

A Guide to Selecting and Monitoring Brain Injury Rehabilitation Services

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INTRODUCTION

The first critical step toward achieving maximum recovery is careful selection of rehabilitation services which best meet the needs of the person with brain injury and their family. The second, and equally vital step in the rehabilitation process, is to participate actively in the decision-making and the monitoring of service delivery. Active and ongoing participation means that you will be better prepared to make solid, informed decisions and to maximize available resources.

THE HEALTH CARE SYSTEM IN BRIEF

The advent of the Obama Administration in January, 2009 sparked renewed efforts to reform health care. Ensuring that all Americans have access to affordable health care insurance is difficult at best. Currently, numerous plans are being hotly debated by the Administration and Congress. For the latest news on developments that are important to all those affected by brain injury, go to the Brain Injury Association of America's website at www.biausa.org and select Policy and Legislation to find the Legislative Action Center.

The 1980's brought radical changes to the health care industry in the United States. At the same time, the availability of specialized brain injury rehabilitation programs and services grew dramatically. Competition became a hallmark of the health care industry as first the federal government and then private insurance carriers began to rethink the way health care services were paid for. Reform of the nation's health care system began in earnest in 1993 when the federal government began to wrestle with ways to reduce the rapidly rising health care costs.

While the first major effort to reform health care as a federally-led systems change was unsuccessful, it did spark a dramatic shift in the financing of health care services. The traditional fee-for-services model has given way to a wave of managed care models of funding and delivering health care services. Understanding the manner in which a particular managed care plan works and accessing medical and rehabilitation services has become increasingly challenging. Consumers must now make their way through "gatekeepers," accumulate referrals from a primary care physician to access specialized evaluation and treatment and appeal when requests for care are denied. The brain injury rehabilitation industry has changed in response to the growth of managed care, resulting in many mergers among provider organizations. Additional changes are expected as states recreate Medicaid programs into managed care models.

MODELS OF REHABILITATION

In the past, rehabilitation programs for people with brain injury were largely provided in a "medical model." While this model is still predominant, the trend is toward more community and home-based rehabilitation models. As the average length of stay in hospitals and rehabilitation facilities continues to fall, the importance of community services grows. Fortunately, providers of services are offering more community-based options. Negotiating with insurance companies, HMO's and other managed care entities to assure that a person with brain injury has access to the types, intensity and duration of services he/she needs is frequently necessary.

AN INFORMED CONSUMER MAKES THE BEST CUSTOMER

The purpose of this guide is to enable you to make well informed decisions about the services you or your family member receives. Through general guiding principles and specific questions, it provides a framework for the collection and evaluation of information regarding brain injury rehabilitation programs and services. Contact your Brain Injury Association state office or our national headquarters if you have questions or need additional assistance.

GUIDING PRINCIPLES

1. You Know Your Needs Best

People with brain injury and their families know themselves and their needs best. Rehabilitation professionals can help provide the information you need to make informed choices, but you have to live with the decisions you make.

2. Be Curious

Ask questions. Learn about the program, its staff and rehabilitation philosophy and methodology. If you do not understand something, insist that someone take the time to explain it in the detail you need. Rehabilitation is as much an "art" as a "science."

3. Learn From Others

When researching available programs, talk with at least three individuals who have participated in each program you are considering. You can benefit from listening to their experiences with the program.

4. Explore More Than One Program

There are hundreds of rehabilitation programs and services to choose from. The closest one, or the one which offers the most services is not necessarily the one that will best meet your needs. Many managed care organizations have established contracts with rehabilitation providers.

Since the beginning of the war in Afghanistan and Iraq, the military and veterans medical systems have been working to build internal services to serve the many service personnel who have sustained a brain injury. These efforts are still underway and the military has established contracts with a number of civilian rehabilitation providers. Options available under such both civilian and military/veteran healthcare plans may be

limited, but generally still offer more than one program to choose from. It can help to ask about other options and about when the plan makes exceptions to use non-contract providers when that would be the best option.

5. Listen to Your Instincts

Make decisions when you are ready. If you are unsure or uncomfortable, find someone who has no stake in the decision to help you sort things out. Be wary of anyone who tries to pressure you. If you feel pressured, report this to the program's corporate office, licensing agencies and accrediting organizations.

6. Get It In Writing

This cannot be emphasized enough! Keep a log of who you spoke to, the date, time and a summary of your conversation. Keep copies of all correspondence. During this emotional time, it is easy to forget information. You may wish to tape record your conversations so you can refer to them later. The person you are speaking with should readily agree to be taped. Get any commitments for services (the types and quantities to be provided as well as costs) in writing before you choose a program.

