A BROAD VIEW OF BRAIN INJURY REHABILITATION
COMMUNITY-INTEGRATED NETWORK OF EXCELLENCE

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Brain injury rehabilitation developed rapidly during the 1980s, and as a result confusion now exists as to what form of service delivery is preferable. The post-acute alternatives are hospital outpatient services or comprehensive treatment in residential programs (inclusive of day treatment) or home programs. In recent years, rehabilitation in the home has gained increased support as part of a pattern of social service deinstitutionalization and normalization. Financial providers have promoted this trend through a cost-containment strategy which supports timely “step-down” in rehabilitation service intensity.

It is difficult for most interested parties to argue against the benefit of home programs. After all, is not a return home what persons with brain injury strive for? The problem with the framework is that it can be too narrow in focus. A successful outcome for someone with a brain injury usually cannot be simply defined as a return home. This definition creates the danger of viewing the home as just another physical structure, the equivalent of an institutional or residential “bed.”

Home is only but one element of a community. When relationships are defined in broad terms, the community consists of:

- Family
- Peers, including work colleagues and friends
- Work, or more generally, productive activity
- Education and training
- Other supports such as government and charitable services

The community therefore consists of people and relationships, not physical structures. This allows the environment for post-acute rehabilitation to become much broader, with treatment goals defined in terms of social interactions encompassing the community, not only family in the home. The brain-injured person is thereby transitioned into normalized living settings, supported in relearning and taking risk in the community. It is through this broad focus that social isolation can be fully addressed as part of the treatment plan. Integration into the community is what creates an optimal and durable outcome for the benefit of injured person, family, and financial provider. Such integration will be best obtained when post-acute rehabilitation services develop into a Network of Excellence consisting of community-oriented “Centers of Excellence” and Practitioners of Excellence.

The Starting Point—Individualized Treatment

As health care has moved toward the home, the prevailing assumption has been that it has become more individualized. However, home and individualized treatment do not necessarily co-exist. The real issue is management of treatment services. Individualized treatment can occur only when treatment professionals involve the injured person and family in the treatment plan inclusive of long-term living goals. This involvement can occur in either a residential or home setting. Similarly, it is quite possible that such involvement can be restricted in a home setting in the rush to deliver a defined number of hours of therapy.

When an individual is involved in his or her treatment plan (and his or her family members, as appropriate), the relationship between the treatment professional and individual being treated changes. Dependency is transformed to personal accountability. Brain-injured persons are no different in this need for involvement and accountability. Due to the nature of the injury, treatment professionals and family members may strive to protect the injured person, thereby creating dependency in either a residential or a home setting. Isolation can exist anywhere—in an institution or in the home, if the individual is not integrated into his or her community.

A young adult transitioned “home” and not into the broader community may be as or more isolated than in an institutional setting. Home for a young adult in our society is more normally independent living in an apartment near potential peers and vocational opportunity. Transition into a parent’s home may not be the ultimate transition after all. By not considering a realistic long-term living environment, the durability of outcomes are often compromised, thereby undermining the value of an investment in rehabilitation and leaving the family without financial supports to complete a transition to a long-term living environment. This is a critical issue with home programs that must be carefully evaluated.

Part of the problem in assessing brain injury rehabilitation programs is that the unique needs of brain-injured persons are often not understood by some treatment professionals, family members, or financial providers. Definition of programs in facility terms is a superficial assessment criteria. For example, home treatment for medical interventions is not the same as for rehabilitation. The goal for medical interventions is usually life support and stabilization through an efficient and more user-friendly service delivery system. The goal for rehabilitation is generally physical and cognitive improvement and the development of compensating strategies. It is for community.

The Determining Factor—Functioning Levels

Functionality has become a widely used concept in all forms of rehabilitation. Whether the emphasis is on speech therapy,
physical therapy, or vocational rehabilitation, most rehabilitation professionals are addressing the need to relate treatment plans to functioning levels. This approach relates treatment to goals stated in individual behavioral terms, not directly to units of service. Functioning is the ability to perform a skill in a real world environment. An injured person may not fully recover a function even after therapy, but if he or she can perform the same function adequately, developing a compensating functioning strategy, an appropriate treatment plan has been designed and executed. The real issue for the injured person, family, and financial provider is whether functioning levels can be returned to a level of independence in living situations and personal productivity at work or in other environments.

Functioning levels can be an unfamiliar concept to some medical professionals because it defines post-acute rehabilitation in environmental terms as well as in therapy terms. This is absolutely essential for post-acute rehabilitation services. Facility-based therapies not involving the broader community run the risk of not generalizing in the real world whether they are provided in a residential program, a home program, or on an outpatient basis. There are many reasons why persons with brain injury require this emphasis on functioning levels reflective of community environments.

- The frequent loss of some frontal lobe functions reduces an injured person's ability to generalize skills and apply them independently in new environments.
- Rehabilitation requires an equal emphasis on skill application in the community as well as in skill acquisition. It is for this reason that driver training or simulated store situations in a facility and job skill training without a job coach will not generally meet the needs of brain-injured persons.
- Socialization issues relating to the environment are of utmost importance. Persons with brain injury need to learn to deal with a challenging world which generally does not understand their needs. They require support initially in the community in taking risks and making mistakes while rebuilding their self-esteem. Ultimately, isolation is the greatest risk to a successful long-term outcome.

