

Toronto

**Acquired
Brain Injury**

Network

**REPORT OF THE
SLOW TO RECOVER TASK GROUP**

NOVEMBER 2002

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Toronto Acquired Brain Injury Network

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INTRODUCTION AND BACKGROUND

In 2000 a subcommittee of the Systems Coordination Working Group of the Toronto ABI Network reviewed the needs of clients with severe brain injuries. In October 2000 this subcommittee developed the *Severe Injury Report*, which identified key issues for clients with severe brain injuries, both following the acute phase of the injury and over the long-term.

As follow up to the issues identified in the *Severe Injury Report*, the Executive committee of the Network asked that a time-limited task force be assembled to examine gaps, needs and current resources in the acute phase (i.e., up to 2 years post injury) for clients who sustain severe injuries and who require slow to recover rehabilitation.

MEMBERSHIP AND FREQUENCY OF MEETINGS

It was determined that membership on the task group should reflect Network member organizations that either provide slow to recover rehabilitation or make referrals to these programs. Thus, a task group consisting of representatives from the rehabilitation programs that have slow to recover acquired brain injury (ABI) rehabilitation beds, Network acute cares organizations that refer clients to these programs and complex continuing care was assembled.

There was consideration given to inviting representatives from Community Head Injury Resource Services (CHIRS) as this organization works with clients over the long-term who have moderate to severe brain injuries. However, as the focus of this task group was on acute rehab, it was agreed that a representative from CHIRS would be consulted as needed depending on the direction of the work. Consideration was also given to inviting a representative from Bloorview MacMillan Children's Centre, the only pediatric provider of inpatient slow stream rehabilitation. However, as most of the issues identified a need to enhance coordination between the two adult providers of slow to recover rehabilitation, it was suggested that an invitation for a pediatric representative to participate be considered only as appropriate to the work of the task group.

The task group began meeting in January 2002 and concluded their meetings in November 2002. The task group met every 4-6 weeks with a total of 10 task group meetings and 3 subgroup meetings. For a complete list of members of the task group and subgroup, see Appendix A.

OBJECTIVES AND TERMS OF REFERENCE

The first few meetings of the task group were spent discussing the needs of clients who access slow to recover ABI rehab beds and refining the mandate and terms of reference of this task group.

It was agreed that this task group would engage in a thorough review of issues pertaining to clients who require slow to recover rehabilitation and that deliverables of this task group would include:

- Definition of slow to recover rehabilitation
- Information for providers and/or family members that describes slow to recover rehabilitation
- Guidelines to consider for providers when referring clients to slow to recover rehabilitation
- Outline/protocol of the referral process for slow to recover rehabilitation and management of slow to recover referrals while on the wait list
- Outline of current slow to recover services in Toronto including how each program defines slow to recover, the admission criteria and services provided
- Outline of services typically provided in complex continuing care programs – a location where clients are often discharged to await a slow to recover rehabilitation bed
- Characteristics of what the ideal system for slow to recover rehabilitation should look like
- Identification of gaps in service/recommendations based on review of current services and what is seen as the ideal
- Report to the Toronto ABI Network outlining the work completed and recommendations that arise out of the work of this task group

APPROACH

Once the terms of reference were developed, the first step was to establish a definition of slow to recover rehabilitation. To do this, representatives from Toronto Rehab and Bridgepoint (the two organizations that provide slow to recover rehabilitation) were asked to provide the task group with an outline of the services and admission criteria for these programs.

ADMISSION CRITERIA FOR SLOW TO RECOVER REHAB

In discussing the slow to recover program at Toronto Rehab, the following points were highlighted:

- Discharge is not based on a designated length of stay but on the client's functional needs and progress in therapy
- There are 5 slow to recover beds at TRI that are part of a 31-bed unit for clients with acquired brain injury
- The 5 slow to recover beds are funded differently than the regular stream beds
- Slow to recover clients have access to the same resources clients in the regular stream program do – the differentiation between slow and regular stream is largely for administrative purposes

With respect to admission to the slow stream program at Toronto Rehab, the following 3 factors were outlined as key in deciding if clients are appropriate for the program:

- Client demonstrates responsiveness to the environment
- Client is able to tolerate 10-15 minute sessions, 2-3 times per day
- Client must be medically stable

In review of the program description from Bridgepoint, it was clarified that there are differences in the slow to recover programs at Bridgepoint and Toronto Rehab. There is no difference in funding between the slow to recover ABI beds and regular stream ABI beds at Bridgepoint. Similar to the criteria for the regular stream program, Bridgepoint will only take clients at a cognitive level of Rancho V into their slow to recover program. The difference in the slow to recover program at Bridgepoint compared with Toronto Rehab is that a longer length of stay, i.e.,

3-6 months is anticipated. Thus, Bridgepoint admits clients who are at Rancho V into both the regular stream and slow to recover programs but for the latter, anticipate a long length of stay. Toronto Rehab admits clients who are at a Rancho V into the regular stream program but admits clients who are more severely impaired (i.e., Rancho level III-IV) into the slow to recover program.

It was noted that in addition to regular and slow to recover ABI rehab, Bridgepoint and Toronto Rehab both provide complex continuing care. In addition, Bridgepoint has an 'activation' program within their complex continuing care unit that is for clients who are continuing to make gains, but at a slower pace than clients in the slow to recover program (i.e., 6 months to 1 year). Clients are then discharged to the most appropriate location. These clients receive therapy 2-3 times per week. There are 10-15 activation beds on the 52-bed complex continuing care unit.

In a preliminary discussion as to the procedure for application to slow stream, it was suggested that there might need to be an additional sheet attached to the existing application that outlines the client's functional level in more detail, i.e., through use of the Western Neuro Sensory Stimulation Profile (used at St. Michael's Hospital) or the Kennedy Coma Recovery Scale (used at Sunnybrook & Women's). It was agreed that a subgroup would be assembled consisting of representatives from Toronto Rehab, Bridgepoint and acute care to review the current inpatient profile and determine if appropriate information is requested for a slow to recover application and decide if a separate sheet should be attached to the profile for slow to recover applications, i.e., the Western Neuro Sensory Stimulation Profile or the Kennedy Coma Recovery Scale. The subgroup was also given the task of developing a draft definition of slow to recover rehabilitation for review and further development by the larger task group.

