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Special Projects and Demonstrations for Spinal Cord Injuries

SECTION 1

(a) Research Project Design

RESEARCH AIMS

"NIDRR research focuses on crucial areas of functional loss, disability, and socio-environmental aspects of the continuum. In keeping with the new paradigm, NIDRR emphasizes the importance of explicating the connection between the person and the environment, an interface that determines the disabling consequences of impairments and conditions. This study of the dynamic interaction among various individual and environmental variables requires NIDRR's continued and increased attention to shaping the structure, management, and capacity for research. Methodologies are needed, often in an interdisciplinary context, that can illuminate multiple facets of disablement and enablement from numerous perspectives." (Federal Register, 64, 234, p.68584)

Impelled, in part, by the above paragraph, the Texas Model Spinal Cord Injury System (TMSCIS) is proposing an analytic longitudinal investigation of disability models to explore and quantify the interaction among various individual and environmental variables. The two most prominent models for consideration in this investigation are the models proposed by the Institute of medicine (IOM) (Brandt et al., 1997) and the World Health Organization (WHO) International Classification of Functioning and Disability (World Health Organization, 1999). Models are abstract representations of theories of disability and functional limitations in that they attempt to show how different aspects of functioning and disability are related to each other. These two models demonstrate the complexities involved in investigating disability. However, models are only theoretical unless they are tested and supported by data. Therefore, to better understand the intricacies of the interrelations involved in these models, they need to be tested for fit with objective data. Methods exist that can analytically investigate models of this complexity (Hoyle, 1991; Hoyle, 1995; Bollen, 1989).

When investigating complex models, measurement issues become very important. The first step in testing a model is to select measures that will define (operationalize) the concepts included in the model. This complete set of measures that will sufficiently define models for testing is called the measurement model. TMSICIS is planning to utilize current state-of-the-art Item Response Theory (IRT) and measurement procedures to construct the measurement models (Hambleton, 1989; Hambleton et al., 1991; Nunnally et al., 1994). These IRT techniques will not only provide interval level measures derived from the observed ordinal data from the measures chosen for the measurement model, but will also provide more information than classical theory.

The research plan outlined in the following sections will make several unique and significant theoretical contributions to spinal cord injury rehabilitation. First, this investigation will improve the methods used to investigate the full spectrum of disability, as conceptualized by the IOM model. By operationalizing the entire continuum of the current models of disability, the investigators will be able to clarify the complex interrelations of the many variables, factors, and processes that are involved in the enabling/disabling process during the first two years following injury; and move toward a quantification of disability that is measured in terms of the ratio of the individuals need and the environmental supports available to meet those needs. Second, this investigation is intended to expand the current theory by operationalizing the IOM model of disability. By defining measures and determining the fit of the model to observed data, it will be possible to delineate the interrelations that exist between variables when considered as a complex dynamic system. Third, testing these comprehensive models of disability with longitudinal data, will allow the investigators to develop and test models of service delivery and understand the influences of specific variables such as hours of therapy, therapy intensity, or therapy efficiency (Graves et al., 1999). Fourth, longitudinal data will allow investigation of the complex interaction of person and environment variables, over time, with methods appropriate for the complex nature of the subject.

The investigators propose that this investigation will also make several significant methodological contributions. First, that the methods chosen for this investigation will demonstrate the utility of SEM and IRT models in combination. Second, that the combination of state-of-the-art measurement methods with comprehensive statistical techniques will not only improve upon past methods but, also extend current theory into practical application for

hypothesis testing and program evaluation. SEM is designed to test theoretically derived models with complex interrelation of variables (Hoyle, 1995). Many other multivariate statistical methods utilized in disability research (e.g., factor analysis, analysis of variance, multiple regression etc.) are limited in how interrelations between variables are explained (Chinn et al., 1995). While these methods are well suited for specific isolated investigations, when attempting to understand the interrelation of variables in a complex model, the limitations of these methods can lead to spurious results and obfuscation of the true nature of disability and functional limitations. Third, that by defining a measurement model for the IOM model with efficient theories of testing it will be possible to minimize the amount of data collection needed to maximize the information and test the structural model with the observed data. Fourth, that this combination of methods will support the notion that the classical measurement methods and simplistic analyses are no longer sufficient (Embertson, 1996).

The three broad objectives of this proposal complement NIDRR's commitment to the new paradigm and the need to explicate the interactions between the person and his/her environment (Federal Register, 1999), to fulfill the priority to design and test models of service delivery, and to address the priority to refine measures of medical rehabilitation effectiveness in SCI to incorporate environmental factors in the assessment of disability (Federal Register, 2000). Over all the objectives of this proposal are to develop a full measurement model for the IOM theoretical model, and test this model for fit to observed data. This project will involve organizing consumers, direct care providers and research personnel to facilitate the development of the structural components of the models for testing.

This study has five specific objectives. These four objectives are 1) Apply IRT techniques to data in existing SCI databases to determine the most efficient measures to include in the measurement model; 2) define a complete measurement model for the IOM theoretical model and initiate data collection; 3) design and test multiple models of the enabling process for newly injured patients with SCI following them for two years post discharge from rehabilitation; 4) test structural models for fit with the complete measurement model, national database data and other existing data sources; 5) test the models ability to quantify disability as defined by IOM (Brandt et al., 1997).

The first research objective is to utilize IRT procedures on existing data to help relieve the burden of data collection. The measurement strategies involved in this project represent the

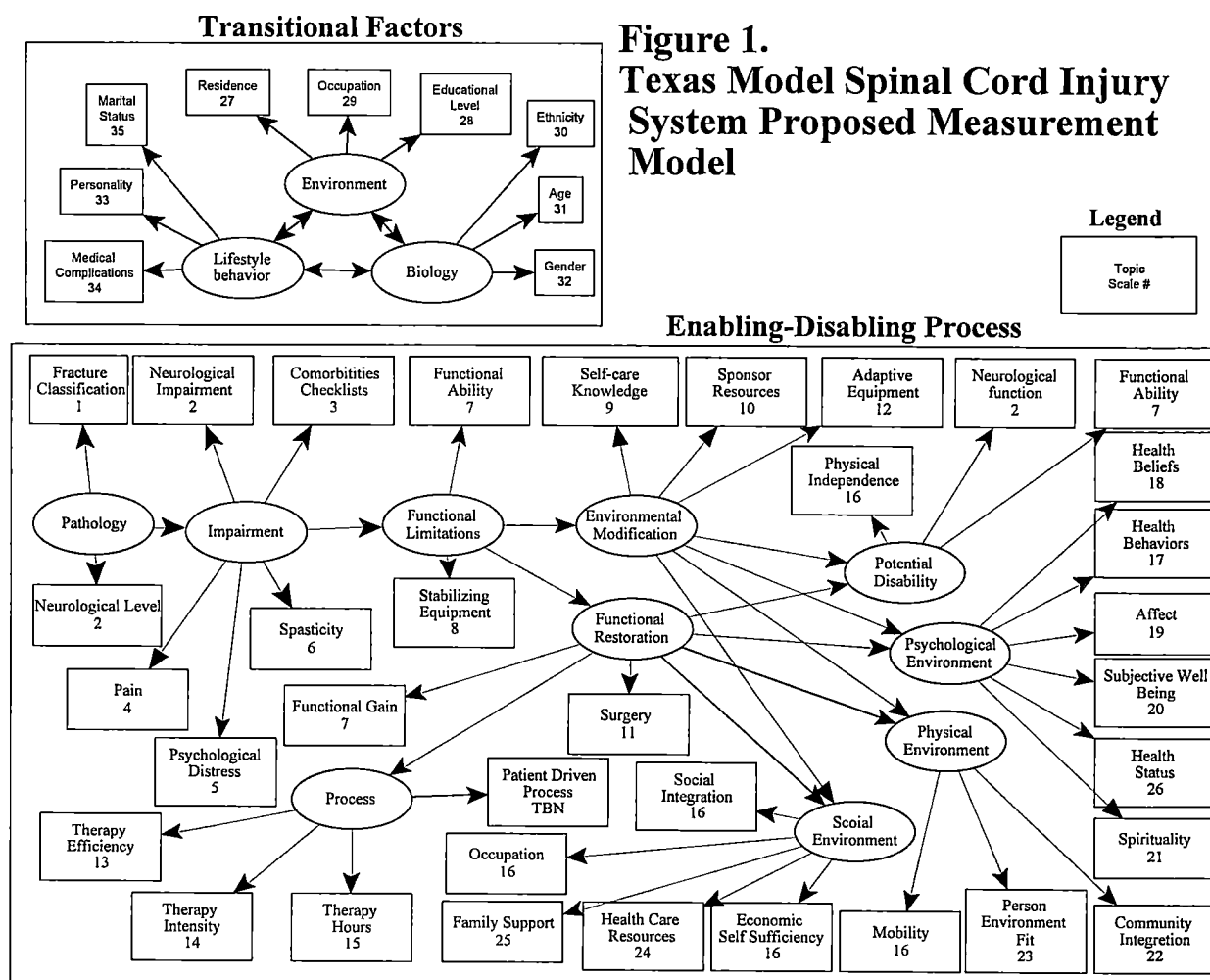
state-of-the-art measurement methods (Emberson, 1996; Hambleton, 1989; Hambleton et al., 1991; Nunnally et al., 1994). The measurement models cannot be finalized until potential measures have been investigated with IRT techniques. This is due to the lack of objective testing data in the literature. Measures and scales that will be included in the final measurement model will be those measures that provide the maximum amount of information about the construct they measure. In IRT theory, unlike classical test theory, the information gained from analysis of test data is independent of the sample and the test (Wright et al., 1979). Therefore, the item calibrations and test and item information functions can be utilized in different groups of similar ability (Hambleton et al., 1991).

To expedite model development and minimize data collection efforts the TMSCIS will utilize existing data sources to every extent possible. Several measures are available in the National Database; however, many are not. There are several other sources of SCI data that can be accessed to facilitate the analysis of measures. Two such sources are the database from the Rehabilitation Research and Training Center on Community Integration with SCI and the Database of the VA Center of Excellence on Aging with a Disability. The Scientific Directors of both of these databases have agreed to share data for the purpose of calibrating measures for this project (see letters of support in appendix). In addition, the data from the Model Program Evaluation System Database (MSPE)(Graves et al., 1999) will offer a wealth of model development information for investigating the efficiency and intensity of therapy. This database contains over 1500 records covering initial rehabilitation of traumatic SCI, and 1200 follow-up records.

The second research objective is to operationalize the IOM model. This involves selecting the indicators and measures that best define all of the concepts and factors involved in the model. Figures 1 and 2 depict two draft measurement models. Figure 1 shows a draft of the proposed measurement model for the full model. Figure 2 show the measurement models that are developed with the current National Database Data. These figures represent only drafts as measures and indicators are chosen, these drafts will be revised.

