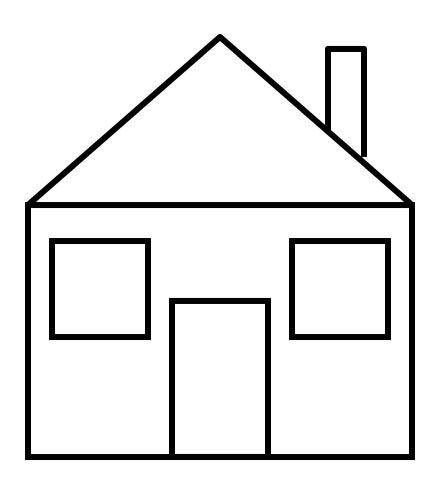
## Module VII. Recovering from Brain Injury- Rehabilitation, Treatment Planning, and Person Centered Planning

"I am a Lonesome Cowboy Far Away From Home" (Lucky Luke)



## **Instructions to This Module:**

- Get in contact with your Supervisor if you have problems accessing the State Plan on the Internet
- You are encouraged to talk to the ABI Program Manager to help you guide you through the State Plan and what to look for.

## **Objectives of This Module:**

- a) Understand the implications for rehabilitation
- b) Understand the models of rehabilitation
- c) Understand who belongs on the Brain Injury Rehabilitation Team
- d) Understand how to access the Utah Medicaid State Plan to identify if a consumer qualifies for Physical or Occupational Therapy

## What is known about mechanisms underlying functional recovery following ABI, and what are the implications for rehabilitation?

ABI represents an evolving dynamic process that involves multiple interrelated physiological components that exert primary and secondary effects at the level of the individual nerve cell (neuron), the level of connected networks of such neurons (neural networks), and the level of human thought (cognition). Many damaging changes to the connections among neurons (axons) and to the neurons themselves have been described. These include chemical changes to the basic molecules of metabolism (especially calcium), to mechanisms of the human cellular response to injury, and to the quantities of certain molecules that can be dangerous in excess (oxygen free radicals, nitric oxide). A protein substance that is present in Alzheimer's disease (beta amyloid) also can be deposited in neurons. Communication molecules in the brain (neurotransmitters) have either excitatory or inhibitory effects. The most prevalent of these excitatory molecules are the amino acids glutamate and aspartate, which can occur in massive amounts following TBI, leading to overexcitation and ultimately the death of neurons. At the cognitive level, alterations in neural networks and neurotransmitter systems (especially ones involving the transmitters acetyl choline, dopamine, and serotonin) can affect cognition and behavior. Although the pathophysiology of TBI is under intense investigation in animals, application of these findings to the understanding of neurobiological mechanisms underlying functional recovery in humans remains to be delineated. The relative importance of each mechanism to recovery potential at different stages after TBI remains unclear.

The basic mechanisms of injury and recovery have motivated the evaluation of experimental treatments in animals (e.g., protection of neurons from overexcitation or the effects of damaging molecules), whereas basic understanding of the capacity of neurons to grow and form connections with other15 neurons (cellular plasticity) has motivated others. The injured brain does have some capacity to recover. Elements of neural plasticity include increases of chemicals that promote growth of neural connections (growth factors) and alterations in the number and nature of these connections through changes in neuron structure. Promising strategies in neuroplasticity include nerve growth factors, other mediators of growth, and tissue transplantation. Ultimately, gene therapy may be a way to deliver such growth factors to targeted locations. Interventions to improve neural network and cognitive function may involve particular types of experience and stimulation (e.g., complex environments), with experience-dependent changes demonstrable in the biology of neural connections, small blood vessels, and even the organization of brain layers. The temporal course of recovery is probably lengthy (months to years), and the rate of recovery may vary over time. Recovery may incorporate particular substages that have unique pathophysiology. The temporal course may exhibit regional and functional differences. For example, at the cellular level, a particular type of cell death (apoptosis), which is normally present only during early brain development, may occur in different regions at different times, including many months following injury. At the neural network level, experience dependent changes related to activity or learning have been demonstrated at various times after experimental brain damage in animals.

Cognitive recovery proceeds in overlapping stages, with more marked improvements in particular skills occurring at different times. In addition, great variability in behavior is characteristic after ABI. Mechanisms currently used for reestablishing appropriate and adaptive behaviors in adults with ABI include learning, the development of supportive contexts, and environmental manipulations. These mechanisms focus not only on persons with ABI, but also on their families and the communities in which they live. Given the complexity of the recovery processes, treatment protocols likely will need to be carefully designed and systematically staged to introduce these potential therapeutic interventions consistent with the temporal sequence of pathophysiological and plastic events.

The gap between animal model studies of interventions and human clinical practice is particularly wide. Four reasons for this gap are (1) the differences between induced animal injury (e.g., fluid percussion injury) and human ABI, (2) the differences in severity of injury, (3) the timeframes of interventionsfor particular impairments, and (4) the presence of intolerable side effects. Furthermore, studies in animals are unable to address the complicated behavioral characteristics of human cognition after ABI. Successful study of brain/ behavior relationships after ABI may depend on comparing cognitive domains (e.g., learning, attention, concentration, and memory) with biological processes, which can be studied only in humans.

Several conclusions from this review are possible. The time course of ABI is prolonged and, in some cases, lifelong. The neural and cognitive mechanisms of injury and recovery are myriad, complex, and interrelated. Different underlying mechanisms are active at different times during recovery; consequently, specific interventions might have beneficial effects at certain times and not others. Although certain rehabilitative interventions probably should be started immediately, others probably should be delayed to maximize effectiveness and minimize adverse effect.

# What are the common therapeutic interventions for the cognitive and behavioral sequelae of ABI, what is their scientific basis, and how effective are they?

