placed a limit on the age at
first admission, being 17 years or still at school. Most would readmit up to 21 years,
if the young person was still living at home and still in school or college. Australian
hospital and health services should consider the multiple advantages for young people
in having access to a paediatric rehabilitation service, at least until school leaving.

**Relationship of Rehabilitation Centre to Trauma Centres**

All services that provided inpatient rehabilitation services were separate to trauma
centres. Stand-alone rehabilitation services had feeder hospitals (paediatric and adult)
with trauma units. Many such acute hospitals had a trauma team of allied health
professionals, nursing, as well as medical staff, which would be mobilized for early
rehabilitation and support for patients suffering catastrophic injury.

The rehabilitation specialist or admissions coordinator attending “trauma rounds” at
the acute hospital facilitated successful liaison between trauma centres and
rehabilitation services.

The separation of acute (trauma) and sub-acute (rehabilitation) phases of care meant

- A clear point of transition to rehabilitation phase.
- An opportunity for clear pre-admission planning for admission of “high risk”
  patients (such as slow recovery or technology-dependent patients) to
  rehabilitation.
- No continuity of care.
- Milder or rapidly improving patients may miss the opportunity to access the
  rehabilitation service (and therefore miss out on long-term follow-up or
  detection of emerging issues).

Gillette Children’s Specialty Healthcare had some innovative programs and unique
solutions to some of the above potential disadvantages of institutionally separate
rehabilitation services.

1. Gillette is a separate hospital but is co-located with a general paediatric
   hospital (Regions Health). This provides great opportunities for close
   consultation and liaison.
2. Gillette owns and operates the paediatric intensive care unit (PICU) on behalf of the general hospital, ensuring access to PICU beds for their elective postoperative neurosurgical and orthopaedic cases, but also ensuring that severely injured and ill children can easily enter the Gillette system.

3. Rehabilitation consultants (physiatrists) provide consultation – liaison services to the children with milder head injuries, requiring admission to hospital, but not needing or qualifying for a rehabilitation program. They review these children in the PICU or on the general wards, and arrange assessment and follow up as required. They provide these families with educational material, an individualized printed brochure.

4. The chaplaincy program at Gillette and Regions is very strong. The program provides spiritual support for all patients and their families, regardless of their belief system. As they work across both Regions and Gillette, they provide continuity of emotional support and advocacy.

**Group Rehabilitation Interventions**

Group programs were widely used at the rehabilitation centres I visited. Groups provide a wonderful opportunity for therapy to be offered in a stimulating and motivating environment, with the additional positive benefits of providing opportunities for peer interaction, development of social skills and practice of communication strategies. They are also cost-efficient, excellent for team building, encourage transdisciplinary therapy, and provide opportunities for rehabilitation assistants or technicians, parents, friends and volunteers to participate in providing rehabilitation under the supervision of the professional therapists.

At the Rehabilitation Institute of Chicago (RIC), these programs were highly developed. For example, adult patients receiving rehabilitation for acquired brain injury had access to a group nearly every hour during the working day. Such a program is clearly easier to organize when you have a large group of patients with similar needs, abilities and disability profiles.

The challenge in a paediatric program must be the range of ages, interests and abilities represented – a feature with any mixed group of children – as well as the heterogeneity of the disabling conditions with which the children present and the relatively small number of paediatric inpatients (particularly in the rehabilitation services that spanned all ages).

The structure of groups in the RIC paediatric program provided some nice opportunities for children to participate, regardless of their age, developmental stage and type or level of disability.