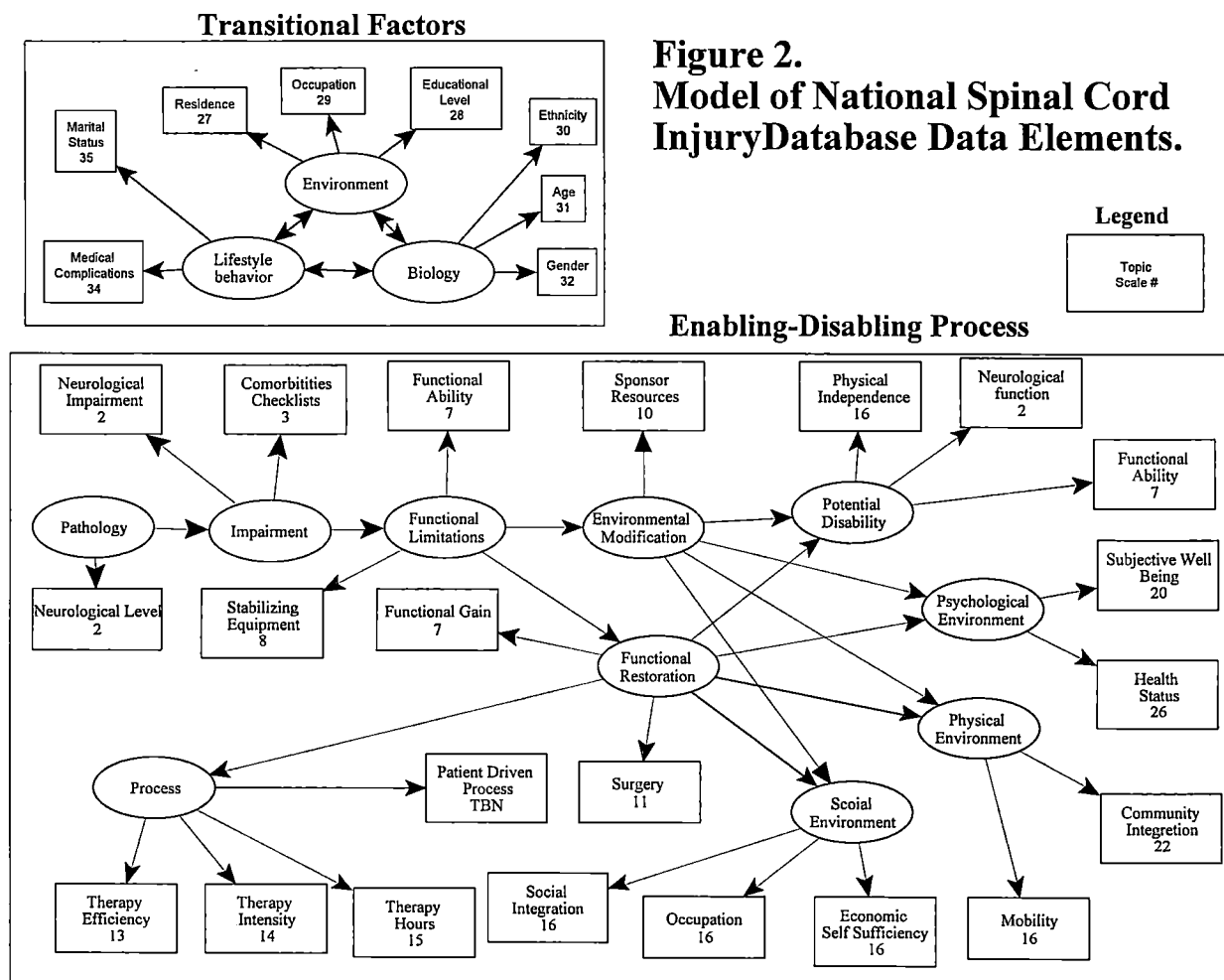
The third research objective is to develop multiple models. Once the measurement models are finalized the next step is to generate structural models. Specifying the nature of the relations between variables develops the structural models. These structural models will be developed for specific portions of the IOM theoretical model. TMSCIS will then fit these

smaller models together into a comprehensive model. For instance it is well known that ASIA motor score is highly related to degree of independence in mobility and self-care (Graves et al., 1999). This type of information will help develop models for rehabilitation process as part of the enabling process. The models generated in this investigation will be refined with the help of consumer participation and consultants. Focus groups will be held to discuss specific topic, such as environmental access, for instance. In these groups consumers and care providers will be asked to use their experience and knowledge help design and refine models to be tested against observed data. No statistical knowledge will be required to participate in these meetings. The reason for developing multiple structural models from different theoretical perspectives is that several models may fit the data equally well. In this case it will be the model that is the most parsimonious that will be further investigated.



The fourth research objective is to test the comprehensive models for fit with observed data. Structural Equation Modeling (SEM) is a comprehensive statistical approach to testing

hypotheses about relations among observed and latent variables (Hoyle, 1995). The models will be developed from theory and hypothesized to fit the data; and subsequently tested for fit assessing several different fit statistics. Utilization of SEM provides for hypothesis testing by measuring the degree to which hypothesized models based on theory, fit with objective, observed data. The fit of the hypothesized structural model to the observed data from the measurement model can be tested statistically. SEM is appropriate for empirically testing the structure of models. In addition, Structural Equation Modeling (SEM) methods have been successfully utilized in clinical research in testing models (Hall et al., 1993; Douglas, 1999).



The fifth objective is to determine the extent to which these measures and model will allow the quantification of disability in terms of the pathology, impairment, functional limitations and environmental factors. This objective can be best achieved if models can be developed to that have small residual covariance matrixes.

This investigation seems highly plausible to the investigators in that it builds on past work by using existing theory and improves on past methods. Operationalizing and testing the IOM model of disability in a SCI rehabilitation program will extend model from the theoretical realm into practical use. In addition, by testing the model with objective data, it will extend the quantification of disability as defined in the IOM model. The quantification of potential disability, and environmental supports will make it possible to develop an index of disability as proposed in the IOM model. Logistically, the additional data collection necessary for this investigation will occur concurrently with data collection procedures for the national SCI database. These existing data collection pathways and mechanisms will facilitate the data collection process.

TMSCIS is an ideal location for this investigation. TMSCIS has contributed over 8,000 records to the national SCI database. These records include 1,289 Form I and 6,568 Form II (National Spinal Cord Injury Statistical Center, 1999). The TMSCIS receives over 300 admissions per year; counting approximately 110 newly injured patients with SCI per year. In addition TIRR offers long term follow-up and outpatient clinics. The majority of TIRR patients do return for annual follow-up clinics. Since the eligibility criteria for this investigation will closely parallel the national SCI database criteria if we have a 70 % acceptance rate similar to the national database, TMSCIS will provide over 300 patients in the four years of data collection for this investigation. The newly injured patients with SCI receiving rehabilitation in the Texas model SCI system will be representative of patients with SCI from other centers.

BACKGROUND

"The true significance of traumatic SCI lies not primarily in the numbers affected, but in the substantial impact on individuals' lives and the associated substantial health care costs and living expenses. A traumatic SCI has far-reaching repercussions on the lives of the injured persons and their families that can be devastating if not addressed effectively. (Federal Register, 2000), p. 14349).

No consideration is of greater importance for medical rehabilitation than analysis of its intended outcomes. In the field of rehabilitation, quality of life (QOL) measures have been widely used for evaluating program outcomes (Fabian, 1991) as well as the impact of disabilities (Fuhrer et al., 1992). More recently, QOL has become a key concept in rehabilitation with SCI (Boswell et al., 1998) (Fuhrer, 1994); (Kannisto et al., 1997); (Andresen et al., 1999); (DeVivo

et al., 1992); (Clayton et al., 1994). However, conceptions of QOL have remained prevalent since World War II. Two conceptions of QOL are most relevant in the SCI rehabilitation literature. The SCI patients "subjective" responses to QOL, and the "objective" factors (the reciprocal relation between persons and their environment) that influence QOL (Alexander et al., 1981); (Dijkers, 1999).

Environment

Although the interrelation of environment and disability has not been entirely neglected, the lack of attention to environment in models of rehabilitation has retarded the development of policy that would facilitate many other needed environmental interventions. In rehabilitation practice, the narrow focus of research on environment factors has restricted the development of fundamental knowledge about the relation of disability to environment that would help professionals assess individual need and identify both optimal and cost-effective interventions for their clients (Steinfeld et al., 1999a).

The pressing need for more research on the mediating influence of the physical environment and better methods of measurement can be demonstrated with the changes in the economics of health care. These changes are creating more pressure to reduce the length of patient stay in acute care settings. Rehabilitation clients are spending less time in inpatient facilities (Fielder et al., 1997) and more time in subacute facilities and at home (Beckley, 1996). In subacute and home environments, physical barriers in the near environment, such as stairs and bathroom design, have a significant effect on rehabilitation outcomes as experienced by the individual in day-to-day life. Gain in functioning measured at discharge from inpatient rehabilitation by current measures, such as the FIM, may not be an accurate indicator of actual independence in the community. Improvement in previous measures and new improved measures will be explored. Danford & Steinfeld (Danford et al., 1999) document how the physical environment mediates functional ability and caregiver burden and demonstrate that those effects can be measured quantitatively. With new tools for measuring the impact of the environment, it is now possible to measure the degree to which environmental interventions impact outcome in terms of functional independence (ability) and caregiver burden. Tying intervention to outcomes with a quantifiable measure can help rehabilitation practitioners, consumer, and insurers predict the impact of home modifications and use that knowledge to decide on the best mix of interventions for a particular household.

Knowledge from both practice and research demonstrates that what is best for one person is not necessarily best for someone else. Therefore, we propose the operationalized IOM model that better reflects the process through which individuals experience and adapt to the environment. Steinfeld & Danford propose that due to the complexity of each individual and their relation to the environment, multi-method research strategies are needed to measure fit, methodologies that incorporate both professional and consumer perspectives and global and fine grained measures. These methodologies can unite researchers by providing a widely accepted and more rigorous approach to research (Steinfeld et al., 1999b).

Quality of Life

The most popular conception of QOL has focused on the use of subjective measures such as the self-assessment of a person's functioning and circumstances (Dijkers, 1999). This conception places emphasis on subjective responses to life satisfaction. Shin and Johnson (1978) defined life satisfaction as a "global assessment of a person's QOL according to his/her own criteria." Diener et al. describe three separate components of subjective well being including (1) positive affect; (2) negative affect; (3) and life satisfaction (Diener et al., 2000). In this way, judgment of how satisfied people are with their lives is based on a comparison with a standard that is unique to the individual. This process makes it essential to ask the person for his/her overall evaluation (Richards, Bombardier, Tate, 1999). Using this technique, researchers have identified employment status, income, education status, mobility, perceived control, self-assessed health, and a number of social activities to be associated with perceived QOL (Clayton et al., 1994); (Fuhrer et al., 1992).

Alexander & Willems (1981) reported that subjective methods of deriving quantitative measures of QOL are not sufficient for a "complete or mature understanding" of QOL. They posit that subjective responses neglect the necessary foundation of QOL, which should measure actual functioning, and adaptation to the surrounding environment. They conducted research on objective measures of QOL at Baylor College of Medicine and The Institute for Rehabilitation and Research. Their findings suggest that objective measures be utilized focusing on the "molar level" (everyday level) of behavior meeting the minimum requirements for an accurate assessment of rehabilitation progress and QOL. They identified two major dimensions of patient functioning: behavioral, and environmental-behavioral. The behaviors identified included independence, mobility, hours out of bed, activity level, family involvement, and activity in the

hospital. Conversely, more “global levels” such as marital adjustment or vocational development were not deemed to provide enough information for accurate assessment of QOL (Alexander et al., 1981). “By focusing on the behavior and the content of the behavior, it embodies a more mature, more complete, and, in many ways, more straightforward view of QOL” (Alexander et al., 1976; Alexander et al., 1981). More recent research has identified indicators such as employment status, income, capacity to carry out activities of daily living, physical, and psychological functioning through objective measures. Using this method, QOL was inferred from the findings based on patient percentage of activities in each domain measured (Meenan et al., 1980); (Bergner et al., 1976),(Baird et al., 1985),

The shift of the medical management of SCI from an emphasis on survival to the QOL for persons with SCI has paralleled the independent living movement, which in turn has focused on the QOL of persons with disabilities. According to the independent living movement, QOL is significantly affected by the environment’s accessibility (DeJong et al., 1984). In fact, the Long Range Plan for the National Institute on Disability and Rehabilitation Research (NIDRR) describes a “new paradigm” for examining disability that explicitly defines disability as the interaction between the individual and the environment(Federal Register, 1999). Environmental factors deemed critical to the well being of disabled people in general include timely assistance with in home needs, appropriate housing, and accessible transportation (DeJong et al., 1984).

The physical environment is a very important factor in determining an individual’s degree of independent living and in defining the status of people with disabilities in society. Environmental barriers can tremendously hinder independence. As a result, removal of barriers to independence has been an important part of the disability rights movement. People with impairments have been successful in making accessible design a major aspect of the civil rights legislation (Steinfeld et al., 1999b). Even though individuals with impairments and professionals alike recognize the importance of the environment, the research community and policymakers have not given it the attention it deserves. Part of the problem may be that traditional rehabilitation theory has focused primarily on the person. Current changes in theory are putting much more emphasis on the environment.