The goals of cognitive and behavioral rehabilitation are to enhance the person's capacity to process and interpret information and to improve the person's ability to function in all aspects of family and community life. Restorative training focuses on improving a specific cognitive function, whereas compensatory training focuses on adapting to the presence of a cognitive deficit. Compensatory approaches may have restorative effects at certain times. Some cognitive rehabilitation programs rely on a single strategy (such as computer assisted cognitive training), while others use an integrated or interdisciplinary approach. A single program can target either an isolated cognitive function or multiple functions concurrently. Despite many descriptions of specific strategies, programs, and interventions, limited data on the effectiveness of cognitive rehabilitation programs are available because of heterogeneity of subjects, interventions, and outcomes studied. Outcome measures present a special problem,

since some studies use global 'macro'-level measures (e.g., return to work), while others use 'intermediate' measures (e.g., improved memory). These studies also have been limited by small sample size, failure to control for spontaneous recovery, and the unspecified effects of social contact. Nevertheless, a number of programs have been described and evaluated. Cognitive exercises, including computer-assisted strategies, have been used to improve specific neuropsychological processes, predominantly attention, memory, and executive skills. Both randomized controlled studies and case reports have documented the success of these interventions using intermediate outcome measures. Certain studies using global outcome measures also support the use of computer-assisted exercises in cognitive rehabilitation.

Compensatory devices, such as memory books and electronic paging systems, are used both to improve particular cognitive functions and to compensate for specific deficits. Training to use these devices requires structured, sequenced, and repetitive practice. The efficacy of these interventions has been demonstrated.

Psychotherapy, an important component of a comprehensive rehabilitation program, is used to treat depression and loss of self-esteem associated with cognitive dysfunction. Psychotherapy should involve individuals with ABI, their family members, and significant others. Specific goals for this therapy emphasize emotional support, providing explanations of the injury and its effects, helping to achieve self-esteem in the context of realistic self-assessment, reducing denial, and increasing ability to relate to family and society. Although the use of psychotherapy has not been studied systematically in persons with ABI, support for its use comes from demonstrated efficacy for similar disorders in other populations.

Pharmacological agents may be useful in a variety of affective and behavioral disturbances associated with ABI. Although specific studies in persons with ABI are few, these agents are typically used in ABI for their direct and indirect pharmacological properties. People with ABI may be more likely to experience detrimental side effects from these drugs than people without ABI; therefore, additional caution should be used in prescribing and monitoring psychopharmacologic treatment. Behavior modification has been used to address the personality and behavioral effects of ABI. It also has been used in retraining persons with ABI in social skills. Many descriptive studies and a single prospective clinical trial provide limited support for the efficacy of this approach.

The value of vocational rehabilitation strategies, such as short-term and long-term supported employment and job coaching, is indicated by observational studies. This is particularly important since return to work is among the most significant outcomes of successful rehabilitation. Community colleges and other structured educational institutions may be valuable resources for some persons with ABI. For children, most rehabilitation services occur in the school setting. Children with TBI frequently attend special education services. The effectiveness of these services for children with ABI has not been well studied. Unfortunately, problems specifically related to ABI in children frequently are not identified. Comprehensive interdisciplinary rehabilitation treatment, provided by a diverse team of experienced professionals, is commonly used for persons

with ABI. These programs use individually tailored interventions, both restorative and compensatory, in order to achieve both intermediate goals in cognitive functioning and larger scale (global) outcomes.

This personalized approach leads to great difficulty in the scientific evaluation of effectiveness, because there is significant heterogeneity among both persons with ABI and their comprehensive treatment programs. Nonetheless, uncontrolled studies and one nonrandomized clinical trial support the effectiveness of these approaches.

Other interventions, such as structured adult education, nutritional support, music and art therapy, therapeutic recreation, acupuncture, and other alternative approaches, are used to treat persons with ABI. These methods are commonly used, but their efficacy has not been studied. There are many reports of interventions for family members of individuals with ABI, including psychological and social support and education. Although no empiric studies have evaluated the efficacy of these interventions, they are supported by substantial clinical experience. Despite the relative paucity of rigorous investigation and the heterogeneity of subjects, study design, and outcome, several common and consistently recurring themes emerge from a detailed review of the scientific evaluations of cognitive and behavioral rehabilitation interventions. Evidence supports the use of certain cognitive and behavioral rehabilitation strategies for individuals with ABI in particular circumstances. These interventions share certain characteristics in that they are structured, systematic, goal-directed, and individualized and they involve learning, practice, social contact, and a relevant context. It is important to recognize that a great deal of the scientific evidence to support the use of these approaches derives from relatively limited studies that should be replicated in larger, more definitive clinical trials.

## What can be recommended regarding rehabilitation practices for people with ABI?

- Rehabilitation services should be matched to the needs, strengths, and capacities of each person with ABI and modified as those needs change over time.
- 2) Rehabilitation programs for persons with moderate or severe ABI should be interdisciplinary and comprehensive.
- 3) Rehabilitation of persons with ABI should include cognitive and behavioral assessment and intervention.
- 4) Persons with ABI and their families should have the opportunity to play an integral role in the planning and design of their individualized rehabilitation programs and associated research endeavors.
- 5) Persons with ABI should have access to rehabilitation services through the entire course of recovery, which may last for many years after the injury.
- 6) Substance abuse evaluation and treatment should be a component of rehabilitation treatment programs.