WORK OF THE SUBGROUP

In order to develop a working definition of slow to recover rehabilitation, the subgroup found it easier to first describe the characteristics of clients who are appropriate for the program. Thus, the first accomplishment of the subgroup was to develop draft guidelines for providers to consider when referring clients to slow to recover rehab. Throughout the development of this document, subgroup members reviewed the content with their teams at their organizations and

brought feedback to the subgroup that was then incorporated into further changes of the document. Once completed, subgroup members used the guidelines as a framework to develop a definition of slow to recover rehabilitation.

In developing the definition, the most commonly used term, *slow stream* was discussed. It was suggested that a change of name to slow to recover conveys a more positive outlook in that clients accepted to this program are seen as having potential to recover, albeit at a slower pace. A draft definition based on the guidelines and this new terminology was developed and finalized with the larger task group (see Appendix B and C for Slow to Recover ABI Inpatient Rehabilitation: General Guidelines for Referring Facilities and Definition of Slow to Recover ABI Rehabilitation, respectively).

Through discussions among members of the subgroup, it was decided that it would be helpful to develop a one-page Family Guide to describe slow to recover rehab to families who have a loved one in acute care. As a first step to developing the Family Guide, subgroup representatives from acute care consulted with family members in the acute care setting about their information needs regarding slow to recover rehab.

Frequently asked questions were identified as follows:

- What is the difference between regular and slow stream rehab?
- What is the family's role in the client's rehab?
- What is the physical layout of the program/floor?
- What is the average length of stay?
- What are the staffing ratios?
- What happens if there are medical complications?
- How long is the wait list for slow stream rehab?
- What is the frequency of therapy the client will receive?
- What are the discharge criteria?
- What is a typical day in rehab?

As many of the answers to the above questions would not differ between regular and slow stream rehab, it was suggested that a one-page Family Guide be enhanced to describe all three inpatient

rehab programs at Toronto Rehab, Bridgepoint and West Park, with further information to clarify the difference in the slow stream program and length of stay. It was also suggested that a brief outline of the services provided in complex continuing care be included as this is often a destination for clients who are awaiting a slow to recover rehab bed. For a description of the services typically provided in complex continuing care please see Appendix D. The intention is for the Family Guide to be given to family members who have a loved one in acute care in Network organizations, as well as making it accessible via the Toronto ABI Network website.

Prior to piloting the information with clients and families, the content was reviewed by a consultant to adjust the format and reading level of the information. The Family Guide was piloted during the month of September 2002 at St. Michael's Hospital, Sunnybrook and Women's and Toronto Western.

The following information was captured in the pilot:

- Ease of understanding information/clarity
- Number of families piloted
- Whether English is their first or second language
- General helpfulness of the information
- Whether there is any missing information
- Whether the client is being referred to regular or slow to recover rehab
- Whether the Family Guide improved/facilitated the discharge planning process

The Family Guide was found to be a useful tool both for families who were English-speaking and for those who did not speak English as their first language. Both providers and clients/families indicated that they found the information helpful to communicate between them and as a tool to communicate information between family members. The results of the pilot were favourable in that 85% (11/13) of service providers who responded indicated that use of the Family Guide improved/facilitated the discharge planning process. Please see Appendix E and F for the Family Guide to ABI Inpatient Rehabilitation: Regular & Slow-to-Recover Programs and results of the pilot of this document.

At the time of this initiative, the ABI/MS Rehab Pilot project was in the process of developing an information transition guide to educate clients and family members about what to expect at the next level of service. It was noted that development of the slow to recover Family Guide was consistent with and not a duplication of the education package developed as part of the ABI/MS Pilot project. The education package describes the services at each transition and refers clients and family members to their healthcare team for more information about the services they will receive at the next transition. The one-page Family Guide will be given to family members to provide them with this next level of detailed information.

Thus, through the work of the subgroup and larger task group, members were able to:

- Establish consensus on admission criteria to slow to recover rehabilitation
- Develop a definition of slow to recover rehabilitation
- Agree on a change in terminology from slow stream to slow to recover rehab
- Develop guidelines for providers and family members to consider when referring clients for slow to recover rehabilitation
- Develop and pilot a one-page Family Guide on regular and slow to recover ABI rehabilitation and complex continuing care

REVIEW OF SLOW TO RECOVER DATA

In order to provide further background to the discussion about the needs of slow to recover clients, task group members asked that the Network obtain a sampling of the following data from slow to recover applications:

- Discharge destination
- Of the clients who were discharged home, how many had private funding?
- Severity of injury as measured by Rancho level at the time of application
- Length of time on the wait list, i.e., date of referral to date of admission
- Admission date relative to time of injury
- Age at time of injury
- Traumatic versus non-traumatic injury

This information was collected from a sample of 10 applications from fiscal 1998/1999 and 2000/2001 (20 applications in total). Note: In fiscal 1998/1999 and 2000/2001, the total number of referrals to slow stream was 43 and 51, respectively.

This data was manually collated. In review of this information, **the task group was cautioned not to draw any significant conclusions from the data for a few reasons:**

- The sample size was relatively small
- Processes in how applications on the wait list and designation of clients as slow to recover have changed, which limits comparison to more recent practices
- Outliers were included when calculating averages

Looking at the more recent data from 2000/2001, we see that the average time from date of injury to date of admission is approximately 9.5 months (or approximately 7 months if we remove the 2 outliers of 16 and 24 months). Average age at time of injury was 48.7 years. Three people (30%) were admitted from and discharged back to complex continuing care; one was admitted from acute care and discharged to complex continuing care; one was discharged back to the referring hospital; three were discharged home (30%); and there was no discharge destination listed for one. Please see Appendix G for the summary of this data reported to the task group.