Patient driven services:

The concept of patient satisfaction has its origin in two separate needs: to improve patient compliance and to introduce services that are more consumer-centered (Williams, 1994). The

1983 NHS Management inquiry, published in 1984 argued for service evaluation not in terms of patient satisfaction but in how well the service is being delivered by obtaining experience and perceptions of patients and the community (NHS, 1983). The recent growth in interest in the concept is driven by the need for greater professional accountability (Dougall et al., 2000). Although patient centered services are gaining greater attention, not much has been explored concerning this topic with SCI patients. Rehabilitation centers for persons with disabilities in general are beginning to explore centering the entire rehabilitation effort around the patient. Wade posits that rehabilitation can only be effective if the patient and family are fully involved due to the necessity for behavior change and goal setting as it relates to patient satisfaction (Wade, 1999a). Additionally, he explores "goal planning" in rehabilitation incorporating the conceptual framework of the WHO model (World Health Organization, 1980; Wade, 1999a). The WHO model identifies that each patient has unique combinations of strengths and weaknesses creating complexity related to their specific pathology, impairment, and participation concerns. Therefore, each person's course through rehabilitation will be unique in terms of resources needed, processes undertaken, inputs given, and outcomes achieved and achievable (Wade, 1999a). The patient's view of the rehabilitation goals may be different from the health care staff. Often patient's expectations are for a full recovery, which is usually unachievable. Therefore, it is important to establish which areas of life (participation) concern him or her the most. One of the most popular ways to assess this information is through a structured questionnaire. The "Life Goals Questionnaire" and the "Patient's Expectations and Wishes Interview" have been used with stroke patients as a means to identify relative importance of certain life situations such as family, hobbies, work, religion, financial status etc (Wade, 1999b); (Rivermead Rehabilitation Center, 1999). One practical reason for identifying patient's wishes is to maintain his or her motivation and cooperation. Wade proposes that motivation has two components: (1) individual's psychological drive toward change, and (2) the ability to initiate action relevant to that goal (Wade, 1999b).

Evaluating the process of rehabilitation has obtained little formal research. Wade conducted a large search and reviewed outcomes discovered in the process of constructing the British National Clinical Guidelines on stroke (Wade, 1999c). Thirteen randomized control trials and two controlled clinical trials were identified under disability and rehabilitation. Patient participation (or identifying goals with the patient) consistently had favorable results on specific

outcomes. For example, reduced disability and increased participation (Greenfield et al., 1985), decreased pain and increased activity (Stenstrom, 1994), increased improvement in muscular performance by adding collaborative goals in combination with rehabilitation training (Bar-Eli et al., 1994); (Bower et al., 1996); (Theodorakis et al., 1996); (Theodorakis et al., 1997); (Bar-Eli et al., 1997). Increased involvement of patients in rehabilitation goal planning led to maintenance of gains made in rehabilitation (Webb et al., 1994). The combination of patient centered goal setting and behavior modification reduced dependence on ADL but goal setting with patients on it's own was ineffective (Blair, 1995); (Blair et al., 1996). (Kennedy et al., 1999) conducted a clinical controlled study on patient behavior before and after goal planning with SCI patients. Their results indicated that collaborative goal planning was associated with patients spending less time disengaged.

Overall, Wade proposes that rehabilitation should set meaningful, challenging, and achievable goals collaboratively with the patient that are both short and long term goals (Wade, 1999c). Goals should be set at the team level and the individual clinician level.

Essential to the goal of achieving a sense of QOL is a sense of creative participation. Patients need to be encouraged to participate as creatively and as early as possible at each phase of their rehabilitation (Ozer, 1999). Patient centered goals and rehabilitation have several benefits. First, patient participation enables the patient to receive accurate feedback about his or her own performance, to get realistic expectations about the rate at which rehabilitation should be approached, improve self-image and participation through progressing toward personally meaningful goals, and decrease emotional distress that may arise from the disruption of goal directed behavior caused by neurological deficits (McGrath et al., 1999).

WHO Theoretical Model

Evidence of this shift in focus to the interaction of the person and the environment, are the changes to the International Classification of Functioning and Disability (ICIDH) (World Health Organization, 1980). The ICIDH is the most widely adopted conceptual framework for research, practice, and policy related to rehabilitation. The original version distinguished between impairments, or disturbances at the level of the organism; disabilities, or limitations in activities; and handicaps, or limitations in societal participation. The original view was that impairment, disability, and handicap acted as a linear cause-and-effect process. In this way, impairment causes disability and disability in turn leads to limitations in societal participation or

handicap (World Health Organization, 1980)

Steinfeld reports that the lack of attention to environment in this model has retarded the development of policy that would facilitate many other needed environmental interventions, such as home modification services and universal designs (Steinfeld et al., 1999b). In rehabilitation practice, this lack of focus on environment has restricted the development of fundamental knowledge about the relation between disability and the environment that would help professionals assess individual needs and identify both optimal and cost effective interventions for their patients.

The revision of the ICIDH model has made three changes. The first revision recognizes the context of the person's life (such as age and motivation) and environmental factors (such as physical facilities, consumer products, and family support). The second revision recognizes that the linear relationship between impairment, disability, and handicap is oversimplified. The third revision is to utilize more positivistic language for describing the relation of disablement to environment. The terms Impairment, Disability, and Handicap, have been changed to Body Functions & Structure, Activities, and Participation (World Health Organization, 1999). From this new perspective, the environment can be conceptualized as a mediating factor in both functional ability and social participation.

The relation between the functioning of the body, abilities, social participation, environmental factors, and personal factors is very complex. The new conception of disability suggests not only the need for giving more attention to environmental issues but also that these issues are multidisciplinary and of interest and importance to many different professionals. In particular, there is a need for more research to fully understand how the physical environment affects rehabilitation success. The IOM model addresses these issues and takes a more holistic view of QOL by developing a model that identifies the disabling process of injury, the enabling process of rehabilitation and QOL outcome factors (Brandt et al., 1997).

IOM Theoretical Model

The Institute of Medicine's (IOM) Model of Enabling-Disabling Process expands on the model proposed by ICIDH. IOM suggests that the degree to which a person with a disability is an active, productive member of society, and well integrated into family and community life, is a complex phenomenon influenced by many factors. These include (1) characteristics and

consequences of the injury or pathology, (2) characteristics of the individual, and (3) characteristics of the environment (Brandt et al., 1997).

Enabling-Disabling Process of Disability

The Enabling-Disabling Process is a model that depicts how disabling conditions develop, progress, and reverse, and how biological, behavioral, and environmental factors can affect these transitions (p. 5). According to the model, a person without a disability is considered fully integrated into their environment. In contrast, a person with a disability has increased needs that hinder successful integration with their environment. This creates a “dislocation from the prior integration into the environment” (Brandt et al., 1997).

A disability is acquired through the disabling process. The disabling process begins with the Pathology (P) that is defined as cellular tissue changes, which result in an Impairment (I) defined as a loss of mental, physiological, or biochemical function, or abnormalities in these functions. Ultimately, this process results in Functional Limitations (FL). These functional limitations are depicted as an inability or hampered ability to perform a specific task.

In contrast, the enabling process attempts to reverse this disabling process by either (a) restoring functioning through Functional Restoration (i.e. neural repair, medical rehabilitation) or (b) expanding access to the environment by Environmental Modification (i.e. wheelchair accessibility, social support). According to (Brandt et al., 1997) rehabilitation is the enabling process due to its goal to reverse and or stabilize disability. Rehabilitation attempts this by promoting changes both in the persons functioning level and in the individual's physical and social environment.

Brandt and Pope (Brandt et al., 1997) propose that the amount of disability in an individual is not determined by levels of pathologies, impairments, or functional limitations, but is the difference between a person's capabilities and the demands of the environment; “the interaction of a person's limitations with social and physical environmental factors”. Therefore, disability is the disadvantage resulting from a given person's impairments or disabilities that limit the fulfillment of roles within that person's social or cultural system that would be considered normal for a person of his or her age and sex. Disability emerges from the interaction of that person with the environment. In this way, disability lends itself to mathematical modeling. Although, the IOM model only demonstrates this on a conceptual basis, it provides

quantifiable variables to clarify the relationship that exists between the person and the environment.

Potential disability can be represented mathematically as the composite of pathology, impairment and functional limitations:

$$PD = P + I + FL \quad (1)$$

The theoretical representation of disability is defined as:

$$D = (P + I + FL)/E \quad (2)$$

or

$$PD/E = D \quad (3)$$

The assumptions related to the IOM model are that the sum of the variables pathology (P), impairment (I), and functional limitation (FL), will represents an individual's potential disability. Only the interaction of the potential disability with the environment (E) creates true disability. Therefore the environment is the variable against which the other factors are measured and that determines the existence of disability. In this way, "if the range of PD is 0 to 10 (where 10 is the maximum potential for experiencing disability) and the range of E is 0.1 to 10 (where 1.0 is a neutral environment, 10 is a very accessible and supportive environment), then the resultant quantity of D would range from 0 to 100 (where 100 is maximum disability)" (Brandt et al., 1997).

Utilizing SEM will allow the investigators to not only illuminate the intricate interrelations of the many variables and factors in this model, but will allow an examination of the extent to which the complex nature of disability, as defined by this model, has been defined with the measurement model. The residual covariance matrix provides an indication of how well the model fits with reality. If the model sufficiently describes disability, as defined by the model, then the mathematical quantification of disability can begin. If it is found to not sufficiently describe disability, new models will need to be developed.

Comparing IOM and WHO models

A comparison of the definitions and domains of the IOM and WHO models is necessary. First the WHO model is not intended to model the process of functioning and disability (World Health Organization, 1999). The intent of the WHO model is to facilitate classification of disability. The IOM model on the other hand is intended to work toward a quantification of the enabling/disabling process and disability. Aside from this distinction there are a great number of

similarities in these two models. The definitions of dimensions in the WHO model are generally similar in meaning to the definitions of concepts in the IOM model. Both models include Physiological and anatomical components, ability to perform actions, interaction with the social and physical environment as well as, environmental and personal factors.

The most significant difference between these two models is that the IOM model moves beyond the classification of function and disability to provide a mathematical model for the possible quantification of disability as the ratio of potential disability and environmental support (Brandt et al., 1997). Because of this critical difference the TMSCIS has decided to investigate the IOM model to quantify and further clarify the relation that exists between the SCI individual and the environment as it relates to disability. While concepts of the WHO model will be utilized in model development, the mathematical quantification of disability in the IOM model takes precedence.

TMSCIS Measurement Model of SCI

Incorporating these theories into practice, the TMSCIS has produced a draft of a measurement model for the IOM theoretical model and applied it specifically to individuals with SCI. The depiction of the TMSCIS model serves two purposes: 1) the model demonstrates the underlying justification for data collection and research being conducted in SCI; 2) the model helps to direct future research by identifying areas of need. The distinctive aspects of this investigation are that it will test current theoretical models using state of the art measurement techniques (Hambleton, 1989) and comprehensive statistical methods (Hoyle, 1995; Bollen, 1989; Kline, 1998). The following paragraphs are intended to provide a brief overview and introduction to both IRT techniques and SEM procedures.

Item Response Theory

Emberson has stated that the classical theories of testing are no longer sufficient (Emberson, 1996). This is a view shared by the investigators on this project. While the wealth of classical theory information should not be completely discarded, classical testing theory alone does not provide a sufficient base for a project of this complexity. TMSCIS has decided to utilize IRT techniques to overcome the shortcomings of classical test theory (Hambleton, 1989) and to maximize the amount of information that can be collected while minimizing the amount of data necessary to capture that information. This can be accomplished because of the shift in paradigm from classical reliability theory to IRT techniques. In classical reliability theory it is assumed that the degree to which a test is internally consistent determines the amount of the observed

score that is related to the true score or construct measured. Under this assumption increasing the number of items in a particular test will increase the reliability of that test, and by extension increase the amount of information collected related to the construct under consideration (Nunnally et al., 1994; Traub, 1994). This is the 'more is better method' of testing.