- 7) Medications used for behavioral management have significant side effects in persons with ABI, can impede rehabilitation progress, and therefore should be used only in compelling circumstances.
- 8) Medications used for cognitive enhancement can be effective, but benefits should be carefully evaluated and documented in each individual.
- 9) Community-based, non-medical services should be components of the extended care and rehabilitation available to persons with ABI. These include but are not necessarily limited to clubhouses for socialization; day programs and social skill development programs; supported living programs and independent living centers; supported employment programs; formal education programs at all levels; case manager programs to support practical life skill redevelopment and to help navigate through the public assistance and medicalrehabilitative care systems; and consumer, peer support programs.
- 10) Families and significant others provide support for many people with ABI. To do so effectively, they themselves should receive support. This can include inhome assistance from home health aides or personal care attendants, daytime and overnight respite care, and ongoing counseling.
- 11) Rehabilitation efforts should include modification of the individual's home, social, and work environments to enable fuller participation in all venues.
- 12) Special programs are needed to identify and treat persons with mild ABI.
- 13) Specialized, interdisciplinary, and comprehensive treatment programs are necessary to address the particular medical, rehabilitation, social, family, and educational needs of young and school-age children with ABI.
- 14) Specialized, interdisciplinary, and comprehensive treatment programs are necessary to address the particular medical, rehabilitation, family, and social needs of persons older than age 65 with ABI.
- 15) Educational programs are needed to increase the degree to whichcommunity care providers are aware of the problems experienced by persons with ABI.

## What research is needed to guide the rehabilitation of people with ABI?

- 1) Epidemiological studies on the risk factors and incidence of ABI are needed for different age groups, gender, and race.
- 2) The relationship between substance abuse and ABI should be studied.
- 3) Existing CDC surveillance systems based on hospital discharge summaries or death records should be expanded to include emergency department encounters in order to augment the current database for research.
- 4) Studies of the placement of persons with ABI in nursing homes and psychiatric facilities are needed to clarify what constitutes appropriate placement.
- 5) The epidemiology of mild ABI should be studied.
- 6) The duration, natural history, and life-course manifestations (neurological, cognitive, social, psychological, economic, etc.) of mild, moderate, and severe ABI should be studied.

- 7) Gender differences in survival rates, patterns of severity, and long-term manifestations of TBI should be studied.
- 8) The consequences and effects of rehabilitation after ABI in the elderly should be studied.
- 9) The experience of minority group members with ABI should be studied.
- 10) Research training is needed in the areas of injury epidemiology and clinical research in order to enhance he quality of all research related to ABI.
- 11) The time course of TBI should be studied in animals with respect to injury severity, influence of age and gender, and effects of interventions.
- 12) Research is needed on the appropriate timing of therapeutic interventions after ABI.
- 13) Research is needed on the effectiveness of pharmacological interventions for the cognitive, behavioral, and emotional consequences of ABI.
- 14) The neurobiology of ABI in humans should be studied with modern imaging techniques (e.g., positron emission tomography [PET] and functional magnetic resonance imaging [fMRI]) and correlated with neuropsychological findings.
- 15) Promising treatments of ABI derived from animal studies should be tested in humans.
- 16) The epidemiology and management of ABI in sports should be studied.
- 17) Well-designed and controlled studies of the effectiveness of rehabilitation interventions are needed.
- 18) Economic analysis of ABI, including major determinants of costs, is needed.
- 19) Innovative rehabilitation interventions for ABI should be developed and studied.
- 20) The predictors of quality of life for persons with ABI, their families, and significant others should be studied.
- 21) Studies are needed to evaluate the relationship between specific cognitive deficits and global outcomes.
- 22) Validation of generic health-related quality of life assessment instruments for use in ABI is needed, as well as the development and validation of ABI-specific instruments.
- 23) Uniform standards and minimal data sets to describe injury type, severity, and significant interacting variables, which could provide a total injury profile across a continuum of recovery, should be developed.

Source: http://consensus.nih.gov/cons/109/109 statement.pdf

When individuals first began to survive head injuries, "spontaneous recovery" was thought to occur for 6-18 months. With the clock ticking, family members frantically attempted to pack rehabilitation into that small "window of recovery." Once the time expired (if not before) intensive structured efforts to regain skills ceased and it was assumed that the injured individual would make no further progress. It soon became painfully clear, however, that the major long-term problems faced by head injured individuals and their families were in the area of cognition and behavior. Physical problems, while important, were managed more readily than the decreased memory, impulsivity, poor judgment, and social inappropriateness, which frequently accompanied head injury. In fact, many family members discovered that if the injured individual remained in a wheelchair, he/she was much easier to supervise and control than when

fully ambulatory. The wheelchair itself served as a reminder that the injury had occurred and that some behaviors were no longer possible.

Fortunately, it has also become increasingly clear that even individuals who sustain severe head injuries continue to recover old skills and learn new skills throughout their lives when appropriate learning strategies and environments are provided. This does not mean that the individual is unchanged by the injury or will ever be exactly the same as before the injury: a wheelchair may be required for mobility, writing may be done with the non-dominant hand, or adaptive equipment used to perform some activities. The critical point is that individuals who have sustained head injuries, like the rest of us, have the ability to learn, to modify their behavior, and to lead satisfying and productive lives.

The following points may help family members understand head injury and the ways in which recovery can be maximized:

### Head injuries make the injured individual different but not necessarily worse.

The first task of a rehabilitation program is the identification of the injured individual's strengths and weaknesses. Within a medical model, this assessment may focus on CT scans, neurologic examinations, nursing and other therapy evaluations and, in some cases, brief neuropsychological screening. Such procedures, conducted in a medical setting, overlook critical data about how the individual functions in the home setting and how the individual's family deals with behavioral and cognitive problems. Furthermore, these assessments tend to focus on deficits to be remediate to the exclusion of assets, which could be developed and strengthened.

Even when the evaluations of health care professionals suggest that the injured individual will not recover, family members need to maintain hope. That hope should, however, be supported by detailed information obtained from health care professionals and supplemented by your own observations of the individual's behavior in a variety of circumstances. Pay particular attention to how the individual behaves in familiar environments with familiar people. Ask friends and neighbors for their observations. The more information that is used to make decisions, the better the decisions will be.