A classic “group” usually involves all participants in the same activities. Examples are an Exercise group playing Balloon Tennis, or an Orientation group, reading the paper and talking about the day’s events. The RIC paediatric program utilizes “classes” as well as groups. In a class, every child performs an individualized program but within a class setting.
The Kennedy Krieger Institute had a very well developed group program within their Therapy Centre (see also Child Life and Recreation Therapy). Each day, a number of groups were available, catering to different levels of participation, and including crafts, sensorimotor activities, games and exercise, and discussions. The child life specialists, recreation therapists and representatives of each discipline meet weekly to plan the groups, based around the rehabilitation goals of individual children, but then made available to any child for whom that group would be beneficial. The groups are also themed (for example around an underwater theme when I was visiting) to assist those children with cognitive impairments to carry over contextual learning from day to day. Group interventions were also widely used to provide weekend therapy in a fun and cost-effective way, and to provide therapy during holiday and respite programs.

Group programs can be an effective and efficient mode of providing rehabilitation and the “class” therapy model in use at RIC is of particular interest for Rehabilitation Services, which have relatively small numbers of patients with diverse needs and goals.

Allied Health Roles and Systems

Some distinct differences to our systems were observed. Of note, social workers were largely employed as case managers in the USA. They fulfilled a very important role in liaison between the patient – family and the insurance company or Medicaid public health insurance. They advocated for services and had an important role in helping the family to set realistic rehabilitation goals. They made sure progress was clearly documented and communicated this to the insurer. They often did not appear to have a large role in counseling, education or family support. This role seemed to be taken on more by psychologists, nurses, child life specialists (see below), youth workers or chaplains.

On a related point, consultation - liaison psychiatry in the rehabilitation setting was highly visible in the children’s service of Spaulding Rehabilitation (Boston). This unit had a number of patients with chronic pain syndromes and this close relationship with psychiatry appeared highly beneficial to the complex mix of patients. Other services appeared to utilize in-house psychology services, and consult psychiatry as required.

Physical therapy, occupational therapy and speech language pathology appeared to have quite similar roles as in Australia, but units in North America had a greater number of therapy aides / assistants providing hands-on therapy under therapist supervision than is seen here.

Nurse practitioners, not generally seen in Australia at the current time, take on much of the planning, coordination, education, and parts of the medical role. In Australian rehabilitation services, these duties would be more commonly performed by registrars (specialists-in-training), consultant physicians or therapists.
Therapeutic Recreation and Child Life Specialists

One or both of these allied health disciplines were members of all the rehabilitation teams observed. Their roles appeared to be somewhat institution-specific, as their duties varied from place to place.

Child Life Specialists (CLS) assess the developmental needs of children within the context of their adjustment to illness and hospitalization. In acute and rehabilitation hospitals across North America, CLS plan and implement developmental and therapeutic interventions in the playroom (a "safe" area where no medical procedures may be performed) or at the bedside. In individual or group sessions, young patients are assisted to deal with various issues, stresses, and the trauma of hospitalization. For the acutely ill child in hospital, the aim will often be for the child to continue their normal developmental growth while in hospital, through activities appropriate to their intellectual, motor, emotional, and social skills. Child Life Specialists provide social, emotional and developmental support, to decrease psychological and developmental distress and increase coping with health care experiences (through medical play, medical education and procedural support).

These activities become even more important for the child restricted from activities such as school and normal play, through the effects of catastrophic injury and the requirements of the rehabilitation program. Two different approaches were apparent to me in visits to rehabilitation facilities.

One approach was for the CLS to provide unstructured, supportive “down time” for children on rehabilitation programs, especially inpatients. The CLS usually worked in a playroom, and the children could choose if and when they visited (outside of scheduled therapy or school sessions) and could fully control the content of their play. This type of therapy appeared to be largely supportive, providing emotional release and unstructured (child-driven) play, rather than rehabilitation (goal-driven) activity. Some CLS tried to gently support rehabilitation goals but this was not seen as the purpose of the service.

A quite different approach was seen at the Kennedy Krieger Institute, where a large department of child life and recreation therapists occupy and operate the Therapy Centre. The Therapy Centre program is a structured, group treatment-based day program held in the playroom, with activities designed to the achievement of functional skills based on specific therapy goals. Rehabilitation goals are important and explicit.