REVIEW OF THE LITERATURE

A review of the literature was conducted using key words such as “slow stream rehab”, “slow to recover rehab”, “brain injury”, “head injury” - both traumatic and acquired. While the literature contains information on clinical outcomes of slow to recover clients, assessment tools and the effectiveness of treatment, it does not contain information on management of these referrals within an ABI system and does not address issues of access. However, the literature does indicate that people continue to make functional gains several years post injury.

In discussing the different slow to recover programs across the Network, Dr. Mark Bayley, Medical Director of the Neurorehabilitation Program at Toronto Rehab, indicated that research in the literature has not shown if there is a difference in outcome between clients who receive a greater intensity of therapy over a shorter length of stay versus clients who receive a lesser intensity of therapy over a longer length of stay. Please see Appendix H for references.

REFERRAL PROCESS AND WAIT LIST MANAGEMENT

The Toronto ABI Network maintains the waiting list for clients referred to the slow to recover program at Toronto Rehab where there are five designated beds for ABI slow to recover rehab. In the fall of 2001, Bridgepoint opened seven slow to recover beds to which clients with stroke and ABI may be admitted. The number of beds is not designated further for each population. The Network does not manage this waiting list however, applications for the slow to recover program at Bridgepoint are still referred through the Network office. At Bridgepoint, once an application is approved, it is maintained on the wait list based on the date of the application. This is different than how slow to recover referrals are managed by the Network office where applications are placed on the slow to recover wait list based on the date of acceptance to the slow to recover program at Toronto Rehab.

The Toronto ABI Network process for management of referrals on the wait list for the slow to recover beds at Toronto Rehab is as follows:

1. Application for slow to recover program is received at Network office
2. Application reviewed for appropriateness and completeness of information
3. If meets criteria, accepted to program by Toronto Rehab and put on wait list (managed by the Network) based on date of acceptance
4. If does not meet criteria, put into a “pending” file managed by the Network
5. Network communicates with referrers once/month to get updates on “pending” files and resubmits information for review by the admissions team

Please see Appendix I for illustration of this referral process.

It was identified that some organizations submit slow to recover referrals to the Network before clients are actually ready for the program. As long as organizations understand that clients are not put on the wait list until they are accepted, this practice can be helpful in situations where clients are transferred back to their community hospital and the trauma centre wants the Network to be aware of and track the client to ensure he/she receives ABI services when appropriate. It is recommended that the Network communicate this information to member acute care organizations to promote coordination and tracking of slow to recover clients.

In addition to ensuring clients who are referred back to community hospitals are connected to the Network, it was suggested that there may be some clients who are referred to complex continuing care who may improve such that they could benefit from slow to recover rehab later in their recovery. Thus, it was recommended that the Network send out an information package that includes the client profile and information on the slow to recover programs to complex continuing care programs across the Greater Toronto Area. In this way, complex continuing care programs will be aware of the Network should they have a client with an ABI who demonstrates improvement and a need for slow to recover rehabilitation.

REVIEW OF OTHER PROGRAMS

In addition to the ‘slow stream’ or ‘slow to recover’ ABI beds at Toronto Rehab and Bridgepoint, contact was made in March 2002 with the patient care manager of the extended rehabilitation program at Providence Centre as it was thought that Providence also provided ‘slow stream’ rehab. Information obtained regarding this program at the time of the consultation is as follows:

- Have 40 slow stream “Neuro-stroke” beds. Most clients have a diagnosis of stroke
- Clients admitted to the program have a reduced tolerance for rehab and need a longer length of stay, e.g., LOS is 3-4 months
- Approximately 75% of clients admitted to this program are discharged home with community service and/or family support
- Most clients admitted are older (mid-70’s) and may have had a 2nd stroke and thus require longer rehab
- The program provides a two week trial at home – if discharge is deemed unsuccessful, the client can return to Providence to await nursing home placement
- Services provided include physiotherapy, occupational therapy, speech language pathology up to 3 times/week as tolerated with occupational therapy assistants and physiotherapy assistants provided daily. Other services include nursing, recreation therapy and psychology consult as needed
- Beds are funded under complex continuing care

At the October meeting of the task group, Teri Czajka, Clinical Specialist, ABI Program, Hamilton Health Sciences gave a presentation on the ABI slow to recover program. Please see Appendix J for a copy of this presentation.

The admission criteria for the slow to recover at Hamilton Health Sciences program include clients who meet most, but not necessarily all of the following criteria:

- Minimally or intermittently responsive (Rancho 2-3)
- At least 6 months post-injury
- Severe physical deficits (SIRUS* 3)
- Significant nursing needs
- Medically stable

Clients may access the program at any point following their injury so long as they meet the admission criteria and there are defined goals. *This is a resource utilization measure that was developed by the Hamilton Program.

There are 5 slow to recover beds in the Hamilton program. These are located on a 32-bed unit that also serves clients with stroke and spinal cord injury. In the transitional (west-cottage program) there are 8 beds, 6 regional and 2 provincial beds. Clients who cannot access appropriate services within their region access provincial beds. In the behaviour (east-cottage program) there are 5 beds, which are located in the same unit as the transitional beds. In addition, there are also 10 provincial psychiatric behaviour beds.

The philosophy of the program is to enhance clients' quality of life. For example, helping clients establish mechanisms of communication, reducing the time on which they are dependent upon a tracheostomy to increase time allowable for community access. They assess clients in person in order to see their environment and resources available. They also connect with existing service providers and provide education to clients' direct providers/supports.