### Successful rehabilitation treats the whole person in his/her normal environment.

Since head injured individuals tend to have difficulty generalizing from one situation to another, rehabilitation efforts must consider the complete person at all times. Little progress will be made if speech therapy is conducted 2-5 times per week and never practiced outside the therapy setting. Similarly, if speech is only practiced in a seated position, the client may be unable to utilize new skills when standing or walking. The more new and emerging skills are practiced, the better they become. Repeated practice in a variety of settings facilitates making the new behaviors habitual.

### Behavior control must precede cognitive and physical rehabilitation.

The individual who survives a head injury may be confused, frustrated, angry, embarrassed, depressed or any of the other emotions we all experience. When simple everyday tasks become insurmountable challenges, the injured individual may lash out with words or fists, become extremely demanding, refuse to follow through on activities, which would lead to independence, or engage in a variety of other behaviors that, while understandable, are inappropriate and destructive. Family members may understand the reasons for such behaviors, but if they are tolerated they will continue and probably worsen. It is critical that the injured individual be required to behave as appropriately as possible at all times.

If the injured individual's behavior is out of control, it is unreasonable to expect new learning to occur. Therefore, it is critical to develop effective behavior control by changing the environment, the caregiver, or the injured individual before directly addressing cognitive problems. Until the individual can attend and concentrate, learning will not occur. Inappropriate behavior may preclude admission to a rehabilitation program and severely increases the stress on family and the head injured individual. Many behavior problems of the head injured individual have little to do with the injury.

## There is no such thing as a "plateau" in rehabilitation.

Many rehabilitation professionals expect head injured individuals to "plateau", i.e., cease making progress, at some point in their treatment program. This belief usually terminates the formal rehabilitation program and ignores what we know about human development: growth ceases only with death. It is much more useful to view periods of apparent lack of progress as times of "consolidation", where the individual is gaining sufficient practice with new skills to make them become habits. When learning skills are impaired, it is unreasonable to expect the individual to learn new information and behaviors every day. Allow the individual a chance to glory in success before presenting new challenges.

## Head injured individuals require tight structure in their daily lives to survive, grow and improve.

Most of us lead highly structured lives: we awaken at the same time, follow the same pattern in morning hygiene, eat meals at the same time, and work the same hours each day. Grocery shopping, laundry, etc. are done on a schedule. This kind of structure allows us to put most of our lives on automatic pilot and reserve creativity, memory, and novelty for more important areas. Far too often, head injured individuals have no structure in their daily lives and therefore accomplish very little each day: they nap throughout the day and then can't sleep at night; they eat meals at varying times and therefore can't recall if they have eaten at all; they leave things wherever they please and then can't find them. Tight structure reduces the need to continually make decisions, vastly increases the capabilities of the injured individual, and significantly reduces the demands placed upon the caregiver.

## The most effective rehabilitation following head injury occurs in familiar settings.

Since head injured individuals frequently have difficulty generalizing new skills from one environment to another and learning new information, the most effective rehabilitation programs occur in the home setting/community where old learning is maximized. When injured individuals are transported to another city or state, much of what they learn cannot be applied when they return home: the familiar cues which facilitated recall in the treatment setting disappear and the new behavior cannot be elicited. Therefore, whenever possible, rehabilitation should occur in the individual's home and community.

### Unconditional positive regard is unfair to the head injured individual.

Head injured individuals have enough problems without increasing their burden by accepting any and all behavior. If family members tolerate behavior, which drives others away, the injured individual becomes increasingly isolated from human contact and the burden on the caregiver becomes immense. The real world never offers unconditional positive regard and an individual who expects it will be sorely disappointed. One of the most constructive things you can do for head injured individuals is to provide accurate and realistic feedback on their behavior and its consequences.

## Brain tissue may not re-grow, but we have only begun to explore the ability of the brain and body to find creative ways to accomplish tasks.

Clinical practice and research are just beginning to explore the plasticity of the human brain and the results are overturning long-cherished beliefs about human potential. In my practice, for example, I have used hypnotherapeutic relaxation strategies to decrease severe ataxia and a variety of cognitive strategies to increase function in paretic extremities. In a more traditional vein, I have found that computers can be extremely powerful tools in rehabilitation. Unfortunately, the computer is a highly sophisticated tool, which can do more damage than good. It is critical that programs be selected to meet the needs of the particular individual and that the material is presented at the appropriate level. It is frustrating to discover a head injured person who hates computers because they were presented at an inappropriate time or used inappropriate material.

## One head injury is enough!

Individuals who sustain a head injury are 3 to 8 times more likely to sustain additional head injuries. Some of these added insults occur because of the cognitive and behavioral deficits following the original injury: the impulsive person who has poor judgment may repeatedly place him/herself in dangerous situations and then be unable to cope. Adequate supervision reduces the risk but does not eliminate the possibility of additional injury. What can be prevented, however, is the additional risk presented by:

- A) Exposure to toxic materials. Anyone who has sustained a head injury should avoid environments, which have high concentrations of fumes or toxic substances. This includes paint and solvent fumes, chemicals, non-prescription drugs and alcohol.
- B) Exposure to megavitamin therapy. Many vitamins and minerals are toxic in dosages above MDR and may interact in unknown ways with prescription medications or be metabolized differently by a damaged brain. A balanced diet may be one of the few pleasures left to a head injured individual and should meet nutritional needs without supplementation.
- C) Failure to use seatbelts and protective headgear
- D) Failure to take medications, particularly those required for seizure control, as prescribed.