In addition, transdisciplinary goals for each child are set at a weekly meeting in the Therapy Centre. Transdisciplinary implies crossing individual allied health discipline boundaries and skill areas. The goals identified can be addressed by any discipline and across all sessions. This goal setting process was one of the most interesting I observed, and provided rapid goal attainment and reinforcement, and team building and cooperation.

Other activities of the Kennedy Krieger Institute Therapy Centre included the provision of social and recreational activities in the playroom on evenings and on weekends, therapeutic community reintegration outings and Therapeutic Recreation (TR) treatment intervention.
“Therapeutic Recreation is provided by professionals who are trained and certified, registered and/or licensed to provide Therapeutic Recreation. (© ATRA, 1986) Therapeutic Recreation is a process that utilizes treatment, education and recreation participation to enable persons with physical, cognitive, emotional and/or social limitations to acquire and/or maintain the skills, knowledge and behaviours that will allow them to enjoy their leisure optimally, function independently with the least amount of assistance and participate as fully as possible in society. Therapeutic Recreation intervention is provided by trained professionals in clinical and/or community settings.” (TRO Board of Management, 1995).

TR Specialists provide therapy for patients requiring rehabilitation after a traumatic injury, illness or disabling conditions. Recreational Therapy aims to restore, remediate or rehabilitate in order to improve functioning and independence as well as reduce or eliminate the effects of illness or disability. The primary purposes of Recreational Services are to provide recreation resources and opportunities in order to improve health and well-being.

TR uses therapy sessions, leisure education and special recreation programs to assist patients in reaching their maximum potential. Special programs may include adapted aquatics, wheelchair sports and community outings. Recreation activities provide healthy and positive outlets and are used as modes for coping with hospitalization, illness and/or disability and for reinforcing the goals of the interdisciplinary team.

Again, somewhat different models were seen. Some services provided outings, in-hospital leisure and diversionary activities. Others provided a strongly goal-centred approach through investigation of leisure activities, adapted sports, and development of self-awareness and motivation.

An outstanding Therapeutic Recreation program was seen at the GF Strong adolescent rehabilitation centre in Vancouver. During the inpatient stay, emphasis is placed on the development of leisure activities for the post-discharge period. In addition, peer support evenings, the introduction of the adolescents to successful older role models, and “Have a Go” nights patients to try out at various adapted sports are organised with the British Columbia Wheelchair Sports Association. The annual Teen Independence Camp is a highlight for many graduates of the rehabilitation program.

Another highlight of this program, as stated elsewhere in this report, is the ability for young people on the GF Strong rehabilitation program to achieve credit towards their high school subject of Health and Physical Education by involvement in health education and participation in the therapeutic recreation program.

**Therapeutic Leave of Absence**

In Brisbane Australia, public rehabilitation services offer therapy on a 5-day per week basis, excluding emergency or acute requirements. For inpatients, the weekend period is used for rest, with rehabilitation nursing care continuing towards education and rehabilitation goals. Patients who are well enough are usually given weekend leave. Weekend leave is seen as a very important way of gradually integrating patients back into their community, providing opportunities to practice relearned skills in their own
homes, identify any access problems which may be a barrier to discharge, increase independence and have a welcome break from the hospital routine.

Inpatient rehabilitation services in many centres in the United States of America provide therapy services seven days per week, because it is demanded by the paying Health Insurance Organizations. This was not always felt to be of any clinical benefit, and did not appear to reduce length of stay, according to some of those I interviewed. Some centres were permitted to send patients on “therapeutic leave of absence” (TLOA) - leave from hospital with the express purpose of achieving home or community rehabilitation goals.

I found the TLOA concept appealing and it may be useful to introduce. By documenting the goals and outcomes of weekend leave, and to see this as a valuable part of rehabilitation, helps families to understand their important role, and to achieve competence and confidence in caring for their disabled family member. We should, however, guard against overly prescriptive requirements for therapy based on payers requirements, rather than evidence-based outcomes.