If the goal of brain injury rehabilitation is to achieve functional outcomes, it is apparent that functioning levels should be considered in all aspects of treatment. Initial evaluations need to focus on functioning level. At that point, the treatment plan must consider three important issues:

- Management of risks in terms of "protecting" and challenging the injured persons;
- The quality and cost effectiveness of various forms of treatment;
- Consideration of environmental issues on an individualized community basis.

Due to the complexity of these issues, selection of post-acute brain injury rehabilitation programs needs to move past the arbitrary distinctions of residential programs versus home programs versus outpatient services. Any one of these options can be community oriented and ultimately effective for the right type of placement, whereas any one of the programs may limit the type of therapies available or be facility, not community, oriented.

**Management of Risk**

Risk is the essence of the human condition. Risk can be defined as the uncertainties associated with human activities. Life has personal meaning when we are allowed to take risks in living situations, in relationships, and in work and leisure activities. Persons with brain injury are no different. Both the treatment plan and the long-term living situation require consideration of risk. "Protection" from risks for liability reasons must be balanced by the use of risk as part of rehabilitation. Reintegration back into the community requires the use of controlled risk. For some injured persons, risks may always be controlled by families or an attendant, but for many others, risks will be self-managed on a long-term basis.

Management of risk, therefore, requires the involvement of the injured person, family, and the treatment professionals representing the service provider. Post-acute rehabilitation is an effective means to transfer accountability for risk when co-management of risk takes place with accountabilities transitioned during treatment.

Risk can be best managed when it is related to functioning levels. Current functioning defines the need for protection from risk, whereas functional outcome goals define the potential for therapeutic gain from risk-taking. Brain injury rehabilitation needs to encompass both aspects in treatment. It is for this reason that the management of risk needs to be assessed when selecting a post-acute rehabilitation program and related services. Potential limitations include:

- Excessive protection from risk in a residential program which is institutional in design, not community-integrated.
- Lack of focus on risk-taking in the community (the long-term living environment) in a home program oriented toward the initial transition only.
- Lack of supports in either residential or home programs in managing personal risks, particularly in facility-to-facility transfers. A transfer from a hospital or an acute rehabilitation setting to home can be just another facility-to-facility transfer if the community environment and related risks are not considered.

The ultimate test for programs is whether controlled risk-taking is supported. Both residential and home programs need to pass this acid test; otherwise they will be neither functional or community-integrated.

**Network of Excellence**

In response to the challenge of assessing so many brain injury rehabilitation options, there has been a call for the establishment of selection criteria for post-acute services based on the "Centers of Excellence" concept. All interested parties— injured persons, families, rehabilitation providers, and financial providers—would benefit from such an approach.
Families in particular need to hear of the importance of receiving the highest quality treatment versus the possible limitations of localized rehabilitation services.

"Centers of Excellence" are proposed through specialization, emphasis on best practices, and the deployment of a critical mass of rehabilitation services to ensure financial stability as well as treatment excellence. Apart from quality staff, it is essential that staffing consists of mostly full-time employees and that there be tenure in key positions. Staff turnover in clinical positions can indicate program weakness. An untrained staff or staff unfamiliar with each other will not produce the best outcomes, regardless of credentials.

The “Centers of Excellence” concept has great potential for improving the quality of brain injury rehabilitation. Quality will be best obtained from an open system in which post-acute rehabilitation providers compete in terms of quality measures. A closed system in which the choice of “excellent” rehabilitation providers is restricted is contrary to the interests of injured person, families, and financial providers. Today’s “Center of Excellence” can become tomorrow’s inferior option if there is no incentive to compete on the basis of quality and cost effectiveness.

Apart from the need to ensure that provider quality is recognized, but not protected as part of a closed system, the interests of the injured person and family need to be considered. Once medical stability is achieved, centralized approaches in acute medicine must give way to community approaches in post-acute rehabilitation. It is implicit that a focus on functioning levels and functional outcomes requires a broad view of the community. Therefore, “Centers of Excellence” cannot fall back on a centralized approach to rehabilitation.

The optimal solution will be a Network of Excellence consisting of “Centers of Excellence” and Practitioners of Excellence tied in an informal network of services consisting of the following components:

- Residential programs capable of community-integrated rehabilitation from the onset of treatment and through the use of re-entry teams in remote locations or transition to a local home program.
- Home programs which can provide rehabilitation for single-functional deficits in the community, not just the home. When comprehensive services are required, a residential program is likely to be the optimal location. The costs and logistics of delivering interdisciplinary therapies into a home are generally excessive and the use of contract staff has its limitations.
- Outpatient services to handle ongoing single-functional deficits of a physical or speech nature after transition out of a residential program, home program, or hospital.
- Individual practitioners knowledgeable in rehabilitation (physiatrists for example, who will remain the family physician for the long-term on medical rehabilitation issues).

A developed Network of Services will involve communication and transfers between programs within the same company or cooperative group and between unrelated companies and groups. If the needs of injured persons and families for functional and community-integrated rehabilitation across wide geographies are to be met, it is apparent that no one company or group can meet all individual needs. A Network of Excellence rooted in ethical and clinically appropriate admission and discharge practices will ensure that all of these interests are appropriately balanced.

**REFERENCES**