#### WHAT IS THE REHABILITATION PROCESS?

- 1. The rehabilitation process is different for everyone. Rehabilitation programs should be individualized, catering to each person's unique needs. Just as no two people are exactly alike, no two-brain injuries are exactly alike. The person with a brain injury and his or her family should always be the most important members of the treatment team. Cultural, religious, social and economic backgrounds must always be taken into consideration when planning a person's rehabilitation program.
- 2. Rehabilitation channels the body's natural healing abilities and the brain's relearning process so than an individual recovers as quickly and efficiently as possible. Rehabilitation also involves learning new ways to compensate for abilities that have permanently changed due to brain injury. There is much that is still unknown about the brain and brain injury rehabilitation. Treatment methods and technology are rapidly advancing as knowledge of the brain and it's functions increases.
- 3. The goal of rehabilitation is to help people regain the most independent level of functioning possible.

### MODELS OF REHABILITATION

In the past, rehabilitation services for people with brain injury were largely provided in a "medical model," located in a medical facility with a cadre of physicians, nurses, and trained professionals providing services. While this model still predominates, the trend today is toward more community-based rehabilitation models, and more options are available than ever before. Rehabilitation service delivery and funding are changing rapidly as managed care continues to replace the traditional fee-for-service and indemnity insurance plans.

### **Medically Based Rehabilitation:**

Early intervention is crucial. Rehabilitation should ideally start in the Intensive Care Unit. At this point, rehabilitation is generally preventive in nature. Range of motion, bowel and bladder hygiene (i.e. initiation of regular bowel program and removing indwelling catheters), prevention of pressure sores, and orientation are all very important, right from the beginning. Frequently, rehabilitation activities initiated in the ICU can reduce complications and sometimes, the length of hospitalization.

Acute Rehabilitation: Once a person is medically stable, transfer to an acute rehabilitation facility often occurs. There, he or she will spend several hours a day in a structured rehabilitation program. This program usually includes a team of professionals with training and experience in brain injury rehabilitation such as Physical Therapists (P.T.), Occupational Therapists (O.T.), Speech-Language Pathologists (SLP), and Neuropsychologists. Additional staff support the brain injury rehabilitation team's efforts, and often includes case management, respiratory therapy, pharmacy, lab, nuclear medicine and radiology and dietary. A doctor with a specialty in Physical Medicine and Rehabilitation (PM&R), also known as a "physiatrist", may head up the team.

"Sub acute" Rehabilitation: People who are minimally aroused for a prolonged period often have limited attention and stamina, and need a less intensive level of rehabilitation services, over a longer period of time. Sub acute rehabilitation may be provided in a variety of settings, but is often in a skilled nursing facility or nursing home. It is important to note that the services provided by sub acute programs vary widely, as there is no generally accepted definition of sub acute services at this time.

It is important to recognize that "more therapy" does not make a person "better", but that "appropriate" therapy does. Sub-acute rehabilitation programs require the same appropriately trained professionals as acute rehabilitation programs do. The goals of sub-acute rehabilitation should include minimizing morbidity, maintaining functional positioning, hygiene, nutrition, and medication management, as well as providing support for the person with a brain injury and his or her family. Sub-acute rehabilitation programs may also be designed for persons who have made progress in the acute rehabilitation setting and are still progressing, but are not making rapid functional gains.

<u>Day Treatment/Day Rehab</u>: Day rehab (sometimes called "Day Hospital") provides intensive rehabilitation in a structured setting during the day and allows the person with a brain injury to return home to their family at night. The treatment team is often made up of a variety of the same sort rehabilitation professionals found in acute rehabilitation.

## **Community-Based Rehabilitation**

<u>Outpatient Facilities</u>: Following acute rehabilitation or sub-acute rehabilitation, a person with a brain injury may continue to receive outpatient treatment in specific areas (i.e. ongoing speech pathology to continue to work on cognition, or occupational therapy to

work on driving, physical therapy, and vocational therapy.). Often, this treatment can also be provided in the home by a home-health agency.

<u>Home-based Rehabilitation</u>: There are a few rehabilitation companies, which focus on providing acute rehabilitation within the home, or community setting. Once medically stable, some persons with a brain injury may be able to participate in such a program, if there is such a program in their community.

Community Re-entry: Community re-entry programs generally focus on developing higher level motor and cognitive skills in order to prepare the person with a brain injury to return to independent living and potentially to work. Treatment may focus on safety in the community, interacting with others, initiation and goal setting and money management skills. Vocational evaluation and training may also be a component of this type of program. Community Re-entry programs generally run for part or all of the day, with participants returning home to sleep and be with their families.

<u>Transitional Living Programs</u>: Transitional Living programs provide housing for persons with brain injury, with the goal of regaining the ability to live as independently as possible. Sometimes, programs will have several different levels, depending on the level of need of the individual. In addition to physical, occupational, speech and recreation therapists, these programs usually have life skills technicians, who assist the person with a brain injury acquire skills and learn compensatory techniques so they can live in the most independent setting.

Areas covered in brain injury rehabilitation programs may include:

Survivor need:	Example:
Self-care skills, including activities of daily living (ADLs)	Feeding, grooming, bathing, dressing, toileting, and sexual functioning
Physical care	Nutritional needs, medications, and skin care
Mobility skills	Walking, transfers, and self-propelling a wheelchair
Communication skills	Speech, writing, and alternative methods of communication
Cognitive skills	Memory, concentration, judgment, problem solving, and organizational skills

Socialization skills	Interacting with others at home and within the community
Vocational training	Work-related skills
Pain management	Medications and alternative methods of managing pain
Psychological testing and counseling	Identifying problems and solutions with thinking, behavioral, and emotional issues
Family support	Assistance with adapting to lifestyle changes, financial concerns, and discharge planning
Education	Patient and family education and training about brain injury, safety issues, home care needs, and adaptive techniques

## Who belongs to the Brain Injury Rehabilitation Team?

The Brain Injury Rehab Team will be working with survivors and their families to help the survivor become independent and understand the effects his/her injury.