Management of Slow Recovery Patients

Slow recovering or low functioning patients may have limited ability to benefit from a prolonged intensive rehabilitation program. Different rehabilitation facilities dealt with this area of “risk” in a variety of ways.

At Bloorview MacMillan Children’s Centre, Toronto, these young people are admitted for a six-week period of assessment. During this time, their ability to participate in a rehabilitation program, reach identified rehabilitation goals (often assessed by goal attainment scaling) and their care and family education needs are assessed. At the end of this period, children who are not deemed suitable to continue on a rehabilitation program are either discharged or transferred to an “alternate level of care” arrangement. Discharge planning (such as equipment trialing, family training and home modifications) continues and the child receives the same level of therapy intervention they would be given in the community.

At TIRR, a “high risk conference” is conducted prior to accepting for admission a patient who may be difficult to discharge, because of their high level of disability or other factors.

At Sunny Hill Hospital, Vancouver, they have developed a care path for patients admitted in a low-level state of recovery. Following a 4-month period without further benefit from rehabilitation, they may enter a program known as “Transition Planning”. This focuses on patients with a very severe level of disability who need to spend a prolonged period of time in hospital awaiting availability of a suitable placement, modifications to their home, etc. During this program, they receive a maintenance level of therapy and the team involved focuses on development of community supports to allow discharge.

At the Kennedy Krieger Institute, a program called Home and Community Rehabilitation, operating for approximately 5 years, offers a unique alternative solution to this group of patients. Both children and adults may be referred to the
service, which provides short-term, goal-focused rehabilitation. For patients undergoing slow recovery, or patients in coma/near-coma, who do not meet criteria for admission to an inpatient rehabilitation program, this program allows for home assessment, hands-on therapy and training to allow the family to take over the rehabilitation role in their home setting.

**Use of Enclosed Beds for Patients at Risk of Falling**

Patients suffering acquired brain injury are commonly confused and agitated in the recovery period. They are at risk of falling out of bed and otherwise injuring themselves in relation to their confused cognitive state. Many such patients will also be unable to communicate verbally.

Enclosed bed systems were used in all facilities that managed patients with brain injuries, and two basic types of beds were seen - the Vail Bed or net bed (Figure X) and the bed enclosure as pictures at The Institute for Rehabilitation and Research(Figure X). These beds were considered to be a form of restraint in some, not all, institutions. In those that did consider it restraint, use of the bed required following of a Restraint Use Pathway, which ensured their safe and appropriate use. This was closely monitored by the accreditation bodies.

![Figure 2 Vail Bed](image)

![Figure 3 Bed Enclosure at TIRR](image)
Family Resources

Many services provided excellent print and internet resources for young patients and their families, and staff to manage resources and support family independence in this area. Highlights in this area included Sunny Hill Hospital, the Rehabilitation Institute of Chicago and the internet-based services (kidshealth.org) offered by the Alfred I. duPont Hospital. The program management system at Gillette Children’s Specialty Healthcare was unique. Clinicians working in the area of interest are given special responsibility and time release to develop resources for patients, referrers, insurers and the public in a role that combines marketing and public relations with professional development.

Figure 4  Family Resource Room at Sunny Hill Hospital, Vancouver

Day Hospital Rehabilitation Programs

Day rehabilitation programs are integrated medical, therapy and (usually) school programs, which allow rehabilitation patients to continue with intensive therapy but without staying overnight in the hospital. This phase of care is therefore less expensive than the inpatient phase, but is also important in beginning the community reintegration for severely injured and medically fragile patients.

Most of the rehabilitation centres offered a day hospital or day rehabilitation program. This was either the same program on the same site but without staying overnight in a bed, or a separate program, often on a different site, with a different model.