7. Looks Are Not Everything

The quality of rehabilitation services cannot be judged by how nice the facilities or marketing materials look.

8. The Ultimate Goal is Take Charge

Rehabilitation programs should promote self-determination to the fullest extent possible and maximize integration in the community. Self-determination can be achieved by taking charge of the decision-making process - for example, deciding how you wish to use your own time, energy and money.

9. Know Your Financial Situation

Talk with the insurance carrier, managed care organization or other health care payer to find out how much it will pay, for what services and under what conditions. Ask about deductibles and co-payments. Get a copy of your policy or plan and re-read it. Find out the extent of your financial obligations. Ask about the long-term implications of decisions you make today. Get regular (weekly or monthly) updates about where you stand financially with the payer and program. Find out about public or other private benefits you may be eligible for and apply promptly.

10. Be Involved

Distance is no excuse for poor communication. Participate in team meetings, even if that is only possible by teleconference or webinar. Establish regular verbal and written contact with key people in the program. Voice your opinions, questions and concerns promptly. You should be welcome to visit, observe or participate at any time.

11. The Customer is Always Right

As a consumer of brain injury rehabilitation services, you are the customer. While someone else may pay the bills, you are the one who must be satisfied with the

services provided. If you are not satisfied, work with the program and funding source to remedy the situation promptly.

In these difficult times, choosing brain injury rehabilitation programs and services may be the single most important decision you make emotionally, financially and in terms of outcome. Take the time to make good decisions. Once you are receiving services, stay on top of what is being provided and what other options exist. Be an informed consumer.

SPECIFIC QUESTIONS

The questions below may not apply to all programs in all settings. We encourage you to select those questions that make sense for your particular situation. There may be other questions you feel are important as well, so add them. Write down the responses you get.

Ask the same questions of each program you are considering, and then compare the responses. If you need more information, or something is not clear, do not hesitate to call the program and ask again. Please do not be concerned about the amount of time it may take you to ask the questions you have selected. Selecting a program that meets your needs is important. Monitoring services once they have begun is also important.

Refer to this guide from time to time and reflect on how well the program staff is doing what they said they would. Ask questions you did not consider during the selection process but which become important as rehabilitation progresses. Remember, information is power.

A. DISCHARGE PLANNING

Planning for discharge must begin at admission. It is imperative to have an understanding of what the next step is after discharge, as well as what kinds of services might be needed and their availability. Be clear about your intent to be involved in discharge decisions. As with other information, it is important to get discharge planning commitments in writing. It is virtually impossible for anyone to tell you the particular level of recovery that will be achieved. They can, however, commit to what they will do to achieve maximum recovery.

1. What are all the possible options after discharge?
2. What is the role of the person with brain injury and their family in decisions about discharge?
3. Where do you think the person will go after discharge?
4. How and who decides when the individual is ready for discharge? What would make the program extend or shorten the anticipated discharge date? If this is done, how much notice is given, and what is the role of the individual and their family in this decision?

5. What if a person decides to leave the program with or without advance notice?
6. How does the program help research discharge options? Who does this?
7. What kinds of follow-up after discharge are provided to the person with brain injury? What kinds of follow-up are offered to the family? Why is follow-up offered? How long is follow-up offered? What are the charges for this service?
8. What is the average length of stay?
9. How do I get a complete set of records for my files upon discharge? Is there a charge for this? How much will this cost and who pays?
10. Where are people with brain injury the program that your program served in the past now?
11. What happens if the place the person is expected to go after discharge falls through?
12. What happens if it appears the person has no discharge options except with family, and the family is unable to provide the care or supervision needed, or for any other reason they feel they are not a viable discharge option?
13. What does the program do to locate affordable community housing with a package of supports provided by a variety of state and community agencies to afford the individual the opportunity to live independently (i.e., transportation, recreation, vocational, educational and personal assistance)?

B. FINANCIAL RESPONSIBILITIES/ARRANGEMENTS

People with brain injuries have had to leave programs before they are ready because their funding has been exhausted. Large unexpected bills for rehabilitation services have surprised many people and dramatically changed their financial stability and status.

The best way to prevent these occurrences is to stay informed about your continuing financial strains both with the program and with your funding source.

1.
 - a. What is the daily cost of the program?
 - b. What does this include (room & board, medications, physician services, therapy, transportation, etc.
 - c. What services are billed as extra (i.e., telephone, laundry)?
 - d. How are charges calculated (e.g., per diem, per unit)?
2. What agreement does the program have with my funding source?