The survivor is the most important member of the ABI Rehabilitation Team.

(M.D.) - The Physiatrist is a physician who is a specialist in physical medicine and rehabilitation. The physiatrist is the Team Leader who directs your care.

(RN) - The Nurse is also a very important person. She/he will:

- Assess you physically and obtain pertinent information necessary to design your personal care plan
- Take care of you and instruct you and your family so that you will be as independent as possible. The concept of independence is very important for

you and your family to understand, as nursing care is based on this goal. Your nurse will encourage you to do as much for yourself as possible - and then some!

Follow through with your other therapists' recommendations for your care.
 After the first few days, you will be given a daily therapy schedule. You will be expected to keep your therapy appointments on your own whenever possible. If you are unable to get to your therapy appointments independently, a transporter will assist you.

## SI<sub>(OT)</sub>

## (OT) - The Occupational Therapist will help you:

- Improve your well-being and prepare to return to a meaningful "occupation" or routine of day-to-day activities. These activities can include work, leisure, school, and social responsibilities. Daily activities, such as getting dressed, eating, preparing a meal, and bathing or using the toilet are often difficult to manage following a brain injury. The occupational therapist will help you relearn the skills necessary to perform these activities of daily living (ADLs) as independently as possible
- Learn to function with changes in your thinking and physical abilities by teaching you other techniques and the use of adaptive equipment. For patients in a coma, the occupational therapist works with other members of the Rehab team to provide a structured program of multi-sensory stimulation
- Increase your overall endurance and the strength and function of your upper body and arms, with splints or positioning aids when necessary
- Evaluate changes in your visual and perceptual skills and the impact of these changes on your functioning at school, work, and in the community, including driving, thinking, managing money, memory, etc.
- Design a treatment plan based on your injury and needs. The primary goal is for you to improve and relearn the skills necessary for living as independently as possible.

- The Physical Therapist is often thought of as a specialist in walking. However, for patients with a brain injury, physical therapy encompasses many aspects of function. Although walking is often a realistic goal, the physical therapist will:

- Help you meet other goals as well, such as:
  - Increasing the structure of your day
  - Increasing your upper and lower body strength
  - Improving function in all activities
  - Increasing your balance

- Obtaining maximum endurance and independence in mobility
- Instruct you in a variety of activities that you can perform to help you reach your goals, such as range of motion, strength, coordination, balance, mobility, and safety activities, and design a treatment plan to suit your rehabilitative needs, which may include a brace, orthotic device, or walker;
- Review any precautions your physician may have ordered, such as cardiac, safety, or orthopedic precautions, and instruct you how to incorporate them into your daily functional activities, such as using a cardiac monitor;
- Instruct you and a family member in a home exercise program or other activities that let you continue your strengthening program, and may recommend home therapy, day treatment, outpatient therapy, special equipment, or community resources following your discharge from the hospital

- The Speech/Language Pathologist addresses a variety of issues in brain injury rehabilitation, including speech quality (articulation), understanding and expressing the spoken and written (language/communication), thinking (cognitive skills), and swallowing problems. The speech therapist will:

- Thoroughly evaluate changes in communication and cognitive skills due to the brain injuryand the impact of these changes on day-to-day activities. For some problems, the therapist may recommend evaluation by a hearing specialist (audiologist) or an ear, nose, and throat doctor (otolaryngologist)
- Emphasize the relearning of cognitive skills which are affected by the brain injury, such as attention, memory, sequencing, planning, reasoning/problem-solving, judgment, and self-monitoring of thoughts and behaviors, and the ability to use the relearned skills in other settings and situations. The therapist works with other members of the Rehab Team to help the patient address cognitive skills in all daily activities
- Evaluate the skills necessary for effective school, work, and community
  functioning and focus on relearning those tasks that are specific to the individual's
  previous work or school responsibilities when possible. The therapist may consult
  with a vocational counselor for optimal assistance and may evaluate additional
  (augmentative) communication needs for patients who may require an alternative
  system to help them communicate needs and thoughts, such as a letter or word
  board or an electronic or computer system
- Evaluate and manage swallowing (dysphagia) problems

- The Recreational Therapist will focus on leisure activities, hobbies, and crafts that integrate goals and functional tasks begun in other therapies. An integral part of therapeutic recreation is the community re-entry program, which consists of outings into the community, movies, shopping malls, etc. These outings provide an opportunity for you to apply techniques learned during therapy sessions and reach

your maximum level of independence in the "real world." Family members are invited and encouraged to participate in the community re-entry program.

- The Psychology Department provides assessment and therapeutic services to you and members of your family who are learning to cope with the effects of your disability, whether temporary or long term. When illness or trauma causes changes in levels of function and lifestyles, support and positive motivation are crucial to a successful adjustment by you and your family. You may meet with a member of the psychology department several times a week, in individual or group sessions. Services provided by the psychology department include:

- Initial cognitive and emotional evaluation, as well as neuropsychological testing
- Individual and/or group psychotherapy to facilitate your involvement in the rehabilitation process, your adjustment to your injury or disability, and the alteration in your physical, cognitive, and emotional functioning.
- Marital and family therapy that focuses on changes in family dynamics caused by illness, trauma, and/or disability, as well as sexual counseling
- Biofeedback and relaxation techniques

- The Case Manager/ Support Coordinator is a vital member of your rehabilitation team. She/he will assist you with many aspects of your care, such as preparing and implementing your discharge plan, arranging meetings with you and your family, arranging a schedule for family observation and training days, working with other interdisciplinary team members, and working with your insurance carrier to communicate the rehab team's short and long term goals. Your case manager will also arrange any equipment and/or home modifications that may be necessary.