Under the assumptions of IRT, parameters can be estimated for single test items (questions) that operate individually and provide differing amounts of information. In the process of estimating these parameters the individual items work together to define a single continuum that is assumed to align with the construct of interest. The test items would be placed along this continuum according to how much information they provide about the construct (Wright et al., 1979). The amount of information an item or test provides can be objectively demonstrated by plotting the item and test information functions. Therefore, using IRT it is possible to construct tests (questionnaires, surveys, rating scales, etc) from the items that provide the maximum amount of information (Hambleton, 1989). This is the 'better is better' method of testing. Utilizing fewer items for each scale in this measurement model will significantly reduce the overall data collection burden for patients and staff.

There has been a great deal of discussion about IRT models in psychometric literature in the past few years (Wright, 1992; Masters et al., 1984; Wright, 1996; Wright et al., 1994). Additionally, the appropriateness of ordinal data in mathematical and statistical analyses has long been debated (Merbitz, 1989; Johnston et al., 1992; Wright et al., 1989). These debates have lead to the introduction of Item Response Theory Models into the practice of research. The most commonly used IRT method is Rasch Analysis (Wright et al., 1979). Rasch analysis is a special case of the one-parameter IRT model developed by Lord (Lord F.M., 1952). The assumptions behind Rasch analysis are not always tenable in clinical studies; thus the data will not fit the model. IRT techniques have been developed that are appropriate for a wide variety of data types for Rasch (Masters et al., 1984) and more general IRT procedures (Hambleton, 1989; Hambleton et al., 1991). Therefore, the TMSICIS will explore the use one, two or three parameter IRT techniques, including multidimensional IRT models, to obtain interval data from the measures included in the measurement model. The measurement properties of all measures specified in the preliminary measurement models will be investigated using Item Response Theory (IRT) methods (Hambleton, 1989; Hambleton et al., 1991). These methods will be employed 1) to create linear measures from ordinal data, 2) to maximize the amount of

information measures provide with the least number of measures and, 3) identify areas of important concepts which need more or less coverage with measures. IRT models have been increasingly used in clinical research in recent years (Bode et al., 1999).

To accomplish these objectives the TMSCIS staff has gained access to other sources of data on persons with SCI. These links will supply data in sufficient quantity for most of our IRT investigations without the need for extraordinary data collection efforts. Two such links are the databases associated with the Rehabilitation Research and Training Center on Community Integration and the Veterans Administration Center of Excellence on Aging with a Disability. The Scientific Directors of both centers have provided letters of support for this project (See letters of support in Appendix). In addition to these sources, TMSCIS houses the Model System Program Evaluation (MSPE) database developed as a collaborative effort of ten Model Systems (Graves et al., 1999).

Structural Equation Modeling

The TMSCIS has expanded its research methodology to provide continued excellence in research design, techniques, and research findings by incorporating state of the art research methods. One such method is the utilization of Structural Equation Modeling (SEM). SEM is a comprehensive statistical approach to testing hypotheses about relations among observed and latent variables (Hoyle, 1995). SEM represents innovative procedures for evaluating the consistency of theoretical models with empirical data. In essence, fairly complex theoretical models can be statistically represented and evaluated based on how well these models reproduce the observed pattern of empirical relations in the data. Of particular interest is the ability of SEM procedures to allow researchers to evaluate theoretical models that include latent constructs that are indicated with multiple measurement instruments. SEM can also be used to compare competing theoretical models and reject alternative models based on the relative consistency of these models with the pattern of empirical relations reflected in data (Quintana et al., 1999).

SEM represents an extension of the collection of statistics belonging to general linear model (GLM) including path analysis, canonical correlation, factor analysis, discriminant analysis, multivariate analysis of variance, and multiple regression analysis. SEM-based procedures have substantial advantages over these first-generation techniques due to the greater flexibility that a researcher has for the interplay between theory and data.

For example, prototypical SEM can be conceptualized as a marriage of path analysis to

factor analysis (Quintana et al., 1999) SEM, like path analysis, allows researchers to posit rather complex models that can involve a construct that is theorized to be a predictor of some constructs and also be predicted by other constructs. A second advantage is that SEM, like factor analysis, allows researchers to posit latent constructs that are presumed to be underlying causes of observed manifest variables (Bollen, 1989; MacCallum et al., 1996). Most theories posit latent constructs that can be measured only incompletely by a single manifest variable, scale, or questionnaire (Heppner et al., 1999). Third, SEM can be employed to calculate the reliability of measurement instruments as well as estimate latent constructs while accounting for measurement error (Bollen, 1989; Kenny, 1979). Fourth, SEM provides evaluations for the general compatibility (e.g. goodness of fit) of the model for the data in addition to evaluating the strength of the relations among the constructs (Hoyle, 1995).

RESEARCH DESIGN & METHODS

Data Collection Procedures

This project entails the collection of a substantial number of measures. The data for this investigation will be collected in accordance with the measurement models shown in Figures 1 and 2. These measurement models were created to fully operationally define the IOM Model of disability (Brandt et al., 1997). The measures specified in the measurement model will be collected in conjunction with the national database data collection. Collection methods and timeframes will be the same as the standard practice for the national database and include interviews of patients and families, medical records searches and self-report questionnaires given to the participants. This data will be collected for two years following discharge from rehabilitation. Table 1 lists the preliminary measures included the draft measurement model.

The initial interviews with the patient will occur soon after informed consent is obtained. At this time the investigators wish to obtain some measure of the patient's emotional distress as well as an understanding of the patients pre-morbid functional level. The interview will contain standardized instruments and inventories. Data concerning the patient's health status, occurrence of secondary conditions and acute care course will be collected from the medical record of both the acute care facility and the rehabilitation facility and during the annual follow-up periods. Follow-up interviews will be collected either through in person interviews or by

phone. Mailing surveys will be utilized only when the patient cannot be reached and all other methods of collection have failed.

Measurement Strategies

The measurement models for this investigation were devised to provide complete coverage of all concepts contained in the IOM model of the disabling enabling process. These measurement models are depicted in Figures 1 and 2. In accordance with structural equation modeling (SEM) standards (Hoyle 1995) main factors or latent variables (LV) are depicted by ovals: these LV's cannot be directly measured. Each LV has arrows leading to boxes with specific indicators of that construct. There is a minimum of two indicants for each LV. Some LV's are complex by nature and have several indicants. These complex LV's will most likely be found to be higher order factors. That means that these complex factors will actually consist of constellations of several other related factors that will be discovered once the data is analyzed.

An examination of Figure 2 reveals that the data from the national database leaves several areas of the model sparsely measured. Figure 1 shows the preliminary measurement model describing the data to be collected for this investigation. This figure demonstrates that all major concepts of the IOM model of disability are represented in the measurement model. These measurement models are only preliminary; they may be altered as information from the IRT analyses and consumer seminars is incorporated into the model.

Many measures were evaluated in the process of defining the preliminary measurement models. Each measure was evaluated on the basis of the published classical theory reliability data, the applicability of the measures to spinal cord injury, and published research results relating the measure to identified constructs. In addition to data collection for the National Database TMSICIS has been collection additional data routinely for the last six years. Several of the scales in the measurement, which are not included in the national database are already collected as a matter of course. Table 1 describes the measures that have been selected for the initial measurement models. This table describes the scale, classical reliability data, point(s) in time for collection and the primary reference information. Measures and indicators, which are not currently collected on a routine basis, are also designated in Table1.

In some areas of the measurement model there are no standardized, published measures for specific information necessary for specific constructs. For example, one of the indicators of the environmental modification factor would be access to adaptive equipment. There have been

several published attempts to quantify this indicator; most are reports of unmet equipment needs (DeJong et al., 1984). In this case there is not a published standard that could be assessed for inclusion. There are however, published standard minimum equipment lists for Patients with SCI by level of injury (Consortium for Spinal Cord Medicine Clinical Practice Guidelines, 1999). A scale will be developed from this list. A similar situation exists for indicators of spinal stability and educational program evaluation.

DESIGN OVERVIEW

This investigation will be a quasi-experimental longitudinal observational study without direct manipulation of any variables during the course of rehabilitation or the two-year follow-up period. Model comparisons will be conducted on models developed for naturally occurring groups. For instance TIRR provides charity care to a large number of patients who would not otherwise receive rehabilitation. Charity care is generally limited to the shortened rehabilitation program (Rehab III). One planned comparison is to compare models developed for patients with charity care vs. patients with managed care vs. patients with private insurance. Since it is not possible to control who will be funded which payer source, there will not be random assignment of patients to groups.

A tracking database will be developed to aid in monitoring the data collection process. This database will query data from the automated data collection system, and produce daily and weekly reports outlining problems with data (i.e., validation rule violations, missing data, or duplicate data), upcoming evaluations and interviews and summary reports of database status. All data collected for this project will be collected using either data collection forms for scanning, or online transaction processing. Using this configuration of database elements allows for very thorough data validation processes. Data entered with on line transaction processing forms will be validated automatically using database validation triggers and referential integrity constraints (Oracle Corporation, 1998; Morrison et al., 1998). Entering data from scannable forms provides validation through validity checks, form verification in addition to the database validation rules (Cardiff Software, 1996).

External Validity

The structural equation model represents a series of hypotheses about how the variables in the analysis are generated and related ... It is used to evaluate a substantive theory with empirical data through a hypothesized model (Hoyle, 1995). There is a chance that if models

are adjusted to fit the data, once a fit was attempted, the model may not generalize beyond the sample tested (Bollen, 1989). There are specific Steps involved in generating models for testing against objective data. All models must be developed from theory. Strict adherence to this principle will provide support to the conclusions. In addition, interim models will tested against data from other sources. Some models can be tested utilizing National Database data to keep from exploiting the data collected for this investigation.

Sample

There is little agreement on sample size considerations for SEM procedures (Quintana et al., 1999). There are however some helpful indicators for estimating sample size and power. Early estimates have suggested five to ten subjects for each parameter to be estimated in the analysis(Chou et al., 1995). Other estimates have suggested a sample size of 200 or more when goodness of fit tests are utilized. Statistical methods for estimating power and sample size have suggested that small samples can be powerful when the models to be tested are complex compared to less complex models (MacCallum et al., 1996). Utilizing the power estimates developed By MacCallum et.al. a sample size of approximately 200 subjects will be required to test an a priori model of the complexity planned in this investigation.

Admissions to TMSCIS have historically averaged more than 110 traumatically injured patients with SCI per year. In addition TIRR offers long term follow-up and outpatient clinics. The majority of patients do return for annual follow-ups. This average should provide over 300 patients in the four years of data collection for this investigation. This estimate will provide more patients than the 200 patients that has been estimated as necessary to achieve adequate power to test the a priori models developed (MacCallum et al., 1996).

Models developed in the model generation phase of this investigation will utilize existing data sources (e.g., National SCI Database, Model System Program Evaluation System) to protect the integrity of the significance tests for the full model.

Analysis

Several fit statistics utilized in SEM are fairly robust against violations of assumptions of normality of distributions(Hoyle, 1995; Kline, 1998). The distributions of all interval measures will be studied for normality following IRT procedures. The individual item characteristics of all items included in the composite scores will be recorded for possible replication studies. A second preliminary analysis issue rests with missing data. Missing data is a serious concern

when dealing with any large database (Marshall et al., 1995). SEM cannot, as yet, produce statistical estimates of fit or residual variance/covariance matrices when there are missing data. Therefore, a missing data analysis will precede all tests of model fit. Imputation procedures will be investigated for all variables found to contain missing data (Spiess et al., 1999; Schemper et al., 1997; Brancato et al., 1997; Reilly et al., 1997).

Models will be tested for fit utilizing maximum likelihood (ML) estimates of fit. ML statistics have been shown to be stable with larger sample sizes (Hoyle, 1995) and to perform well in a variety of analysis configurations (Chou et al., 1995). The ML estimates are considered to be practical, general-purpose estimates compared to the Generalized Least Squares (GLS) alternatives (Quintana et al., 1999).