At the time of the presentation, the slow to recover program was staffed as follows:

- 1 clinical specialist: ½ time as a community intervention coordinator and ½ time as the coordinator for the slow to recover program
- 1 rehabilitation therapist
- 0.5 occupational therapist

- 0.5 speech language pathologist
- 0.4 therapeutic recreation
- 1 physiotherapist
- 0.5 social work
- Other services shared on the unit include nutrition, respiratory therapy, pharmacy, RN, RPN

The team at Hamilton Health Sciences convenes intake meetings twice per month for the slow to recover program. They use the same approach as the Network to manage the wait list in that clients are only put on the waiting list once accepted to the program and those accepted are deemed ready to enter the program. Further, a “pending” file for those clients not yet accepted into the program is maintained and clients’ status is monitored. They may sometimes bypass people on the waiting list to admit those clients who best fit with the needs of the unit at any given time and request take back letters on almost all referrals.

It was agreed that the Toronto and Hamilton slow to recover programs would try to communicate as much as possible, with client consent, when it is known that a client is on both waiting lists. This will enable the Toronto and Hamilton programs to determine which program best fits the client’s needs when a bed is available.

Further to the presentation by Teri Czajka of the Hamilton Health Sciences ABI slow to recover program and discussion within the task group, it was agreed that the Network would:

- Continue to maintain the waiting list for clients referred to the slow to recover program at Toronto Rehab in the same manner, i.e., place clients on the slow to recover wait list based on the date of acceptance to the program, maintain a ‘pending’ file for those clients not yet accepted and contact the referring organizations on a monthly basis to request updates on client status
- Whenever possible, facilitate communication between Toronto Rehab, Bridgepoint and Hamilton Health Sciences regarding common referrals to the slow to recover programs at various sites to ensure the client is referred to the most appropriate program to meet the client’s needs

SUMMARY AND RECOMMENDATIONS

Through review of the literature, consultation with other programs and discussions among members of this task group, the following *deliverables* have been achieved:

- Definition of slow to recover rehabilitation
- Information for providers and family members that describes slow to recover rehabilitation and includes information addressing frequently asked questions by clients and family members
- Guidelines for providers to consider when referring clients to slow to recover rehabilitation
- Outline/protocol of the referral process for slow to recover rehabilitation and management of slow to recover referrals while on the wait list
- Outline of current slow to recover services in Toronto including how each program defines slow to recover, the admission criteria and services provided
- Outline of services typically provided in complex continuing care programs – a location where clients are often discharged to await a slow to recover rehabilitation bed
- Improved communication between the Toronto ABI Network and Hamilton Health Sciences regarding referrals/management of mutual clients.
- Characteristics of what the ideal system for slow to recover rehabilitation should look like

Recommended steps to enhance communication about slow to recover rehabilitation include:

- Attach the definition of slow to recover rehabilitation and guidelines for referring facilities to the inpatient profile and post this on the Toronto ABI Network website (completed, summer 2002)
- Send an information package to complex continuing care programs in the Greater Toronto Area that includes the inpatient profile and information about the Network and slow to recover rehabilitation
- Post the referral process chart for how slow to recover referrals are managed on the Toronto ABI Network website

- Circulate the Family Guide to Network referring organizations and, to frequent non-Network referring organizations and post the document on the Toronto ABI Network website
- Explore the possibility of collaborating with acute care and rehabilitation partners to assist in funding translation of the Family Guide into other languages, i.e., Chinese, Korean, Vietnamese, Spanish, Portuguese.
- Share the Family Guide and definition developed by this task group with Bloorview MacMillan Children's Centre as some of the information may be used for families of children who require slow to recover rehabilitation.
- Ask Bridgepoint to communicate with the Network, via census reports, where ABI clients are on the slow to recover wait list at Bridgepoint.
- Consider the information required for slow to recover clients when next updating the inpatient ABI profile

COMPONENTS OF AN IDEAL SYSTEM

Through discussions among task group members, components of an ideal system were brainstormed as follows:

- Greater number of slow to recover ABI beds to facilitate more timely access to slow to recover rehabilitation
- Greater staff training and resource allocation for dual diagnosis clients who are slow to recover (e.g., clients with persistent, severe agitation, aggression and/or psychiatric needs)
- Greater number of appropriate discharge destinations for younger ABI clients who are severely injured
- If clients are being discharged to complex continuing care, the team in complex continuing care should be aware of the Network so that they may access service for ABI clients as required

While it is recognized that the Network may not be able to achieve all of these components, it is suggested that they be considered within a larger systems approach when advocating on behalf of the needs of individuals with a severe acquired brain injury.

SLOW TO RECOVER TASK GROUP MEMBERS

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**SLOW-TO-RECOVER ABI INPATIENT REHABILITATION:
GENERAL GUIDELINES FOR REFERRING FACILITIES**

ALL of the following are taken into consideration when reviewing ABI slow-to-recover applications:

- **Severe Brain Injury:** If applicable, clients typically present at Rancho* levels between III-V, i.e., demonstrate a localized response but which may be inappropriate; they often demonstrate confusion, decreased attention span, limited continuous memory, i.e., still experiencing post-traumatic amnesia.
- **Complex Needs:** Clients who are appropriate for slow-to-recover rehabilitation typically have complex physical, medical and cognitive needs requiring a specialized ABI rehab program and significant nursing care.
- **Attention/Responsiveness:** Clients appropriate for slow-to-recover rehabilitation are able to participate in 10-15 minute sessions, several times per day and demonstrate meaningful responses to their environment, i.e., able to communicate via verbal or non-verbal means, able to visually track and focus and able to demonstrate a consistent, purposeful motor response.
- **Slower Rate of Recovery:** Typically, there is a greater amount of time from the date of injury to the date of readiness for rehab (i.e., a few months). Clients demonstrate improvement/progress in the acute/sub-acute phase of recovery. Clients' length of rehab stay may vary widely and is determined by the progress demonstrated towards established goals appropriate for an inpatient rehabilitation setting.
- **Clients must be medically stable** i.e., a client's medical condition should not preclude him/her from actively participating in therapy sessions.
- **Clients with multiple pre-existing co-morbid conditions** may be suitable, though depending on the stability of these, clients may be more appropriate for other programs, e.g., geriatric program.
- **A plan for discharge post rehab** should be in place prior to admission and **letter of return** is often requested.
- Clients are typically **18 years or older**, however those younger than 18 will be considered on an individual basis.
- **Psychiatric needs:** Clients who require *acute* psychiatric care are not appropriate for ABI rehab.
- **Clients who demonstrate behaviours** that pose a threat to the safety of themselves or others through directed physical aggression are not appropriate for slow-to-recover rehabilitation.**

* Hagen, C. Malkmus, D. & Durham, P. (1972). *Levels of cognitive functioning*. Downey, CA: Rancho Los Amigos Hospital.