In general, criteria to participate in a day program would include the need for multidisciplinary therapy involvement (2 or more disciplines) and a minimum attendance of 2 – 3 days or half-days per week. The principal focus is the return to school or work, or vocational placement for adults and older adolescents.

One impressive feature of the public education system observed from my rehabilitation perspective, was that children with disabilities were provided with
transport to and from school (which we also have in Queensland) but that this right was transferred to the hospital school when children required their education to be in that setting for a period of time, so providing transport to and from the day rehabilitation program, independently of parents.

**Continuation of Schooling during Rehabilitation Programs**

A number of relationships between the rehabilitation program and the classroom were observed. The types of schooling available depended on the hospital type, rehabilitation program model, and the state or provincial education system. At one end of the spectrum, the classroom was an integral part of the therapeutic milieu, with patients receiving therapy in the classroom, and with rehabilitation goals being integrated into the educational program. Blythedale Hospital has a new school with large, purpose-built classrooms, enabling therapists to provide hands on therapy in that environment.

The GF Strong adolescent brain injury unit in Vancouver has an exemplary program of integrated education, therapy and therapeutic recreation. The teacher works as a member of the rehabilitation team but is funded, not by the hospital but through the Ministry of Education as a “provincial resource program”. She has a number of distinct roles, including liaison with the home school of the student, performing academic assessments, making functional assessments of the amount and type of support needed to return to school, and facilitating school reintegration, through school visiting, provision of resources and in-servicing teachers and peers.

One outstanding aspect of their work has been obtaining for their patients/students credit towards high school subjects, usually health and physical education, as recognition of the learning done by these young people about their own bodies and health needs in the wake of injury. In the difficult early time of return to school, this allows the student some spare time in the day for catching up with other subjects and acknowledges the student’s contribution to rehabilitation.

At the Kennedy Krieger Institute, the SteP program offers yet another excellent model of integrated therapy and education, in transition from the inpatient phase to the community.

Some rehabilitation services had on-site schools, which allowed children to remain enrolled at the school following discharge from rehabilitation, if this provided schooling at the level appropriate to their needs and they were in the catchment area of the school. In these situations, the schools were stand-alone special schools rather than a support service to the hospital. In my opinion, an advantage of this system was the ability to integrate children into a meaningful, individualised educational program in a fully accessible environment, with availability of nursing and therapy support on site. Some fragile young people had their best opportunity of gaining some independence in this way, rather than full integration with one-to-one care.

Taking a different approach to education in the inpatient setting, some rehabilitation services offered individual tutoring (paid for by the student’s school district) which maximised curriculum participation, however did not provide the social skills training
and other opportunities of the therapeutic milieu. This system tended to occur in paediatric units within adult services. The commitment made by individual school districts to support their students meant that transport was provided for young people to attend integrated day hospital programs at the expense of the school district.

Community Rehabilitation Programs
In addition to the day hospital and community integration programs discussed above, most rehabilitation services provided outpatient services at various levels. Patients on rehabilitation programs continued to be reviewed at a Team Meeting with the Rehabilitation Specialist (physiatrist) in attendance. In this way, the physiatrist may participate on many treating teams. The following are examples of specific programs addressing the community-based needs of patients.

Home and Community Rehabilitation
The innovative Home and Community Rehabilitation at the Kennedy Krieger Institute in Baltimore, a program of short-term intensive rehabilitation in the community. This program is available to both children and adults, but is administered from within this paediatric facility.

The service is most commonly used as a transition between hospital and home, but may also be used for developmental transitions, for example, in achieving independence goals in adolescents with spina bifida or other chronic disabling conditions. It provides short-term, multidisciplinary rehabilitation in the home and community, for active goals, usually for periods of 1 – 12 weeks. Differing levels of care are offered under this program. The patient census of the service is usually around 15 – 20, with approximately 6.5 full-time equivalent staff and consultation by rehabilitation specialists and a neuropsychologist.