If models can be developed that sufficiently describe the observed data, these models will then be used to investigate the development of an index of disability using the terms pathology, impairment, functional limitations and environmental factors as outlined earlier.

$$D = PD/E \quad (3)$$

Research Questions

It is not possible to state exact hypotheses for this at this point. However, for every model generated for testing against existing data a hypothesis will be developed that follows the fundamental hypothesis for SEM:

$$\Sigma = \Sigma(\theta) \quad (4)$$

Here Σ is the population covariance matrix of observed variables, θ is a vector of model parameters, and $\Sigma(\theta)$ is the covariance matrix written as a function of θ (Bollen, 1989). From this fundamental hypothesis it is clear that the hypothesis to be tested in any SEM procedure designed to determine the extent to which the theoretically derived model and a set of structural parameters can reproduce the covariance matrix of the observed data. All hypotheses for this investigation will be of this general form.

Specific research questions to be addressed in this investigation are:

1. Can the IOM model of disability be sufficiently operationalized specifically for patients with SCI to fit with observed data?
2. Will the operationalizing of the IOM model allow for a quantification of disability in the terms of the relation between pathology, impairment, functional limitation and environmental resources?

3. Will a specific minimum set of questions, selected by objective testing characteristics, describe the enabling/disabling process sufficiently to allow quantification of disability?

These questions will be addressed in relation to the specific aims of this investigation.

(1) Relationship of objectives to program purpose.

The research project outlined in the preceding section represents a substantial, focused research program. This project was designed to specifically address the NIDRR Long Range Plan (Federal Register, 1999) and the priority published by the Department of Education (Federal Register, 2000). This project focuses the resources of the TMSICIS on investigating the entire continuum of the enabling/disabling process. This investigative approach is designed to explicate complex interactions of individuals and environment throughout the entire continuum. The evidence created in this investigation will allow movement toward the development index of disability in terms of the relation of the individual and his/her environment.

Additionally, this project is targeted to address the priority to "conduct a significant and substantial research program in SCI that will contribute to the advancement of knowledge in accordance with the plan" (Federal Register, 2000, p.14350). Under this mandate, this project addresses two separate issues. First, this project will design and test models of service delivery that illuminate the complex influences of the restrictions imposed by managed care. Second, this project will build on past experience (Graves et al., 1999) developing and refining measures of rehabilitation effectiveness that incorporate environmental factors. The MSPE collaborative project has demonstrated the utility of investigating the therapy process. The MSPE collaborative project collected over 1,500 initial rehabilitation cases and over 1,300. This data will be utilized to further the aims of this proposed investigation. The Project outlined in this proposal is an attempt to expand the scope of the evaluation efforts to include influences outside the rehabilitation process.

#	Instrument Primary	Reference	Norm Group	Collector	Source	Time point	Time (min)	Rel. Val.
1	Spine Fracture Classification System	(Meyer et al., 1997)	SCI	Physician	Radiology	AD	--	-- --
2	International Standards for Neurological and Functional Classification of SCI	(Maynard et al., 1997)	SCI	Physician PT/OT	CE	AD, DC	--	++ +++
3	Co-morbidities Checklist	--	--	RA	CR I	AD	--	N/AN/A
4	The McGill Pain Questionnaire	(Melzack, 1980)	SCI	RA/ Patient I, SR		AD	15	+++++
5	The Medically-Based Emotional Distress Scale	(Overholser et al., 1993)	SCI	RA/ Patient I		AD	?	+ ++
6	Modified Ashworth Scale for Muscle Spasticity	(Bohannon R.W. et al., 1986)	MS SCI	Physician PT/OT	CE	AD	10	++ +++
7	Functional Independence Measure	(UDSMR, 1996)	SCI	RA	CE, PI	AD, DC, 1, 2	10	+ ++
8	Stabilizing Equipment	NSCISC	SCI	RA	CR	AD	5	N/AN/A
9	Surgery	NSCISC	SCI	RA	CR	AD	5	N/AN/A
10	Self Care Skills	--	SCI	PT/OT, RA I		DC	1	N/AN/A
11	Sponsor Resources	NSCISC	SCI	RA	CR	AD, 1, 2	5	N/AN/A
12	Adaptive Equipment	--	SCI	RA	CR	DC	?	N/AN/A
13	Therapy Efficiency	(Graves et al., 1999)	SCI	PT/OT, RA	CR	DC	?	-- --
14	Therapy Intensity	(Graves et al., 1999)	SCI	PT/OT, RA	CR	DC	?	N/AN/A
15	Therapy Hours	(Graves et al., 1999)	SCI	RA	Billing	DC	1	N/AN/A
36	Life Goals Questionnaire	(Rivermead Center, 1999)	TBI	RA	I, Q	AD	15	-- --
16	Craig Handicap Assessment and Reporting Technique	(Whiteneck et al., 1992)	SCI	RA	I	1, 2	15	++ ++
17	Spinal Cord Injury Lifestyle Scale	(Pruitt et al., 1998)	SCI	RA	I, SR	1, 2	10	++ +++
18	Health Beliefs Questionnaire	Holmes (un published)	SCI	RA	I	1, 2	5	-- --
19	Positive and Negative Affect Scale	(Watson et al., 1988)	SCI	RA	I	1, 2	5	-- --
20	Satisfaction with Life Scale	(Diener et al., 2000)	SCI	RA	I	1, 2	5	-- --
21	Jarel Spirituality Well-being Scale	(Hungelmann et al., 2000)	SCI	RA	I	1, 2	5	-- --
22	Community Integration Questionnaire	(Sander et al., 1999)	TBI	RA	I	1, 2	10	++ ++
23	Person-Environment Fit Scale	(Coulton, 1979)	HD	RA	SR, I	1, 2	15	++ ++
24	The Benefits Coverage Inventory	(Tate et al., 1994)	SCI	RA	SR, I, CR	1, 2	?	++ ++
25	McMasters Family Assessment Device	(Novack, 1995)		RA	SR, I	1, 2	?	-- --
26	SF-12 Health Survey	(Medical Outcomes Trust, 1992)	SCI	RA	I	1, 2	5	++ ++
27-32, 35	Place of Residence, Education level, Occupation, Ethnicity, Age, Gender, Marital Status	NSCSCI	SCI	RA	I, CR	AD, DC, 1, 2		N/AN/A
33	Personality	--	--	--	--	--	--	-- --
34	Medical Complications	--	--	--	--	--	--	-- --

Table 1. List of preliminary measurement instruments for draft measurement model. + poor, ++ fair, +++ good; AD=admission; DC=discharge; 1&2 years post DC; I=interview; CR=chart review; Q=questionnaire; CE=clinical exam; PI=phone interview.

As mentioned in the research project design, TMSCIS has a long history in SCI rehabilitation. Current estimates indicate that TMSCIS has contributed the fourth largest number of forms to the National Spinal Cord Injury database (National Spinal Cord Injury Statistical Center, 1999). TMSCIS receives approximately 300 admissions per year with over 100 initial rehabilitation program admissions (see Table 2, P. Given this number of patients with SCI available, the likelihood of obtaining consent from the estimated 200 patients needed for this investigation seems assured over the five-year project. Additionally, significant results will be obtained from the preliminary analyses of existing data sets.

The objectives set forth in this proposal will be met. The allocation of staff time and grant resources in conjunction with additional support from the institutions affiliated with the TMSCIS, will ensure meeting or exceeding the objectives. In addition, the consumer advisory board will be extensively involved in the evaluation of progress and value of the results.

TMSCIS has focused allocated grant resources and staff time to a single comprehensive project. This project was intentionally developed to address the very complex interaction of multiple factors and variables in a complex continuum of the disabling/enabling process. To fully investigate the complexities a single cohesive, comprehensive and focused project is necessary. This project also reflects the shift focus from demonstration of the Model Systems to a focus on research. The proposed project is designed to utilize the most advanced statistical and measurement methods in order to increase the likelihood of success.

Finally, this project represents more than the merger of advanced scientific methods and complex theoretical models. It represents the growth and development of philosophies, ideals and theoretical perspectives long held by current and former members of the TMSCIS staff and faculty. Work conducted at TIRR over 20 years ago by physicians and scientists laid the frame work and influenced many of the thoughts and ideas encompassed in this investigation (Alexander et al., 1976; Alexander et al., 1981).

(2) Likelihood of producing new and useful information

To the knowledge of the investigators, there have been no other studies similar to the investigation outlined in this proposal. The knowledge gained for this substantial investigation will be of great benefit for both rehabilitation theory and methods. There are three specific factors that make this investigation likely to produce useful information. The first factor is the

call for a “significant and substantial research program”. This allows the TMSCIS to consolidate resources and effort into a single project designed to address larger topics of greater complexity. Secondly, the redistribution of resources within the Model System projects has provided needed relief from the burden of following a large number of patients over many years. TMSCIS is the fourth largest Model System in terms of numbers of database records (National Spinal Cord Injury Statistical Center, 1999). TMSCIS has always been committed to collecting data as directed, and has consistently contributed quality data since its inception. Allowing for differential funding of centers will provide adequate resources for collection of National Database data without reducing the amount needed for research. The third factor involved in producing quality information from this project is the data collection history of the TMSCIS. In addition to the National Database data, TMSCIS has routinely collected a significant amount of additional data for both research and program evaluation purposes. The data collection pathways established for these collection efforts efficient, automated and flexible.

(3) Need and target population

The necessity for this investigation is stated in both the program priority

Design and test service delivery models that provide quality care under the constraints imposed by recent changes in health care financing...Refine measures of medical rehabilitation effectiveness in SCI to incorporate environmental factors in the assessment of function (Federal Register, 65, 52, p. 14350).

and the NIDRR Long Range Plan

“NIDRR research focuses on crucial areas of functional loss, disability, and socio-environmental aspects of the continuum. In keeping with the new paradigm, NIDRR emphasizes the importance of explicating the connection between the person and the environment, an interface that determines the disabling consequences of impairments and conditions. This study of the dynamic interaction among various individual and environmental variables requires NIDRR's continued and increased attention to shaping the structure, management, and capacity for research. Methodologies are needed, often in an interdisciplinary context, that can illuminate multiple facets of disablement and enablement from numerous perspectives.” (Federal Register, 64, 234, p.68584)

Meaningful and valid measurements are obtained within a dynamic system of interrelated factors of differential influence. The measurement model proposed in this investigation indicates

the complexity of involved in quantifying disability, even limited to the target population of this investigation, patients with SCI. The intended result of testing this theoretical model is to sufficiently define the enabling/disabling process so that it can be quantified. This investigation is intended to move from a theoretical model through operationalizing and testing into practical application of new methods and measures. These measures will be theoretically derived, objectively defined and directly applicable in the lives of persons with SCI.

(4) Likelihood of outcomes benefiting target population

A set of objectively defined indicators that can sufficiently quantify disability as the misfit between a persons needs and environmental support would be directly applicable to patients involved in the day-to-day business of living with a disability. These measures would be valid, with known measurement properties, over a wide range of situational and severity characteristics. The measures and indicators will be widely available and accessible for all interested parties. The advantage of defining measures over the entire spectrum of disability is that the influences of all aspects of the model of disability will be incorporated in the measure of misfit between the individual and the environment in which they are immersed.

(5) Soundness of research hypotheses

The design of this investigation is directly related to the research hypotheses and research questions. Hypotheses concerning the fit of models can be statistically tested with data. These data can be either from existing sources or from the measurement model developed for this investigation. Likewise, the research questions outlined in this proposal are logically consistent with the methods and objectives of this investigation. The answers to the research questions will provide useful and valuable information on theory and methods of rehabilitation and the quantification of disability.

(6) Soundness of research methodology.

It has been suggested that there is an extensive time lag between the introduction of new statistical methods and the representation of the procedures in medical literature (Altman et al., 1994). The TMSCIS is continuing its pursuit of excellence in research by incorporating advanced research methods and techniques. The combination of advanced testing methods and comprehensive statistical procedures in this investigation represent a sound basis for this investigation. SEM-based procedures have substantial advantages over first-generation techniques such as principal components analysis, factor analysis, discriminant analysis, or

multiple regression because of the greater flexibility that a researcher has for the interplay between theory and data. Specifically, SEM will provide the researcher flexibility to (a) model relationships among multiple predictor and criterion variables, (b) Construct unobservable latent variables, (c) model errors in measurements for observed variables, and (d) statistically test a priori substantive theoretical and measurement assumptions against empirical data (i.e. confirmatory factor analysis). Thus, SEM involves generalizations and extensions of first-generation procedures (Chinn et al., 1995).