** An inpatient and outreach ABI behaviour program is available through West Park Healthcare Centre

For further information, please contact the Network office at 416-597-3057

DEFINITION OF SLOW-TO-RECOVER ACQUIRED BRAIN INJURY REHABILITATION

Slow-to-recover acquired brain injury rehabilitation (rehab) is an intensive rehabilitation program provided by an interdisciplinary team to individuals who:

- Have sustained a severe acquired brain injury
- Have complex cognitive, physical and nursing needs
- Demonstrate a slower rate of recovery

Slow-to-Recover rehab is one phase of a long-term recovery process. Many individuals will require additional services and support over the long-term following discharge from the slow-to-recover rehab program.

The wait may be long (e.g., months) to access slow-to-recover programs, as there are a limited number of slow-to-recover rehab beds in Toronto for individuals with an acquired brain injury.

Clients' length of stay in rehab may vary widely and depends on their progress demonstrated towards established goals appropriate for an inpatient rehabilitation setting.

SERVICES TYPICALLY PROVIDED IN COMPLEX CONTINUING CARE

For the purposes of this initiative, services typically provided in Complex Continuing Care (CCC) at Toronto Rehabilitation Institute, West Park Healthcare Centre and Bridgepoint Health were reviewed. The following is a description of the types of services typically provided within the Complex Continuing Care programs in these organizations.

Complex Continuing Care is not resourced for intensive rehabilitation. Rather it provides supportive therapies to patients and assists them and their families in adjusting to and living with significant life altering conditions including acquired brain injuries. Quality of life goals are paramount.

An inter-professional assessment is completed on each new admission. A care plan is then identified that supports patient/family goals within the context of the abilities of the patient and the resources available.

Physiotherapy (PT) and Occupational Therapy (OT) can be provided to a maximum of 2 to 3 times a week depending on the needs and the tolerance of the patient. If further progress is observed this will be integrated into the therapy interventions. If appropriate PT and OT can begin to assess and prescribe for wheelchair, seating and mobility needs; however, this may be too soon for ABI patients admitted to CCC while they await the availability of Slow to Recover rehab beds to continue a more intensive program that will potentially maximize their recovery.

Speech and Language Therapy (SLP) assess only by referral for swallowing, speech and language and AAC (Augmentative Alternative Communications).

Therapeutic Recreation will encourage participation in leisure and recreational activities based on the patients' abilities and interests. Community reintegration goals can be supported through the various outings planned.

Social Work begins adjustment counseling. It also assists patients and families with financial issues and social integration. Chaplaincy attends to the spiritual care issues that arise with traumatic injuries through pastoral counseling and grief and loss work with both patients and families.

FAMILY GUIDE TO Acquired Brain Injury Inpatient Rehabilitation:



REGULAR & SLOW-TO-RECOVER PROGRAMS

Who offers regular inpatient acquired brain injury rehabilitation programs in Toronto?

Three centres offer programs for patients with an acquired brain injury, also called ABI. They are:

- ✓ Bridgepoint Hospital
- ✓ Toronto Rehabilitation Institute
- ✓ West Park Healthcare Centre

Please turn the page for a chart comparing these centres.

What is a Slow-to-Recover program?

A slow-to-recover rehabilitation program is usually for patients who are recovering slowly from a severe brain injury. They often have complex medical needs. Toronto Rehab and Bridgepoint offer Slow-to-Recover programs.

How are people referred to an inpatient rehabilitation program?

The Toronto ABI Network directs all referrals to inpatient programs. Referrals depend on the specific needs of the patient. They also depend on the discharge policies of the patient's current hospital.

What is the average length of stay?

The length of stay is different for each person. It depends on how quickly he or she meets the rehabilitation goals. Remember, inpatient rehabilitation is just one stage in a long-term recovery process.

What is a typical week like in rehabilitation?

Patients see each of their therapists 4 or 5 times each week. Therapy sessions vary from 15 minutes to 1 hour depending on how well the patient tolerates the therapy. Patients may take part in individual and group therapy sessions. Most therapies take place on weekdays.

How can families help with rehabilitation?

Families can help by encouraging their loved one to work hard at rehabilitation. Families can visit often during the day/early evening and bring reminders of home (photos).

What if a patient develops medical complications?

Patients who develop medical complications during rehabilitation will be sent back to the referring hospital. If they need urgent medical treatment, the rehabilitation staff will send them to the nearest Emergency department.

How long is the wait for rehab?

The wait for regular inpatient ABI rehab may be a few weeks. The wait for slow-to-recover rehab is longer because there are only a few beds. Patients may have to wait many months and are often sent back to a community hospital or to a Complex Continuing Care program while they wait.

What is Complex Continuing Care?

Complex continuing care provides supportive therapies to people with complex injuries or progressive illnesses. It does **not** include intensive rehabilitation therapy. It provides specialized 24-hour inpatient care. The main focus of complex continuing care is to promote and enhance the patient's quality of life.

For more information on these and other ABI programs, please call the Toronto Acquired Brain Injury Network at 416-597-3057 or visit our website at www.abinetwork.ca

YOUR AT-A-GLANCE GUIDE TO INPATIENT REHABILITATION PROGRAMS

The Toronto ABI Network directs referrals to the organizations below. Referrals to each organization vary depending on the needs of the patient & discharge policies of the hospital he/she is currently in.