Source: <a href="http://calder.med.miami.edu/pointis/tbifam/tbiteam.html">http://calder.med.miami.edu/pointis/tbifam/tbiteam.html</a>

## Therapy services covered on the Utah Medicaid State Health Plan:

Physical Therapy and Occupational Therapy are therapy services covered on the Medicaid State Health Plan. The picture below shows you how the services are displayed in the Medicaid State Health Plan (Please see next page):

Source: http://health.utah.gov/medicaid/pdfs/PT.pdf

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### PHYSICAL THERAPY PROCEDURE CODES

## For Services by Independent Physical Therapists, including Group Practices, Not in Rehabilitation Centers

INSTRUCTIONS FOR USE OF CODES AND EXPLANATION OF TABLE READINGS
AMPUTATION - LOWER EXTREMITY
AM PUTATION - UPPER EXTREMITY
AMYOTROPHIC LATERAL SCLEROSIS
ARTHRITIS
OSTEOARTHRITIS (DEGENERA TIVE)
BELLS PALSY
BIRTH DEFECTS
BRAIN DAMAGE(other than Cerebral Vascular Accident)
BURNS
BURSITIS
CERVICAL RIB SYNDROME
CHEST SURGERY
CHRONIC OBSTRUCTIVE LUNG DISEASE
CVA - HEM IPLEGIA
DECUBITUS ULCER
DEGENERATIVE OR TRAUMATIC DISC DISEASE
EPICOND YLITIS
FRACTURED HIP
FRACTURE - LOW ER EXTREMITY
FRACTURE - UPPER EXTREMITY
GUILLAIN-BARRE' SYNDROME
LYM PHEDEM A
MASTECTOMY
MULTIPLE SCLEROSIS
MUSCULO-LIGAMENTOUS STRAINS AND SPRAINS
MYOCARDIAL INFARCT
MYOSITIS
NEURITIS OR NEURALGIA
NEURODEVELOPMENTAL DEFICIT
PARA PLEGIA AND QUADRIPLEGIA
PARKINSON'S DISEASE
PERIPHERAL NERVE INJURIES
RECONSTRUCTIVE HAND SURGERY
SCLERODERMA
SYRINGOM YELIA
THROM BOPHLEBITIS
TOTAL KNEE (FIRST TIME AND REVISION)
VARICOSE LICER 24

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The first ten visits are not prior authorized. All treatments beyond the first ten visits require prior authorization. Add a " GO" modifier with the Q0086 code when billing for occupational therapy.

#### BRAIN DAMAGE (other than Cerebral Vascular Accident)

CODES	COMMON DIAGNOSIS OR COMPLICATIONS	AG E	TYPES of PHYSICAL THERAPY	P A	COMMENTS
Q0086	Anoxia, encephalitis meningitis aneurysm tumor clot hemorrhage hydrocephalus contusion concussion decreased range of motion muscular weakness decubiti incontinence infection perceptual deficit decreased balance spasticity confusion and disorientation ataxias athetosis	all	Therapeutic exercise, neurodevelopmental therapy, ADL, gait training, bracing, patient and family education, home environment evaluation, equipment measurement and fitting, kinaestheic treatment supervised pool and hydrotherapy must be related to treatment goals	w	Average number of treatments: 48  Average duration of treatments: 12 months  This is a life altering insult.  Emphasis is placed on both physical and mental healing to reintegrate the patient into society. Keep independent.

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The first ten visits are not prior authorized. All treatments beyond the first ten visits require prior authorization.

Add a " GO" modifier with the Q0086 code when billing for occupational therapy.

### CVA - HEMIPLEGIA

CODES	COMMON DIAGNOSIS OR COMPLICATIONS	AG E	TYPES of PHYSICAL THERAPY	P A	COMMENTS
Q0086	Diabetes peripheral vascular disease decreased sensation spinal cord injury any other immobilizing disease or condition	all	ADL, gait training modalities, evaluation, electrical stimulation, equipment evaluation and fitting, home environment evaluation.	w	Average number of treatments: 30  Average duration of treatment: 3 month  Chronic This can result in a life altering insult. Emphasis is placed on physical and mental healing to reintegrate the patient into society.

#### PARAPLEGIA AND QUADRIPLEGIA

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The first ten visits are not prior authorized. All treatments beyond the first ten visits require prior authorization. Add a "GO" modifier with the Q0086 code when billing for occupational therapy.

CODES	COMMON DIAGNOSIS OR COMPLICATIONS	AG E	TYPES of PHYSICAL THERAPY	P A	COMMENTS
Q0086	Limited range of motion osteoporosis decubiti kidney disease malnutrition bladder and kidney stones	all	Therapeutic exercise, ADL, gait training, ultra-violet light, supervised hydrotherapy must be related to treatment goals, bracing, tilt table, home environment evaluation, equipment fitting and measurement (wheelchair, bath)	w	Average number of treatments: 48  Acute rehabilitation after initial diagnosis Emphasis on instruction and teaching by the physical therapist to establish independence.

## What do you do as the ABI Support Coordinator?

Be familiar with your consumer's Medicaid Identification Card, which states the name of each plan in which he or she is enrolled. Consumers enrolled in an HMO (health maintenance organization) and/or a PMHP (Prepaid Mental Health Plan) must receive all services covered by each plan through that plan. The provider obtains payment from the plan. Typically, each plan requires a provider to be affiliated and follow its coverage and authorization requirements. All questions concerning services covered by and payment from an HMO or PMHP must be directed to the appropriate plan. Telephone numbers for managed care plans and Prepaid Mental Health Plans are available.