Home Care
Home Care allows patients to receive therapy at home if they are unable to attend outpatient appointments. This care may be provided by various agencies and services can include therapy, nursing and provision of a home health aide as indicated. Those children receiving multiple therapies at home require a case conference periodically to demonstrate progress toward identified rehabilitation goals. The rehabilitation physician chairs this conference. Thus, the paediatric rehabilitation specialist functions as a member of many teams as required to meet their patients’ needs and to satisfy Insurers’ requirements. This was evident in the Spaulding model (Boston), with local outreach to hospitals in the surrounding area and a strong consultation - liaison service.
The Medical Home

Not a place, but a concept of care, the Medical Home was a hot topic in Illinois, when I visited the Rehabilitation Institute of Chicago. Since returning from my Fellowship, further investigation reveals that several other states are also heavily committed to the Medical Home.

The Medical Home is a philosophy and a model, whereby primary practitioners (usually paediatricians in the USA) make a commitment to the care of children with chronic, disabling conditions. It is an initiative of the American Academy of Pediatrics. Along with local health authorities and condition-specific advocacy and support groups, they support the Medical Home by providing education, practice tools, resources and, in some cases, financial support.

The American Academy of Pediatrics (AAP) describes the characteristics of the “medical home” as follows. “…the medical care of infants, children, and adolescents ideally should be accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. It should be delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a partnership of mutual responsibility and trust with them. (ref: American Academy of Pediatrics policy statement, Pediatrics: 110 (1) July 2002, pp 184 – 186; available on the Internet at http://www.aap.org/policy/s060016.html).

This appears to be a superb system for empowering primary practitioners, who may not have sub-specialist knowledge in the area of the child’s condition, to take on the care of children with complex, difficult and time-consuming medical needs.

The information is largely web-based and, as such, is also readily available to Australian general practitioners and paediatricians, who may wish to take a more central role in the care of these children. Illustrative web sites include:

http://www.medicalhomeinfo.org
http://www.medicalhomela.org

By way of comment on this subject, Australia’s paediatricians fulfill a different role in the health system, not being primary practitioners. I would say that my general observation in the USA was that children with chronic and complex disabling conditions were more likely to receive care from multiple sub-specialists than here in Australia. The central role that Australian paediatricians already play in the lives of their complicated patients is to be applauded. Nevertheless, the Medical Home has much to teach us. Of particular note, the practitioner’s agreement to take on the care of children in need and the splendid resources developed (with substantial financial support from the community) to support this process.
Spasticity Management Programs

Botulinum Toxin Injection Programs

A large body of research literature now supports the use of Botulinum toxin injections in the treatment of spasticity. These injections have become widely available in Australia for lower limb spasticity. In the USA and Canada, their use was more liberal than here in Australia, with the drug generally being paid for on pre-approval by the Health Insurance Company or Medicaid.

Of great interest to me were the different models under which Botulinum toxin injections were given. In Australia, we generally administer this treatment, to children, under a conscious sedation protocol or with general anaesthesia. In the places I observed in the USA and Canada, this was the exception rather than the rule. Injections were usually given with local anaesthetic cream or spray in an outpatient setting, sometimes with some sort of diversion. It appeared to be well tolerated, especially in the hands of confident practitioners.

A major lesson from this was for us to look at how this medication can be given across different settings, especially with a view to making this treatment more available to patients living in rural and remote locations.

Intrathecal Baclofen Programs

The drug baclofen has long been available as an oral medication to help reduce spasticity. Its effectiveness orally is limited, however, because higher doses can cause undesirable side effects, such as sedation and dizziness. Intrathecal Baclofen Therapy (ITB) uses a pump, implanted under the skin of the abdomen, to deliver baclofen directly to the intrathecal space surrounding the spinal cord. Allowing the drug to be delivered directly to the site of action means much less medication is required to reduce spasticity significantly.