	Toronto Rehab ↓	Bridgepoint ↓	West Park ↓
Location →	550 University Avenue Near University Avenue and Dundas Street West	14 St. Matthews Road Near Broadview Avenue and Gerrard Street	82 Buttonwood Avenue Near Jane Street and Weston Road
Size of unit →	31-bed unit. All patients on unit have ABI.	9 ABI beds on a 50-bed rehab unit. Unit also serves people with stroke and bone-related injuries.	7 ABI beds on a 26-bed neuro- rehabilitation unit
Slow-to-recover program? →	Yes. 5 slow-to-recover beds on ABI unit. For patients at early stage in recovery.	Yes. 7 slow-to-recover beds for patients with ABI or stroke. For patients at later stage in recovery.	No slow-to-recover program.
Security →	Unit has a locked door. Entry code needed to get onto unit.	May wear a bracelet that alerts staff if patient tries to leave unit.	Open access to unit.
Room types →	<ul style="list-style-type: none"> ▪ Most rooms have 3 & 4 beds ▪ 1 semi-private room ▪ 2 private rooms 	<ul style="list-style-type: none"> ▪ 2 or 4 beds in each room ▪ No private rooms 	<ul style="list-style-type: none"> ▪ Most rooms have either 2 or 4 beds ▪ 4 semi-private rooms ▪ 2 private rooms
Washrooms →	Washrooms are located in each room. There are also 2 bathtub and shower rooms on the unit.	Washrooms and showers are in a central location on the unit.	Washrooms are in each room. Showers are located in a central area on the unit.
Other features →	Common area to eat, watch TV. Recreation & Leisure activities.	Common area to watch television. Recreation & Leisure activities.	Common area to watch television. Recreation & Leisure activities.
Getting there by TTC →	1 block north of St. Patrick subway station.	Take streetcar south from Broadview subway station or east/west along College/Gerrard Street.	10 minute walk from nearest TTC bus stop.
Contact →	(416) 597-3422 x 3593 or x 3441 www.torontorehab.on.ca	(416) 461-8251 x 2305 www.bridgepointhealth.ca	(416) 243-3632 www.westpark.org

For more information on these and other ABI programs, please call the Toronto Acquired Brain Injury Network at 416-597-3057 or visit our website at www.abinetwork.ca

FAMILY GUIDE: PILOT RESULTS

The form was piloted at three acute care centres during September 2002.

Number of Forms Returned:

St. Michael's Hospital - 5
Sunnybrook - 3
Toronto Western – 5
Total: 13

Is English the Family's first Language?

Yes - 6
No - 6 (two of whom could read small amounts of English enough to comprehend the form)
N/A - 1 (client had no family)

The client was being referred for:

Regular stream ABI inpatient rehab - 11
Slow to Recover ABI inpatient rehab - 2

Did the family need/ask for clarification on any items in the document?

Yes - 4*
No - 9*

If Yes, what did they ask for clarification on?

- Length of stay and how determined
- Could family stay overnight
- Which one was the best institution for rehab
- "So which is the best?"

*Of the four clients/family members who asked for clarification, two said English was not their first language. Of the nine clients/family members who did not ask for clarification, four said English was not their first language.

Did the family request any additional information?

Yes – 10
No – 3

If Yes, what did they ask for?

Is it covered by OHIP (2)	A Visit
What does parking cost at each place	Which facility was best (3)
Can family stay overnight	Visiting Hours (2)
Does anyone speak Portuguese	Can they choose their facility
What are their phone numbers (2)	
What would happen if their family member were not ready at the end of their rehab	

In your team's experience, did this information:

improve/facilitate the discharge planning process - 11
delay/complicate the discharge planning process - 0
no change - 2

Comments:

- Liked seeing # of beds as they were hoping for another facility than the one selected
- We tell patients that they have to take the 1st bed available at any facility, however the form is useful – particularly addresses & TTC info.
- S&WC felt it improved consistency of info given to families
- Family: 'helpful' to have info to bring home and discuss with rest of family prior to decision (ranking)
- Took form home to show her family
- Case manager comments – she is frequently asked for visitation policy/sleepover privileges & suggested adding info in "other features" e.g., library, park, grounds
- Contact info helpful (web page)

SLOW TO RECOVER DATA - REFERRALS TO TORONTO REHAB ABI PROGRAM

APPENDIX G

April 1998 - March 1999 Random sampling of clients admitted to the slow stream program at TRI in predetermined years

<i>Client</i>	<i>ABI or TBI?</i>	<i>Rancho at applic'n</i>	<i>Age at injury</i>	<i>Time on WL* - referral to date of Admission</i>	<i>Admission Date rel. to date of injury*</i>	<i>LOS</i>	<i>D/C Destin'n & Private \$?</i>
1	ABI - ICB	N/A	39	Sept 9/98 - Jan 7/99 4 months	Jan 7/99 - Aug 11/98 5 months	Jan 7/99-Oct1/99 9 months	Home No
2	TBI - MVC	??	79	Nov 23/98 - Feb 17/99 3 months	Feb 17/99 - July 14/98 7 months	Feb 17/99-Apr 1/99 2 months	Ad from & d/c to Nsg home - Yes
3	TBI - suicide attempt	??	38	Sept 17/98 - Nov 2/98 1 month	Nov 2/98 - July 8/98 4 months	Nov 2/98-Feb 5/99 3 months	Home No
4	ABI - ICH	N/A	48	Sept 21/98 - Nov 17/98 2 months	Nov 17/98 - July 22/98 4 months	Nov 17/98-Apr 29/99 5 months	Home No
5	TBI - MVC	3	24	Mar 30/98 - Apr21/98 1 month	Apr 21/98 - Feb 14/98 3 months	Apr 21/98-Jan 12/99 9 months	Yes
6	ABI - Aneurysm	N/A	40	Aug 6/98 - Aug 25/98 1 month	Aug 25/98 - July 5/98 2 months	Aug 25/98-Mar 17/99 7 months	Home No
7	ABI - Aneurysm	N/A	54	Dec 30/98 - Mar 4/99 2 months	Mar 4/99-Nov 19/98 3 months	Mar 4/99-Aug 5/99 5 months	Home No
8	TBI - Fall	4	45	Oct 29/98 - Mar 11/99 5 months	Mar 11/99 - Sept 29/98 6 months	Mar 11/99-June 23/99 3 months	TQEC No
9	ABI - Aneurysm	N/A	54	Sept 1/98 - Oct 1/98 1 month	Oct 1/98 - July 29/98 2 months	Oct 1/98-Feb 19/99 4 months	? No
10	TBI - MVC	??	27	Nov 13/98 - Dec 3/98 1 month	Dec 3/98 - Aug 17/98 3 months	Dec 3/98-May 4/99 5 months	Home Yes
			Ave Age 44.8	Ave time on WL** 2.1 months	Ave time from injury to admission 3.9 months	Ave LOS 5.2 months	