(b) Service Comprehensiveness

(1) Comprehensiveness in scope of services.

The scope of services for the Texas Model Spinal Cord Injury System (TMSCIS) is comprehensive, covering a range of activities from primary prevention and treatment of injuries at onset including emergency services and acute intensive care, through acute rehabilitation, community re-entry, and long-term follow-up.

Prevention services. The TMSCIS will address the problem of SCI in a proactive manner. In addition to providing the range of services described below for persons who experience SCI, staff of the TMSCIS will be actively engaged in activities designed to reduce the incidence of SCI in Houston and surrounding areas. A major thrust of prevention efforts will be targeted to persons at greatest risk of SCI, specifically adolescent and young adult men. A program that has been functioning for the last ten years under the direction of Ms. Terri Hudler-Hull, MS, coordinator of the TIRR SCI and TBI prevention program, involves a school-focused program through which TIRR SCI staff members visit schools in Houston and surrounding districts and present information on SCI and its causes and consequences. The program is based on the "Think First" approach developed by the American Association of Neurological Surgeons and Congress of Neurological Surgeons. As part of this program, a person with SCI also goes with the TIRR staff person and talks about his or her personal experience, including how he or she was injured, the rehabilitation program, and life since experiencing an injury. The goal of this component of the program is to provide a realistic view of how SCI effects one's life and to stress with young people, using methods and content to which people in this age group can relate, that most spinal cord injuries are preventable if proper measures are taken. In 1993, TIRR staff conducted an extensive evaluation of the effectiveness of the "Think First" program in

imparting knowledge about traumatic brain and spinal cord injury and altering attitudes of middle school students regarding their risks for severe injury. The findings suggested that these efforts had been effective, but that such efforts might be even more effective if initiated prior to the middle school years (Lehmkuhl et al., 1993). Two years ago the prevention efforts of TIRR and the level 1 trauma center at Memorial Hermann Hospital were integrated in order to reach more people at risk, particularly teenagers.

School focused efforts will be continued, and other initiatives concerning risk for SCI and ways of reducing risk are also underway. Ms. Hudler-Hull and other SCI staff make visits to other organizations, including church and civic groups, on request each year. The information provided these groups is targeted to the specific age group being addressed. For older groups, the focus of the discussion is on SCI risks from falls and how to minimize these risks; for parents of school age children, the program usually focuses on teaching children about swimming and diving safety, using car seat restraints regularly, and what steps to follow if they ever "find" a weapon. For parents of infants and toddlers, the focus is on use of proper infant auto seats, the use of seat restraints with toddlers, and the risks of holding children on one's lap while riding in a car. It should be emphasized that wherever possible existing educational materials will be used. Some excellent materials are available from the American Spinal Injury Association, the American Trauma Society, and other SCI research and training centers. TIRR's ongoing collaborative research project on educational and training materials has identified other effective materials for use in prevention efforts as well.

Initial trauma services. Services provided at the time of injury include delivery of immediate on-the-scene support, including life-saving interventions as required, removal of the injured person from the scene of the injury, and conveyance to an emergency room or trauma center. These services are delivered in the Houston area primarily by staff of Emergency Medical Services (EMS) for City of Houston and by the staff of Life Flight, a helicopter rescue service headquartered at Memorial Hermann Hospital. David Persse, MD directs the Houston Fire Department ambulance EMS. Dr. Presse holds academic appointments at Baylor College of Medicine and the University of Texas Medical School at Houston. As indicated by his letter of support in the Appendix, Dr. Persse, along with Dr. Paul Pepe whom he replaced, and his staff have been actively involved in the TMSCIS for a number of years and will continue to be active in the proposed model system. TMSCIS physicians, nurses, and other personnel contribute to

the training of EMS and Life Flight staff in handling patients with suspected neck and back injuries and acquainting them about the altered physiology that results from SCI.

EMS and Life Flight staffs also receive training on the typical problems of persons with spinal cord injuries that are living in the community and may require medical assistance and call the 911 emergency number. This training includes information on management of autonomic dysreflexia, orthostatic hypotension, respiratory problems often experienced by persons with cervical lesions who have impaired respiratory function associated with paralysis of the diaphragmatic, intercostal, and abdominal muscles and common urologic emergencies following SCI. This close working relationship will be continued with initiation of the proposed model system. It should also be noted that volunteer EMS personnel from suburban and rural communities in the Houston area often participate in training provided through the City of Houston EMS program, and that these individuals will benefit from training provided by TMSCIS staff members. The goal of the TMSCIS with respect to on-the-scene management and transport of persons experiencing traumatic SCI is to be sure that emergency personnel involved in these operations are properly trained and act in a manner that will not further exacerbate already serious injuries. Close collaboration with EMS personnel and monitoring of quality of early trauma services will be major priorities for the proposed model system. As indicated in his letter of support in the appendix, Brent King, MD, Director of Emergency Medicine at Memorial Hermann Hospital works closely with TIRR as well as the appropriate neurosurgeons and trauma surgeons so that patients receive the optimum in care, preserving as much circulatory and respiratory function as possible – thereby optimizing any possible hope for improvement in neurological function.

Hospital trauma care and acute care services. As is the case with EMS personnel, medical, nursing, and other emergency room and trauma center staff of Houston-area hospitals, particularly Memorial Hermann Hospital neurosurgical department under the direction of Guy Clifton, MD and Ben Taub General Hospital neurosurgical department under the direction of Dr. Veladka, are provided with consultations and education in the early management of persons with suspected SCI. Hospital personnel are taught the critical aspects of management at this stage. (See letters of support in the Appendix.) These include: careful handling and protection of the injured spine during transport to radiology and the intensive care unit; institution of a skin care program that includes a regular turning schedule with protection of the injured spine; insuring

proper support of the circulatory and respiratory systems and avoidance of complications known to have deleterious effects on neural tissue vis a vis hypotension and hypoxia; providing for drainage of the bladder and taking necessary steps to reduce the risk of urinary tract infection; and initiating support of paralyzed limbs with splinting and appropriate range of motion exercises.

After initial treatment and medical stabilization in the emergency room, persons with SCI are admitted to an intensive care unit of one of the acute care hospitals. Through the liaison nurse program operated by the TMSCIS, all patients with SCI in Ben Taub and Memorial Hermann, as well as patients with atraumatic etiologies referred from The Methodist and St. Luke's Hospitals are transferred to TIRR. Daily rounds of the neurointensive care and shock trauma units of these hospitals are conducted by the TMSCIS liaison nurse and a TMSCIS physician to monitor new admissions and to encourage timely referrals to TIRR by facilitating the transfer as soon as patients no longer require intensive care. Once a referral has been made, the liaison nurse gathers needed information (including demographic, etiologic, insurance information as well as the type and nature of injury, complicating trauma, diagnostic and therapeutic procedures, including surgeries completed and/or planned). The physiatrist and liaison nurse continue to follow the patient and explain to the patient and family members how the transfer process and rehabilitation program will operate. Daily consultation by the physiatrist with the attending neurosurgeon, orthopedist and/or trauma surgeon is ongoing throughout this period. Once the patient and family understand the rehabilitation options available to them and have made the decision to use TIRR for rehabilitation, close collaboration between the acute care attending physician, hospital staff, and TIRR SCI team members is continued over the duration of acute care with the goal of effecting the earliest possible transfer from the acute care hospital to TIRR.

Transition from acute care to acute rehabilitation care. The process of transition from acute care to acute rehabilitation care in a rehabilitation facility has become increasingly challenging. Because of the relatively high costs of providing rehabilitation services to persons with SCI, and because many third party payers limit the services for which they are willing to pay, it is important that all sources of financial support for rehabilitation services be thoroughly explored. For many patients with SCI, there are multiple potential sources of funding for rehabilitative services, including managed care health insurance, motor vehicle personal injury

insurance, workers compensation insurance, indemnity insurance, Medicaid and vocational rehabilitation benefits. Other persons with SCI may have relatively few resources to draw on for rehabilitative services. A major activity of the TMSCIS staff, involving the liaison nurse, staff of the TIRR admissions office, medical social workers, and insurance specialists, is to identify sources of funding to cover delivery of comprehensive rehabilitation services. Perhaps the greatest obstacle to timely transfer of patients from acute care to rehabilitation involves identifying funding sources to pay for rehabilitation services. Notwithstanding the expertise that TMSCIS staff have developed in assembling funding packages from multiple sources to support SCI rehabilitative services, severe problems of service funding remain, including the reluctance of the Texas Rehabilitation Commission (TRC) – the state department of vocational rehabilitation, to fund early comprehensive care for low incidence catastrophic illnesses such as SCI and the severe limitation of funding provided by Texas Medicaid. Therefore, as part of its community obligations, TIRR provides charity care to a number of low-income patients with no resources. This is a planned service, and does not simply reflect cases of uncollected billings. During 1997 and 1998, TIRR provided free care--charging for no hospital or attending physician services to 74 inpatients (1,635 hospital days). During 1999, 12 patients received medical rehabilitation services at no charge; totaling 355 hospital days. The need to provide charity care is attributable, at least in part, to lower patient revenues associated with changing reimbursement patterns and the setting of premiums and/or co-pays beyond the reach of employers and workers in some cases. The trend among third-party payers to negotiate reimbursement packages that may be below actual cost for services has had and is likely to continue to have an adverse affect on the ability of rehabilitation facilities to provide free care to patients with limited resources. In Texas 28% of the population is uninsured. In Houston, the figure is 31%.

Since 1992, when the impact of managed care began to be felt in Houston Texas, admission programs that had been developed and refined over a period of more than 30 years of serving people with spinal cord injury were completely revised in response to significant changes in reimbursement policies. These policies have been imposed by third-party payers--generally by shortening lengths of stay and limiting the amount of time available to clinicians, educators, and others whose missions are to assist the person with an SCI in making the transition from patient to individual with SCI living in the community. These admission programs serve to notify staff of clinical and support departments in advance of the new admission. Through these programs,

staff are alerted to a) goals that may be identified by consumers (which, although they be may be unrealistic soon after injury, either by underestimating or overestimating potential recovery, are still used in planning a rehabilitation program); b) projected length of stay and c) perceived ability for the patient to tolerate a full treatment program based on his or her medical status. In addition, information included in admission programs is useful in developing statistics on use, referral patterns, and average length of hospitalization for each type of program. Details of various program options available for patient admissions (revised 3/00) are provided below.

REHABILITATION I - *Early Medical Management and Basic Initial Rehabilitation*

This is usually the first comprehensive rehabilitation admission for a person with SCI when intensive care is no longer required. The primary purpose is addressing restorative medical and rehabilitation problems in the early post acute recuperative phase. The major emphases of this hospitalization are: (1) to prevent and/or treat medical complications, (2) to establish bladder, bowel, and skin routines that can be carried over to the home setting, (3) to develop a program of physical restoration for improving strength, endurance, and function to the point where the patient can continue on a home program, and (4) to provide intensive patient and family education concerning management of all health and community reintegration needs.

In general, this hospitalization is devoted to three major goals. The first goal is to minimize and treat complications resulting from the patient's paralysis, sensory anesthesia, and/or immobility. The second goal is to improve the patient's strength, endurance, and function to a level so that further improvements can continue to be gained on a prescribed home program of exercise. The third goal is to educate patients/families in order to establish a comprehensive individualized home program designed to prevent complications and unplanned hospitalizations. When the person with SCI has reached a plateau in his/her progress toward independence and the plateau is due to the constraints of a spinal outhouses, external fixator, deconditioning or concurrent medical issue(s) that are expected to resolve he/she is discharged with a plan for a second inpatient admission.