3. What do I need to do to get copies of all correspondence (including bills submitted and payments rendered) between the program and my funding source?
4. Who is billed for services my funding source will not pay for? What happens if the second source does not pay?
5. Am I (or is my insurance) billed for services which are planned or scheduled but not provided (i.e., if a therapy session is missed)?
6. What sources of funding does the program accept?
7. How do home visits or other leaves of absence affect payment? Is there a bed hold charge? If so, who is expected to pay if insurance will not?
8. What assistance does the program offer to determine which other public or private insurance and financial benefits the individual may be eligible for? How will they help you apply and follow the application process for these?

C. ADMISSION PLANNING

1. What are the rights and responsibilities of people participating in this program? How does the program inform the individual of these? Can I have a copy?
2. How do you make decisions about who to admit into the program?
3. How will you get previous medical and other important (i.e., school) records and other information you may need in order to make this decision?
4. I would like a proposed service or treatment plan before I decide. How can I get this?
5. How do you involve the program or service I am in now in the admission and transition process?
6. If I choose this program, what do you need to do prior to admission? How long will that take? What do you need me to do?
7. How can I arrange to spend a half-day or day observing the program?
8. What is your understanding of the role my funding source has in the decision-making process about the program I select?
9. What forms or contracts am I expected to sign prior to admission?
10. How can I get a copy of each to read thoroughly before I sign?

D. INVOLVEMENT OF FAMILY AND FRIENDS

The active involvement of family members and friends throughout the rehabilitation process is a key component to achieve maximum success.

1. How does your program involve family members and friends?
2. How are family members and friends involved in team meetings? How will we be informed enough in advance so we can plan to participate?
3. What do I need to do to get copies of written reports regularly? Who is responsible for sending me these?
4. How will you schedule regular conference calls for me to speak with the team if I cannot personally attend the meeting?
5. If I have a question about a particular area (i.e., physical therapy), what do I need to do to speak with that therapist directly?
6. What kind of family training, support groups and therapy is offered? Is there a charge for participation?
7. Since I live far away, what overnight arrangements are made for me to visit for a few days? How about for the person's friends?
8. What arrangements are made for staff to explain services and reports to me in non-technical terms?
9. What is your policy about visitors?
10. What are your policies which would affect friendships the person being served makes with other people served by your program? What provisions are made for them to spend time together as they might choose?
11. What arrangements are made if we wish to have conjugal visits?

E. LEGAL CONSIDERATIONS

1. How does a legal settlement affect the program's expectations about payment?
2. Has the program ever recommended guardianship, conservatorship or representative payees for people being served? Has the program ever recommended that these are no longer needed? If yes, what assistance is provided to the individual, family members or friends who choose to pursue the recommendation?

3. Is the program licensed? By which entities? How can I contact them to learn more about what they require for licensing? Can I see the license?
4. When was the last state or local inspection and what were the results?
5. Is the program CARF brain injury accredited? Any other CARF accreditation? When was the last survey?
6. Is the program accredited by JCAHO? At what level (1 year, 3 year, type 1) When was the last survey?
7. What recourse does the person being served have if they question or disagree with the quality or necessity of services being provided?
8. What recourse do family members and friends have if they question, or disagree with the quality or necessity of services received?
9. What provisions are made for personal banking services? Where do you keep money that belongs to people being served in your program? How do you account for money which is put into your program's care and who is responsible for this accounting?

F. PROGRAM

Every component of every program is not addressed here. For example, specific questions about physical therapy are not included. The components below are those which tend to have broad implications, that is, to touch more than one specific discipline, often simultaneously. You will also wish to ask questions about the philosophy and methodology used in specific disciplines that are central to the services needed in your individual situation.

A. Observations to make about aesthetics:

- 1 Are the facilities clean?
2. Are people being served clean and dressed in a manner you are comfortable with? Do they appear to be well cared for?
3. Does the staff seem attentive, to know people being served by name and to care genuinely about people in the program (i.e., do they stop in the hall to say hello or joke)!
4. Is the food appealing? How does the program accommodate special diets, personal preferences and requests for a different meal schedule? Is there any charge for this?
5. Do people being served seem comfortable with the way they are being treated? (It helps to ask them.)

B. Experience with people with brain injuries

(Note: answers to these questions may be available as part of the organization's listing in BIAA's National Directory of Brain Injury Services, available at www.biausa.org).

1. How many people with brain injuries has the program worked with in the past year? How many total individuals have they served?
2. What is the average staff turnover rate? Do they recruit people who have experience in serving people with brain injury? What staff training is provided?
3. How long has the program been in existence? When did it begin to serve people with brain injury? Why was it established?