* Approximate (Calendar Days)

** WL data may be skewed as clients may have been designated slow stream post admission in 1998/1999

SLOW TO RECOVER DATA - REFERRALS TO TORONTO REHAB ABI PROGRAM

APPENDIX G

April 2000 - March 2001 Random sampling of clients admitted to the slow stream program at TRI in predetermined years

<i>Client ABI or TBI?</i>	<i>Rancho at applic'n</i>	<i>Age at Injury</i>	<i>Time on WL* - referral to date of Admission</i>	<i>Admission Date rel. to date of injury*</i>	<i>LOS</i>	<i>D/C Destin'n & Private \$?</i>	
11	ABI - SAH	N/A	59	Oct 5/00 - Mar 28/01 5 months	Mar 28/01 - Sept 25/00 6 months	Mar 28/01-May 2/01 1 month	Ad from & d/c to Nsg home - No
12	ABI - hypoxia	N/A	64	Aug 11/00 - Dec 5/00 4 months	Dec 5/00 - July 1/00 5 months	Dec 5/00-Feb 22/01 3 months	TQEC No
13	ABI - Hemorrhage	N/A	50	May 25/00 - Nov 20/00 6 months	Nov 20/00 - Apr 30/00 7 months	Nov 20/00-Feb 20/01 3 months	Home No
14	ABI - Aneurysm	N/A	74	July 26/00 - Dec 4/00 4 months	Dec 4/00 - June 28/00 5 months	Dec 4/00-April 25/01 5 months	Home No
15	ABI - SAH	N/A	60	April 26/00 - May 31/00 1 month	May 31/00 - Sep 21/98 8 months	May 31/00-July 14/00 6 weeks	Home No
16	TBI - Assault	II - III	27	June 1/00 - Sept 21/00 4 months	Sept 21/00 - May 6/00 5 months	Sept 21/00-Feb ?/01 5 months	TQEC No
17	TBI - Assault	??	25	Sept 9/99 - July 4/00 10 months	July 4/00 - July 12/98 24 months	July 4/00-Sept 5/00 2 months	Ad from & d/c to TQEC - No
18	ABI - Aneurysm	N/A	38	Dec 21/99 - Aug 2/00 7 months	Aug 2/00 - Apr 12/99 16 months	Aug 2/00-July 23/01 11 months	Ad from & d/c to CCC - No
19	TBI - Sporting	3	35	Oct 29/99 - May 15/00 6 months	May 15/00 - Aug 14/99 9 months	May 15/00-Nov 8/00 6 months	? No
20	ABI - Aneurysm	N/A	55	July 31/00 - Sept 6/00 1 month	Sept 6/00 - Nov 13/99 10 months	Sept 6/00-Nov 2/00 2 months	North Bay Hospital No
			Ave Age	Ave time on WL	Ave time from injury to admission	Ave LOS	
			48.7	4.8 months	9.5 months	3.95 months	

* Approximate (Calendar Days)

** WL data may be skewed as clients may have been designated slow stream post admission in 1998/1999

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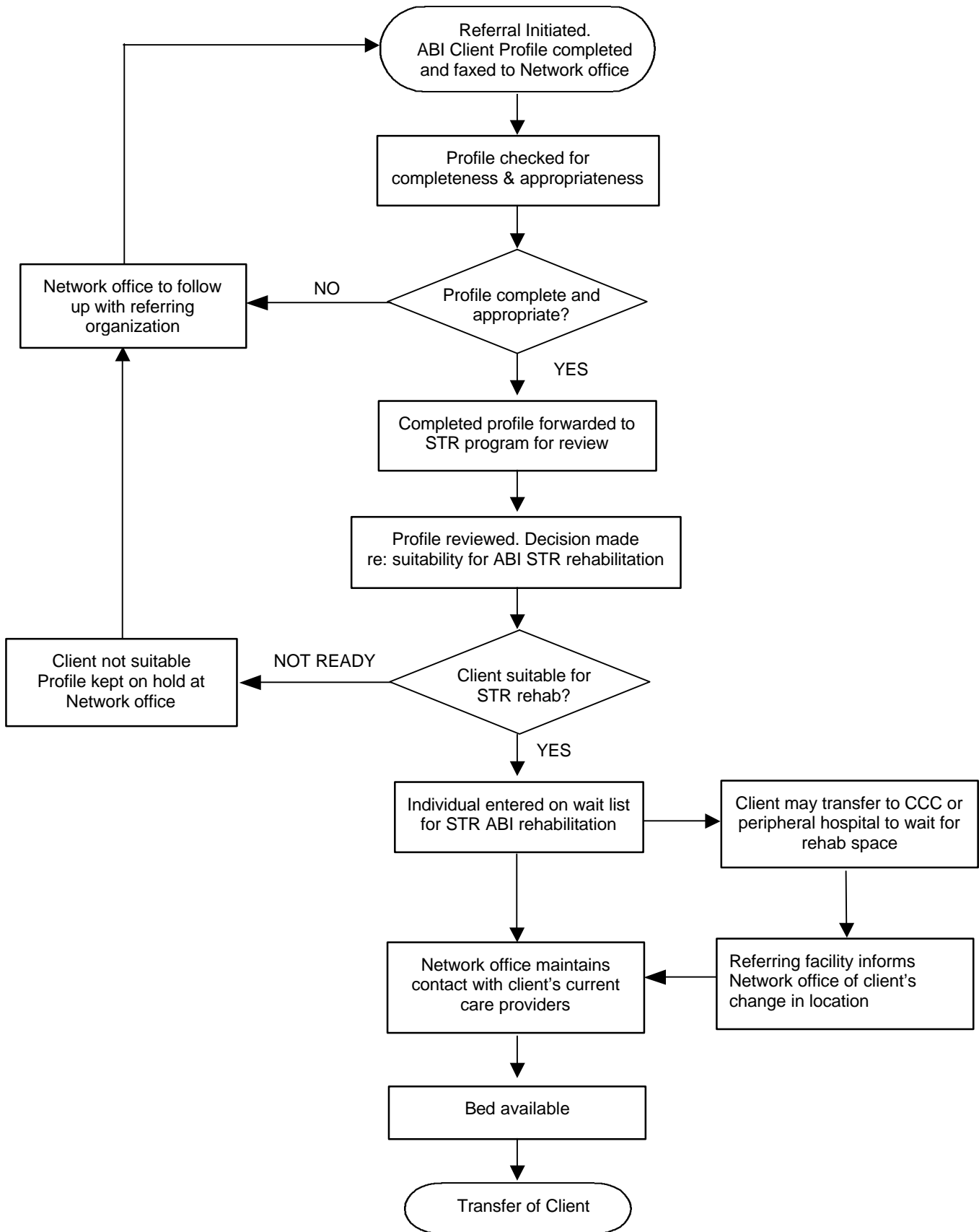
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Rehabilitation and the Slow-to-Recover Client