REHABILITATION II - *Advanced Functional Activities* This admission is for the primary purpose of addressing advanced functional training issues. This is generally the second TIRR rehabilitation admission after external orthoses and conditions listed above have been removed and/or when permanent adaptive equipment e.g., a power wheelchair has been received and general health permits. The patient should have gained sufficient strength and endurance

from his/her home program to enable him/her to participate in advanced functional activities. Whenever possible, the goal is for independence with bathing, bowel and bladder care.

REHABILITATION III - *Limited Comprehensive Program* This is a rehabilitation program for patients who had their initial post-acute rehabilitation in another setting. This program is primarily for patients who are new to TIRR and who may have had inadequate or insufficient initial rehabilitation elsewhere. The primary purpose is to provide additional specialized training and education, upgrading of functional skills, etc. This program is also used for patients who are newly injured but with relatively lesser deficits whose estimated length of stay is short.

REHABILITATION IV - *Medical and Functional Enhancement and Follow-Up* This admission is for the purpose of reassessing and upgrading medical care needs and functional skills. The emphasis during this admission is on enhancing medical care, augmenting functional skills, and insuring that all necessary patient equipment is in working order and still appropriate. This program may include those patients (previous TIRR patients *and* patients who are new to TIRR) who have lost their previously attained level of function due to medical or surgical complications or are being admitted for an annual or biennial comprehensive follow-up visit.

REHABILITATION V - *Acute Intercurrent Surgical Problems* This admission is for the primary purpose of addressing acute intercurrent surgical problems in persons with SCI during their post rehabilitation follow up phase. This includes those patients with preplanned or emergency hospitalizations for surgical interventions such as decubitus ulcers, bladder calculi, obstructive uropathies, or other procedures. TIRR is accredited to admit patients for such surgical problems. It has two operating rooms and a cystoscopy suite.

REHABILITATION VI - *Acute Intercurrent Medical Problems* This admission is for the primary purpose of addressing acute medical problems in spinal cord injury patients. This includes those patients requiring preplanned or emergency hospitalizations for medical management, i.e., pneumonia, urinary tract infection, especially pyelonephritis, osteomyelitis and other conditions. TIRR has sufficient medical consultant e.g., pulmonology, infectious disease, etc. to treat these problems. It is well equipped and staffed to manage ventilator dependent persons with SCI and has an international reputation in this area.

REHABILITATION VII- *Intrathecal Baclofen Trial* This admission category is no longer used, as intrathecal baclofen trials are routinely done on an outpatient basis.

REHABILITATION VIII – *Baclofen Pump Placement* This admission is for the primary purpose of implantation or revision of the baclofen pump following a successful trial for persons with refractive spasticity. The admission category may also be used for repair of a baclofen pump system. TIRR was the second institution in the U.S. to implant a baclofen pump (Paraplegia 29:48-64, 1991).

REHABILITATION IX – *Progressive Sitting Program* This admission is for the primary purposes of progressive wheelchair sitting post-pressure ulcer closure, upgrading or returning to the previous level of function, and reassessing and prescribing necessary equipment. Patients are admitted when their wound is fully healed or there is adequate flap perfusion. The carefully supervised sitting program is progressed slowly based on close observation after each episode of sitting. A wheelchair and cushion assessment and pressure mapping are completed. A Force Sensory Array (FSA) currently measures pressure mapping. The patient and family can see the beneficial effects of pressure relief immediately and observe how this affects the selection prescription of the most appropriate wheelchair cushion. As soon as staff training is completed the TMSCIS will be using a new pressure evaluation system called the Xsensor. The patient and/or caregiver receive education about skin care.

REHABILITATION X – *Ventilator Weaning Program* This admission is for the primary purpose of weaning a patient from a ventilator. Patients are admitted when their physiological status meets the criteria for ventilator weaning and they are motivated to pursue this program. Time off the ventilator is progressed slowly and patients are monitored very closely. As appropriate, this admission may be used to assess needs in therapy areas as well.

Rehabilitation Categories. In addition to being admitted into one of the Rehabilitation Programs described above, each patient is assigned to an activity category during the admissions process. This categorization scheme facilitates communication among various clinical staff regarding the range of activities appropriate for an individual patient. Factors used in assigning patients to one of three categories include medical/ surgical status, spinal stability, and endurance. Patients with complications that preclude readiness to fully participate in a Rehabilitation Program as outlined above for whatever reason, e.g., concomitant head injury, and/or extensive long bone fractures or medical illness will be admitted to TIRR Lifebridge, a subacute or long term acute care (LTAC) hospital contiguous with TIRR Hospital until they are able to tolerate and benefit from the Rehabilitation 1 program. However, most patients who do

not have such complications when admitted for initial rehabilitation are admitted to TIRR for acute rehabilitation and assigned to Category II, the Initial Functional Program. Once strength and endurance have increased sufficiently and/or any complications have been resolved, the patient is reassigned to Category III, Full Functional Program--No Restrictions other than those imposed by orthotic devices. Moving people through this tiered rehabilitation process not only provides a measure of assurance that staff understand the patients' current status and target therapeutic efforts appropriately, it also provides points of achievement or milestones for patients and family members who may otherwise perceive little progress or be impatient with the often slow process of recovery from and/or adjustment to the devastating impact of SCI. Details on the medical, nursing, physical therapy, occupational therapy, social work, vocational and therapeutic recreation services provided patients in each category are included in section (D).

ADMISSION PROGRAM	1996	1997	1998	1999	TOTALS
Pediatric – all SCI admissions	16	28	38	39	121
Rehab. 1 – Initial Comprehensive Rehabilitation	122	111	116	118	467
Rehab. 2 – Advanced Functional Activities	27	32	23	23	105
Rehab. 3 – Short stay, Initial Rehabilitation Training	5	9	15	10	39
Rehab. 4 – Medical & functional reassessment & enhancement	8	10	4	4	26
Rehab. 5 – Acute surgical problems	91	60	45	57	253
Plastics	58	49	37	33	177
Urologic	19	7	8	12	46
Neurosurgery	0	0	0	6	6
General Surgery	14	4	0	6	24
Rehab. 6 – Acute intercurrent medical problem	6	23	13	12	54
Plastics	0	4	3	5	12
Urologic	0	8	0	2	10
Other	0	11	10	5	26
Unknown	6	0	0	0	6
Rehab. 7 & 8 – Intrathecal Baclofen pump trial/implantation/revision	9	14	12	25	60
Rehab. 9 – Progressive Sitting,	10	20	21	16	67
TOTALS	294	307	287	304	1192

Table 2. Inpatients discharged in 1996, 1997, 1998 and 1999 with a primary diagnosis of SCI.

Vocational services. Since a large percentage of TMSCIS patients will not be able to return to the vocational activities in which they were engaged prior to being injured, vocational services will be an integral component of the proposed program. The TMSCIS will conduct initial vocational assessments with referrals being made to the Texas Rehabilitation Commission (TRC) and other vocational rehabilitation sources. The TMSCIS—often under TRC sponsorship—will provide medical as well as vocational support services including physician and hospital services, fabrication of orthoses for functional enhancement, rehabilitation engineering assessment and provision of assistive devices, driver training and wheelchair fitting and modification to accommodate individual vocational needs. The Texas Rehabilitation Commission (TRC) assigns a vocational counselor full time to TIRR who works with current and potential clients who may be admitted under any of the programs listed above. Additional strengthening of the scope of vocational rehabilitation services is planned through the statewide technology-related program operated by TRC that involves the TMSCIS as a collaborating partner, along with other medical, vocational, and community-based organizations, such as independent living centers. Also, through its relationship with the Texas Assistive Technology Partnership, services related to the use of technology in the home, job and other settings are made available to individual who have sustained spinal cord injuries. Lastly, with regard to vocational services, the TMSCIS draws upon the resources of the Southwest Disability and Business Technical Assistance Center (DBTAC) operated by TIRR's ILRU Program. DBTAC services include information for persons with SCI, employers, and others concerning rights and responsibilities under the Americans with Disabilities Act and other disability rights legislation, as well as on-site assistance to employers who are attempting to accommodate employees with SCI and other types of disabilities.

Community reintegration and follow-up program. Planning and preparation for persons with SCI to re-enter the community begins well before discharge from the hospital. Virtually from the day of entry into the rehabilitation program, planning for discharge and for establishing an adequate community support system for persons with SCI is underway. Primary responsibility for guiding and coordinating the development of discharge plans and transitional services belongs to the TIRR social work staff person and the patient's case manager who work

with the patient and family throughout inpatient rehabilitation. Integral to the discharge planning and community reintegration process are the patient and members of the family who are called on to provide significant support services during the immediate post-discharge period and beyond. At every point in the planning process, the patient and appropriate family members are involved in examining their needs with respect to ongoing support, in assessing the availability of resources to meet those needs, in exploring options for securing additional resources, and in developing courses of action for implementing plans and securing needed resources.

A valuable recent adjunct for the preparation of patients and families for reassimilation into society is *TIRR Peers*. This program, started in August 1998, has benefited more than 150 TIRR patients with SCI since its inception. This program provides the opportunity for persons with recently incurred SCI to meet and talk with specially-selected and trained volunteers who share a similar type of injury and life circumstance. The goals of the program are to provide a community support system and resource network for patients and their families. Since 1999 twenty-eight former TIRR patients, ages 18 to 50, served as peers. This program has been so well received that at least one peer is assigned to every patient. The peers go through a training program so that they may avoid the twin pitfalls, laissez-fair and over zealousness. Training for TIRR Peers is standardized and all potential Peers are given a training manual (see appendix). Virtually every patient contacted by a peer has said he or she has learned something from practical matters e.g. dressing or applying a urinary collection device to better strategies for resolving psychosocial challenges e.g. architectural and attitudinal barriers.

Third party funding for comprehensive independent living skills training and community re-entry preparation has become much more difficult to secure, and as suggested from the previous discussion of the six-tiered rehabilitation process, TMSCIS staff has worked to create mechanisms for providing needed education and training during inpatient stays that have been drastically shortened due in large part to significant restrictions in third-party sponsorship of comprehensive rehabilitation. TIRR Peers has helped to meet these needs and will continue to do so as this program is expanded over the next five years. In addition to the use of creative programming to address the needs of persons with SCI using both inpatient and outpatient services, TIRR continues to work closely with community-based support service organizations, including the Houston Center for Independent Living (HCIL) and the Texas Rehabilitation Commission and other statewide and community wide agencies discussed throughout this

application. HCIL provides a full range of nonresidential independent living services to persons with all types of disabilities, including SCI.

TIRR also works closely with the community recreational centers in the greater Houston area, encouraging patient participation after discharge. Houston is fortunate to have a splendid facility, the City of Houston Metropolitan Multi-Service Center that is entirely wheelchair accessible and offers all types of recreational facilities for the handicapped. The Center offers the Michael J. Walsh Aquatic Program free to those persons referred by their physicians who can benefit from aquatic fitness classes. The pool therapy provided is appropriate for people recovering from severe injury and persons with disabilities. TIRR's *Strength Unlimited* program provides an assisted fitness program three nights a week to persons with disabilities in the hospital's physical therapy gym. Offered without charge, due to donations from the Ellwood Foundation, persons with limited resources can use the equipment under the supervision of a trained therapist who also donate their time, on a rotating basis.

The TIRR Foundation sponsors competitive wheelchair athletic programs called *TIRR Sports*. This component of TIRR Systems provides the structure for competition in wheelchair athletics from archery to the popular wheelchair basketball team. Under the leadership of Melissa Duff TIRR Sports has developed into an organization of enthusiastic male and female athletes. During 1999 TIRR Sports activities included:

The TIRR Storms, a N.W.B.A. Division III wheelchair basketball team that formed in 1999 for young adults new to the game. Most players on the team have a spinal cord injury and completed rehabilitation at TIRR. Some are young adults who have moved up from juniors basketball.

The TIRR Hotwheels junior wheelchair basketball team competed against teams from Arkansas, Louisiana, New Mexico, as well as Dallas and San Antonio. The junior players are ages 10 to high school graduation, and participate in one of two categories - those who shoot at a lowered 8-1/3 foot goal and a second group that competes with a 10-foot (regulation height) goal.