The ITB pump, about the size of a hockey puck (a more meaningful comparison for residents of North America!), attaches to a thin catheter, which is placed in the intrathecal space. The pump is programmed using an external programmer to deliver a precise amount of baclofen at specific times. The dose can be adjusted and the pump refilled as an outpatient.

ITB therapy reduces spasticity, especially in the lower extremities and trunk, and can improve functional abilities and independence, prevent contractures, reduce spasticity-related pain and make care easier for a care provider. On the other hand, ITB therapy can further weaken muscles that already lack strength - a concern for children whose neck and trunk muscles, for example, are weak. Careful patient selection and education of the patient, family and health care providers are essential success factors with this program.

Before an ITB pump is implanted, a test dose of baclofen is administered directly into a patient's spinal fluid. The patient's muscle tone then is monitored for several hours. If the test dose reduces spasticity without significant side effects, ITB therapy may be an effective treatment option.
Once an ITB pump is implanted, orthopaedic surgery may be needed to correct bony deformities and muscle contractures. In addition, physical and occupational therapy can help improve a patient's abilities once spasticity is reduced.

In rehabilitation services across the USA, Intrathecal Baclofen is widely considered to be the “standard of care” for individuals with severe spasticity. Children and adults with cerebral palsy, spasticity resulting from traumatic brain injury or spinal cord injury are all assessed for this treatment option. Other indications exist for adults. I saw these pumps in use in every centre I visited, with one exception. That exception was the Shriners Hospital of Chicago, who, as an organisation who did not ask for payment of any sort, did not have funding for this expensive therapy. However, those children were able to access the treatment through the Children’s Memorial Hospital in Chicago.

One issue identified by some of the paediatric providers of this service was the important issue of transition to adult services. ITB, once established and successful, becomes a lifelong treatment, with long-term compliance needed for pump refills and heeding low battery warnings, with pump replacement being required approximately every 7 years. Patients need to remain in regular contact with a doctor and/or nurse practitioner knowledgeable about tone assessment, the interrelationships between tone and function, and trouble-shooting pump problems.

There are also requirements for well-established emergency and after hours on-call arrangements once an ITB program is commenced, as after hours calls are frequent, and after hours emergencies are not rare.

**Selective Dorsal Rhizotomy**

A selective dorsal rhizotomy is highly specialised surgery in which selected nerve rootlets in the spinal canal are cut, easing spasticity. A neurosurgeon makes an incision low on a patient's back, creates a small opening in the spinal canal to expose the nerve roots, and separates each nerve root into its individual rootlets. The neurosurgeon then stimulates each rootlet with a small amount of electricity, while a paediatric rehabilitation medicine specialist watches the patient's muscles respond. If a muscle responds abnormally, the surgeon cuts that rootlet. Rootlets that cause a normal muscle response are left intact. More than 100 rootlets are tested during the surgery, and 20 to 45 percent of them are cut - enough to reduce spasticity while preserving sensation.

Because the surgery is irreversible, candidates for the procedure must be carefully selected. The most common group of children for whom SDR will be helpful are younger children, 4 – 6 years of age, with cerebral palsy, particularly spastic diplegia, in which the legs are affected more than the upper limbs and they have either the ability or the potential to walk. Patients and their families must also be willing and able to take part in long-term physical therapy following the surgery.
Gillette is a world leader in this neurosurgical technique. The critical success factors in their program appear to be:

- Spasticity Evaluation Clinic at which the neurosurgeon, orthopaedic surgeon, specialist physiotherapist and physiatrist (rehabilitation specialist) all contribute to patient selection and clinical decision-making.
- Use of 3 dimensional gait analysis and EMG studies to assist in selection of suitable candidates for the surgery.
- Fastidious operative technique with intraoperative nerve stimulation, monitoring of motor responses of the patient by physiatrist or physiotherapist and careful control of depth of anaesthesia.
- Use of SDR in combination with orthopaedic surgery to correct bony deformities.
- Post operative intensive, inpatient rehabilitation, for a minimum of 6 weeks, with a focus on slow re-education of motor skills.
- Ongoing intensive outpatient rehabilitation for 6 months or more, in which skills are consolidated and new skills are learnt.