Also access the web address <a href="http://health.utah.gov/medicaid/pdfs/PT.pdf">http://health.utah.gov/medicaid/pdfs/PT.pdf</a> to identify if your consumer is eligible for the services indicated on the Medicaid State Health Plan.

## **What Is Person-Centered Planning?**

The most important thing to know about people who have experienced a brain injury is that each person is different (just as each was, prior to injury). Each person has different goals, different capabilities, different challenges, different resources...Differences abound. But people with brain injuries are very similar to each other in that each is likely to experience strong frustration whenever he or she encounters others who seem to be

trying to help but do so by trying to fit him or her into a mold. For example, in a health care setting, a therapist or doctor might tell you what you *ought* to want to do with your life or what "people like you" want to do. Something similar may happen in a vocational rehabilitation agency, in a waiver program or in any of the variety of agencies that people with brain injuries have to deal with in trying to get their needs met. A common reaction is, "I'm not 'people like me', I'm me! Don't treat me like everybody else. Treat me like the person I am."

However, it often is hard for health professionals and others in helping agencies to understand that what they have to offer may not be what the person with an acquired brain injury (ABI) really needs and wants. Their training or the rules of the agency in which they work tell them that "one answer fits all" or "my goal for the client is the only one that makes sense". It is sometimes hard for professionals to see the person with ABI as an individual first and as a person-with-a-disability second. It is equally hard for them to see that real help may not focus on disabilities at all, but may focus on the person's capabilities as the basis for shaping a new life, when the old life is disrupted by brain injury.

To counter the difficulties that professionals experience in seeing people with traumatic brain injuries as individuals, methods have been developed over many years that can help them make the switch, so that they learn to place the person with ABI at the center of planning.

This means that the person with ABI now is asked, "What do *you* want to accomplish?" or "What are *your* goals, and how can we help?"

Methods for doing person-centered planning began about 30 years ago in the worlds of developmental disabilities and mental health. The idea was to use techniques of planning that respected the needs of people with these disabilities. And, if one is to respect the needs of a person, the person has to be a full participant in planning for their own lives. Respect requires that the individuality of the person be honored. Many methods for doing person-centered planning have emerged over the years, but they have certain common elements:

- First, planning involves not just the person with TBI (who we will call the "focal person"), but also friends, family members and others who are identified by the focal person as important to his or her life. This is often called "the circle of support".
- Second, the basic principle underlying all planning activities is respect for the focal person: it is his or her life, and it is his or her voice that has primacy in all activities of the circle of support.
- Third, a focus on capabilities and strengths replaces the usual 'tunnel vision', in which only the person's deficits and challenges are seen and then get defined as 'what gets worked on'. The focal person's challenges are not ignored, but they are not set at center stage.

- Fourth, the focal person's hopes and dreams for the future are the starting point for goals to be developed in the planning circle. A positive vision of the future is insured.
- Fifth, the plan that emerges from the circle of support (with the focal person still
  at the center) is a statement of priorities, with small action steps defined, as well
  as commitments from members of the circle of support. The focal person is alone
  neither in planning nor in carrying out the plan

## Person-Centered Planning differs for people with Brain Injury.

**Key difference:** Individuals with Brain Injury who want to move on after their Injury have to deal with "who I was" in addition to "who I want to be."

Brain injury typically creates a major upheaval in a person's life. Out of the blue, life changes. Often it is only through great effort that the life of the individual who has had the injury, and that of his or her family, can be re-shaped so that the individual can get on with life.

#### Remember

They may feel that control of their lives has been taken from them. In addition to feeling personal loss, people with Brain Injury often can feel overwhelmed. They may be disappointed in the lack of support that they are getting from the community or from agencies that are supposed to help them.

## A Person Centered Plan can help a Person with Brain Injury to:

- Feel whole again.
- Feel good about one's self.
- Have hope for the future.
- Create a vision of a good life

## Remember and consider when developing a plan with an individual with Brain Injury that he/she might deal with:

- short-term memory loss
- long- term memory loss
- slowed ability to process information
- trouble concentrating or paying attention
- difficulty with keeping up conversations
- lack of initiating activities
- difficulty in completing tasks

#### Source:

### http://www.mssm.edu/tbinet/alt/pubs/pubs10.html

Moving on: A personal futures planning workbook for individuals with brain injury. 2nd edition. New York: Mount, B., Riggs, D., Brown, M., Hibbard, M., Fedor, D., Campbell Korves, M., & Shields, R.W. (2003).

Research and Training Center on Community Integration of Individuals with TBI, Mount Sinai Medical Center.

#### Contributors to this module are:

- National Institutes of Health (NIH), "Rehabilitation of Persons with Traumatic Brain Injury." NIH Consens Statement 1998 Oct 26-28; 16 (1): 1-41 Web Site address: <a href="https://www.nlm.nih.gov">www.nlm.nih.gov</a>
- Louis Calder Memorial Library, University of Miami School of Medicine, with friendly permission given by Suzette Burrows. "The Traumatic Brain Injury Rehab Team." Web Site address: http://calder.med.miami.edu
- Mount, B., Riggs, D., Brown, M., Hibbard, M., Fedor, D., Campbell Korves, M., & Shields, R.W. (2003). "Moving On: A Personal Futures Planning (PFP) Workbook for Individuals with TBI and Facilitator's Manual 2nd edition." New York: Research and Training Center on Community Integration of Individuals with TBI, Mount Sinai Medical Center.

Friendly permission given by Wayne Gordon, to place a link to the workbook in this manual.

Web Site address: <a href="http://www.mssm.edu/tbinet/alt/pubs/pubs10.html">http://www.mssm.edu/tbinet/alt/pubs/pubs10.html</a>

Utah Department of Health- Web Site address: http://health.utah.gov/medicaid/pdfs/PT.pdf