Hamilton Health Sciences
Acquired Brain Injury
Teri Czajka Clinical Specialist

Teri Czajka, HHS Clinical Specialist, TRJ October 2002

HHS ABI – In-Patient Resources

- Slow-to-Recover – Provincial (5)
- Transitional – Regional and Provincial (8)
- Behaviour – Provincial (5)
- Psychiatric\Behaviour – Provincial (10)

Teri Czajka, HHS Clinical Specialist, TRJ October 2002

HHS ABI – Community Resources

- Out Patient Clinic (primarily Regional)
- Out Reach (Regional)
- Crisis Team (Provincial)
- Community Intervention Coordinators (both)
- Community Services (Regional)
- Repatriation Monitoring (Provincial)

Teri Czajka, HHS Clinical Specialist, TRJ October 2002

Definition - Slow-to-Recover

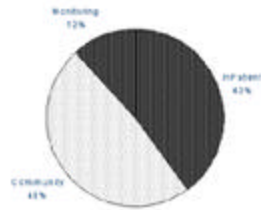
- Minimally or Intermittently Responsive
- At least 6 months post-injury
- Severe physical deficits (SIRUS 3)
- Significant Nursing needs
- Medically Stable

Not a sub-acute program

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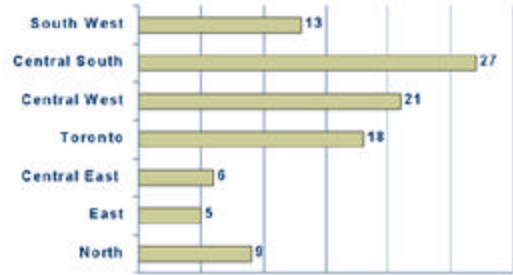
Referrals - Services Used

- Community:
 - OPC, OutReach, Consultations, Assessment
- In-patient:
 - current inpt., consultation before and after
- Monitoring:
 - Repatriation, OPC



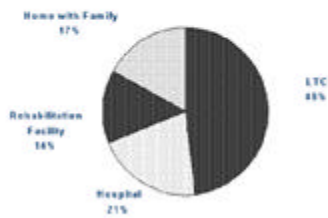
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Referrals - Region of Origin



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Referrals - Sources



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Referrals – STR

- ♦ Approx. 25 referrals yearly
- ♦ Approx. 14 admissions yearly
- ♦ Average LOS approx. 124 days
- ♦ Average waitlist approx 70 days

Teri Czajka, HBIS Clinical Specialist, TRJ October 2002

Rehabilitation and the Slow-to-Recover Client

Hamilton Health Sciences
Acquired Brain Injury
Teri Czajka Clinical Specialist

Teri Czajka, HHS Clinical Specialist, TRI October 2002

HHS ABI – In-Patient Resources

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Teri Czajka, HHS Clinical Specialist, TRI October 2002

HHS ABI – Community Resources

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- ♦ Out Reach (Regional)
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Teri Czajka, HHS Clinical Specialist, TRI October 2002

Definition - Slow-to-Recover

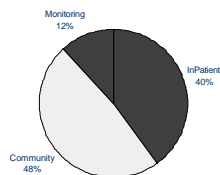
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Not a sub-acute program

Teri Czajka, HHS Clinical Specialist, TRI October 2002

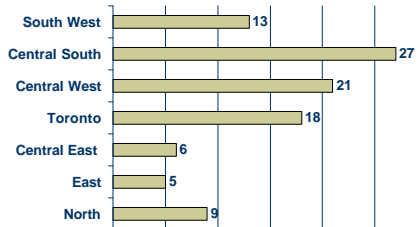
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 - Repatriation, OPC



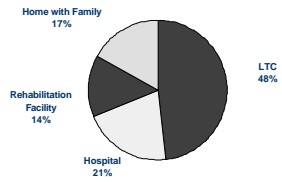
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Referrals - Region of Origin



Teri Czajka, HHS Clinical Specialist, TRI October 2002

Referrals - Sources



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TRI October 2002

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