**Conclusions and Recommendations**

The upper age limit of children and adolescents served by the rehabilitation institutions observed ranged from 17 to 21 years. It appeared that all services accepted children up to 16 years of age at their first admission. First admission between the ages of 17 and 18 (or 19 years) was flexible, with adolescents still living at home, having return to school / college as a goal, or having intellectual impairment / developmental disability tending to favour paediatric admission over an adult service choice. Most institutions appeared to discharge patients at age 21 years, and some restricted age for inpatient admissions, for example, to before 20th birthday for duPont hospital. Australian hospital and health services should consider the multiple advantages for young people in having access to a paediatric rehabilitation service, at least until school leaving.

- Inpatient Rehabilitation Services must be able to provide resource-intensive therapy and support to children and adolescents suffering functional impairment and disability resulting from catastrophic injury or illness, for example traumatic brain injury, near drowning, spinal cord injury or disease, or multiple trauma. Rehabilitation administrators have dealt with the “critical mass” issue in a variety of ways, but keeping the rehabilitation episode separate from the acute episode was a consistent feature.

In all services observed, therapists and other allied health staff had distinct rehabilitation caseload responsibilities. In addition, most staffing appeared to be program specific, with separate discipline structures to maintain discipline-specific training and support.
In the privately funded health systems of the United States of America, the accreditation bodies’ and insurers’ requirements have led to excellent systems of care pathways, resource development and family participation. In particular, I noted a focus on measuring satisfaction of the young person and family, and on awareness and measurement of pain, falls risk and prevention of complications. These are protocol-driven and appear to be faithfully implemented. On the down side, some negative outcomes of these systems included the insistence on seven day inpatient therapy by some payers, whether or not this was deemed a useful rehabilitation strategy by the treating rehabilitation specialists. “Therapeutic Leave of Absence” is a useful concept that may help families to understand their important role, and to achieve competence and confidence in caring for their disabled family member.

In Toronto, the merging of a number of separate rehabilitation services has resulted in a single, well-organized service. This has occurred under the banner of “Ontario’s Promise”, a nonpartisan initiative uniting individuals and organizations from all sectors of society to work together for the children of Ontario. Unification of government and non-government sectors offering services to the same populations presents opportunities for development of the highest quality services.

Group programs can be an effective and efficient mode of providing rehabilitation and the “class” therapy model in use at RIC is of particular interest for Rehabilitation Services, which have relatively small numbers of patients with diverse needs and goals.

- In rehabilitation services across the USA, Intrathecal Baclofen (ITB) is widely considered to be the “standard of care” for individuals with severe spasticity. ITB, once established and successful, becomes a lifelong treatment, and patients need to remain in regular contact with a team knowledgeable about tone assessment, the interrelationships between tone and function, and trouble-shooting pump problems. Consideration needs to be given to setting up this program in Queensland, and a “lifetime” approach for patients, with paediatric and adult specialists pooling their knowledge and skills may be a useful model for Queensland.

- Botulinum toxin injections for the treatment of focal spasticity are given under a variety of models in North America. A major lesson from this was for us to look at how this medication can be given across different settings, especially with a view to making this treatment more available to patients living in rural and remote locations.

- Consideration should be given to starting a selective dorsal rhizotomy program for the treatment of cerebral palsy. This treatment is not currently available anywhere in Australia. In Queensland, we have both have the facilities for 3-dimensional gait analysis and the rehabilitation service to provide the very important postoperative therapy. The critical success factors in the Gillette program need to be observed.

The Medical Home is an excellent systemic model for caring for persons with severe and complex disability.