C. Program administration and organization

1. Who is responsible for the overall supervision of the services rendered to people served? How often are they at the program? How much direct contact do they have with individual people served?
2. What types of people are part of the team? What are the state training and/or licensure requirements for staff? Does the staff meet these standards? Are there Certified Brain Injury Specialists (CBIS) on staff?
3. How does the program integrate the individuals expressed desires and goals in service planning? For example, if an individual dislikes to cook and will not be expected to cook at home, is cooking an expected program component? If it will take a person three hours to feed themselves, and they decide this wastes energy they would prefer to use in another manner, how will the program support them in this decision, and what assistance will be provided to find ways to have feeding done by someone else - both at the program and at home?
4. Is there a consistent schedule for an individual's day? What involvement does the person have in directing the schedule and selecting the program components?
5. What do people generally do during unscheduled times?
6. What is the evening schedule?
7. What is the weekend schedule?
8. How is the need for specialized adaptive equipment identified? How is the equipment provided and paid for?
9. What access do people being served and their families who have been authorized under HIPPA guidelines have to their records? If I wanted to see my record now, what would I have to do? What recourse do I have if I disagree with something in the record?

D. Medical services/medications

1. Who is responsible for providing medical services? What is their background? Is the same person available at different times, or are multiple medical practitioners used?
2. How is my personal physician included in providing medical services while I am in the program?
3. How does the program handle medical emergencies?
4. How are routine medical issues (i.e., regular dental and ophthalmology services) provided?
5. How would the program manage the special medical needs which have resulted from the injury?
6. I have heard that people can have trouble with bedsores. How does this program avoid or prevent this?
7. What is the policy for the use of psychotropic or other mood-altering medications? What role does the individual have in these decisions? What does the program do if they decline, against medical advice?
8. Who monitors medications and medication interactions? How often is this reviewed? What steps are taken to assure that therapeutic levels of medications are maintained and not exceeded?

G. Program components

1. Cognitive services:

- a. What approaches does the program use to address cognitive strengths and limitations?
- b. Is neuropsychological testing done? How much emphasis is placed in test reports on recommendations to build on an individual's cognitive strengths? How much emphasis is placed on reporting test scores and the person's limitations? When is retesting conducted?
- c. If a "cognitive therapist" or "cognitive remediation specialist" is a member of the team, what particular qualifications do they have? How is the effectiveness of cognitive services measured?

2. Behavioral interventions:

- a. What approaches does the program use to address behavioral concerns? What role do the individual and their family play in determining the types of behavioral interventions used?

- b. What steps does the program take to assure that behavioral interventions are clearly understood by all staff the person has contact with and that the plan is being implemented consistently by all staff (even at 3:00 in the morning)?
- c. How is the effectiveness of behavioral interventions measured?
- d. What role does medication play in "behavior management?"
- e. Are physical restraints used? In what circumstances? What policies or protocols exist for the use of physical restraints? Can I see a copy of these?
- f. Is a "secure" or locked unit available? When does the program recommend the use of these? Who decides when a person is ready for an open unit after being on a secure unit? How?
- g. At what point is an individual's behavior deemed unacceptable to the program? How much notice does the program give the individual and their family? What efforts are made by the program to assist in locating a comparable program that can better meet the needs of the person?

3. Vocational services:

- a. What is the extent of vocational services provided by the program?
- b. How are situational vocational evaluations conducted? How are job trials, training or placement provided? How are job coaches used? For how long?
- c. What interface is there between the program and state vocational rehabilitation services?

4. Educational services:

- a. What educational services are offered? To children? To college students? To adults?
- b. Does the program have a teacher on staff with expertise in educating children and adolescents with brain injury?
- c. What is the interface between the program and the person's school?

5. Community Re-entry:

- a. What components of the program take place in the community? How frequently is the individual in the community?
- b. How are the person's ability to get around and to use community services and resources evaluated and addressed?
- c. What local resources are used by the program to address the needs of the individual?

- d. How does the program accommodate an individual's request to participate in community activities (i.e., AA or league bowling)?
- e. What outreach does the program do to help educate the community about brain injury and its consequences?
- f. What does the program do to learn about the individual's home community and to identify resources and contacts there? What linkages are made with these resources and contacts prior to discharge?
- g. What efforts are made to work with the person in their home, even if the program is "facility-based?" How often can this be expected - once for evaluation only, or multiple times to prepare the person for the return home?
- h. What is the interface between the program and the local Independent Living Center?

6. Recreation:

- a. How does the program accommodate the individual's continued involvement in recreational interests and activities? Are modifications of activities or equipment suggested, and opportunity for situational exploration of the effectiveness of modifications included?
- h. What does the program do to support the individual's desires to become active in new recreational pursuits?
- c. How does the program help the individual identify ways to participate in recreation and social opportunities in their community?
- d. What interface does the program have with the local recreation department? With community therapeutic recreation services? With social support and activity groups?