The TIRR Hurricanes rugby team traveled to 6 states to compete during their 1999 season. The "Canes" hosted their annual invitational tournament in January, attracting the top teams from across the country. There are more than 40 rugby teams in the U.S. and in 1999 the Hurricanes moved from 4th to 3rd place nationally.

The Community Recreation and Sports Festival held twice a year, co-sponsored by TIRR Sports and local adapted recreational organizations, introduced persons with disabilities to nearby adapted recreation opportunities. In 1999 the festivals included many outdoor favorites such as water skiing, kayaking, jet skiing, fishing, handcycling, and sailing.

Higher Ground, a three-day biannual weekend retreat for individuals with brain injury and their families blended horseback riding, dancing, singing around a campfire, and fishing with fellowship during 1999 get-togethers. Attendance at these statewide gatherings steadily increases, evidence of the need for such outings for those with brain injury.

An opportunity to enjoy adapted snow skiing at Crested Butte, Colorado was enjoyed by adults with various disabilities in January. Individuals depending on their ability used many types of adapted skis and snow mobiling was another recreational activity. This event will be repeated in the Spring of 2001.

TIRR Sports held its first X-treme Sports Camp for Youngsters Who Use Wheelchairs. Forty-five campers who use wheelchairs, ages 10 to 21, and 25 counselors (most with disabilities) spent a week at Camp for All near Brenham, Texas in July. The 6-day camp was the joint effort of three Texas rehabilitation facilities – TIRR, St. David's in Austin, and Warm Springs in San Antonio. Because of financial help from these three organizations and a generous donation from the Houston Golf Association, the cost for campers to attend was significantly reduced. The camp, which will be held again in the summer of 2000, offered a unique opportunity to youngsters with disabilities such as spinal cord injury, spina bifida, amputation, muscular dystrophy and cerebral palsy. Among the activities enjoyed by campers were horseback riding, floor hockey, and kayaking. Wheelchair athletes from throughout Texas, selected for their expertise and training, volunteered to assist in the cabins, demonstrate and instruct camp activities, and to serve as role models.

As regards personal assistance services (PAS) for persons with SCI who require such support to achieve optimal independence, both the Houston area and the State of Texas still have no formal programs in place to address this issue in a systematic fashion. The lack of PAS for people who require this type of support continues to pose a serious threat both with regard to maintenance of optimal health for individuals who need assistance with everyday activities (e.g., skin care, meal preparation, toileting) and with regard to attaining and maintaining optimal independence in the community. TMSCIS staff are currently involved in efforts to address the

PAS needs of individuals with SCI by working with organizations in Texas that are working toward redirecting state funds currently committed to institutional service programs (e.g., nursing homes and state-operated residential "schools" for persons with disabilities). Thus far, these efforts have led to development of a memorandum of understanding with the Board of Nurse Examiners clearing the way to permit delivery of certain non-medical support services by unlicensed personnel (an important issue in avoiding professional jurisdictional issues that could sidetrack program development). Also, new regulations regarding home care services were put into effect on July 1, 1994 by the Texas Department of Health (TDH, 1994). The new rules and regulations address jurisdictional issues, include standards for provision of PAS and other in-home services, and establish a framework for further development of PAS programs, including commitment of state funds to support these much-needed services. TMSCIS staff will continue to work with ADAPT, and other organizations, such as the Coalition of Texans with Disabilities, to promote development of cost-effective community-based programs essential to attainment of optimal independence by persons with significant disabilities, including SCI.

As a final point regarding transitional and follow-up services, the TMSCIS does not function simply as a hand-off agency that assigns full responsibility for follow-up services to the family, the family physician, an independent living center, or some other community-based agency once the transition is completed. Follow-up services will continue through outpatient clinic visits, outpatient therapy sessions when needed and through written and telephone communication after transition is completed and the patient is back in the community. Between 50 to 75 phone calls per day are fielded by the TIRR Outpatient Clinic concerning medication refills, durable medical equipment prescriptions, requests for unscheduled clinic visits on an urgent basis, requests to have forms completed and many other reasons. Patients are informed via bulletins and other TIRR publications of such items as ongoing and new services available through TIRR. They are encouraged to use the news about former patients, health tips and political developments involving persons with disabilities. TIRR outpatient services are discussed in some detail in the next section dealing with range of services. Patients will also continue to be informed concerning the above mentioned vocational, recreational, and other support services available through TIRR, TRC and other non-medical service providers. A major emphasis of follow-up services will also be to encourage patients to explore options available in their communities so that they can obtain needed support services conveniently and

at least cost to themselves and to third party payers. Also, persons with SCI--patients and others--will continue to be given information on the Client Assistance Program (CAP), operated in Texas by Advocacy, Inc., which has an office serving the Houston area and offices serving other parts of the state (see letter in appendix). Individuals will be encouraged to use the CAP services appropriately to access educational, employment, and service programs that support community living and attainment of optimal independence. Similarly, they will be provided information on the DBTAC and its functions relative to ADA and disability rights, the Texas Assistive Technology Partnership, and other federal and state-supported programs designed to address the needs of persons with disabilities. The intent of TMSCIS will be to continue fostering development of comprehensive services for persons with SCI, and to prepare individuals with SCI to use these services to their maximum benefit in pursuing the full range of life options available to persons without disabilities. TIRR and its partners in the TMSCIS have worked diligently to develop the linkages and networking necessary to foster development and use of a comprehensive service program.

Database Services. This particular component of the service delivery program is not designed as a direct service to the patient, but is rather intended to provide information that is critical in national and regional planning and development of services for persons with SCI.

As a Model System, TMSCIS will continue to be committed to collecting data for the NSCIDB. TMSCIS has a long-term commitment to this database and is currently following about 1,338 patients up to 25 years post injury. TMSCIS has submitted 307 new case records and 1,310 follow-up records since the beginning of the current grant cycle(National Spinal Cord Injury Statistical Center, 1999). Table 2, in section C-4, shows the extent of commitment to data collection at TMSCIS. In addition, TMSCIS remains committed to the evaluating the services provided by TIRR and other Model Systems. The Model System Program Evaluation (MSPE) project, a collaborative research project of ten model systems, compares efficiency and intensity of therapy services and outcomes between individual centers and the aggregate of all other contributing centers. Two reports from the MSPE project for TIRR/TMSCIS are in the appendix.

In summary, the scope of services that are available through the TMSCIS are comprehensive, with attention to all aspects of SCI from prevention through emergency trauma care, acute care, rehabilitative/restorative care, community-re-entry and follow-up. Plans for the

TMSCIS over the next five years are designed to assure that the scope of services continues to address the needs of persons with SCI. Also, through research, developmental and advocacy activities undertaken by TMSCIS staff and collaborators, efforts are underway to fill service gaps that contribute to diminished opportunities for persons with SCI in general and/or specific subsets of persons with SCI. (Such as individuals requiring personal assistance, individuals living in rural areas with fewer resources available, and women with SCI who may have limited access to reproductive health services.)

FORM TYPE	1995	1996	1997	1998	1999	2000 (to date)	TOTALS
NEW							
Registry	2	14	14	17	14	27	88
Form I	30	32	27	72	19	39	219
Form II	302	247	193	219	202	147	1310
TOTAL	334	293	234	308	235	213	1617
UPDATE							
Registry	0	0	2	0	0	1	3
Form I	16	16	79	71	50	32	264
Form II	28	4	73	139	17	47	308
TOTAL	44	20	154	210	67	80	575
DELETED							
Registry	0	0	2	0	0	0	2
Form I	0	0	1	0	0	0	1
Form II	0	0	0	1	0	0	1
TOTAL	0	0	3	1	0	0	4

TABLE 3 – Summary of National SCI Database forms submitted 1995 through April 2000.

(2) Range of rehabilitative and vocational services.

The range of services available through the TMSCIS, as suggested from the previous discussion of scope of services, is likewise comprehensive. These services, which include the traditional rehabilitative diagnostic and therapeutic services, are discussed briefly in this section. A number of new services have been introduced in recent years. These are identified and discussed in somewhat greater detail than are the traditional services.

Emergency trauma services. As previously discussed, the TMSCIS includes as a full

partner, the Houston Emergency Medical Service (EMS) operated by the Houston Fire Department and the Memorial Hermann Life Flight service. These rescue services provide state-of-the-art management of trauma at an accident scene. The personnel working for these services receive comprehensive training in emergency trauma management, including management of suspected SCI and life support services. They have up-to-date extraction and transport equipment that includes telemetry for real-time communication with trauma centers and acute care hospitals. TMSCIS physicians will continue to provide training to EMS personnel on management of spinal cord injury and will continue to monitor EMS service quality as it relates to SCI and feedback pertinent information to Dr. Persse or Dr. King (see section D).

Acute medical services. The TMSCIS includes the two Level 1 trauma centers serving the Houston metropolitan area, Ben Taub General Hospital and Memorial Hermann Hospital, both in the Texas Medical Center. Other major Houston-area hospitals that collaborate in TMSCIS activities are The Methodist Hospital and St. Luke's Episcopal Hospital, both fully accredited teaching hospitals. Ben Taub General Hospital, The Methodist Hospital, and St. Luke's Episcopal Hospital are primary clinical teaching affiliates of Baylor College of Medicine. Memorial Hermann Hospital and Lyndon B. Johnson Hospital are primary clinical teaching affiliates of The University of Texas Health Science Center-Houston. All provide training to a wide variety of health care professionals including nurses, therapists, social workers, vocational counselors, psychologists and epidemiologists (the latter at the University of Texas School of Public Health). The affiliated hospitals are all equipped with the most current diagnostic tools, including CT scan and MRI capabilities, and therapeutic equipment and have highly trained clinical staffs that provide a full range of acute care services. Numerous other hospitals in the area routinely refer acute patients with SCI to Memorial Hermann Hospital who are then transferred to TIRR. TMSCIS physiatrists provide regular contact with orthopedic surgeons and neurosurgeons at the sister teaching hospitals and liaison nurses. In addition contact with other key specialists throughout the area is maintained through participation in activities of medical school faculty meetings, Texas Medical Center events and activities of the Harris County Medical Society and other professional groups. Maintenance of SCI care skill levels of clinical staff of affiliated acute care hospitals will continue to be a high priority for the TMSCIS.

Transfer services. The transfer of patients from acute care to rehabilitative care is a critical juncture in the rehabilitation process. Early rehabilitation of a medically stable patient can

substantially enhance rehabilitation outcomes. Facilitation of the transfer process begins early in the acute care phase for patients with SCI through the TMSCIS services provided by the physician and faculty at the trauma centers and by the TIRR liaison nurse and SCI physicians. It is continued through support provided by TIRR admissions, social work, and nursing staffs.

Special transfer services are provided for high-risk ventilator-dependent tetraplegic patients, many of whom are from outside of the immediate geographic area and frequently from outside the state of Texas. Transfer services for these patients are often handled via air ambulance and are preceded by a conference between the TIRR SCI physiatrist and social worker and the referring physician and family of the patient. Medical and social factors, including patient and family preferences and expectations, are explored during the conference and the SCI Core Group reviews the information before a transfer is approved. Once transfer of a high-risk patient is approved, all arrangements, including securing financial sponsorship, are made prior to transfer of the patient to TIRR. The patient is then transported to TIRR using air and/or ground transportation, accompanied by qualified clinical professionals, and is admitted for a comprehensive rehabilitation program. The goal of transfer services is to provide the earliest transfer possible with all components in place, including funding not only of hospitalization but also of any special equipment, to assure provision of a comprehensive rehabilitation program.

SCI physician services. During the transfer period and throughout the rehabilitative program, medical services are directed by a physician with specialized training and experience in management of SCI. At present, two TIRR physicians, Drs. Donovan and Parsons are handling the SCI caseload. One very specialized area of SCI physician services relates to care of high-risk ventilator-dependent tetraplegic patients. Patients with high cervical spine injuries and who are apneic are referred to TIRR from all over the United States. In cases where patients will need to be maintained on respiratory equipment over their lifetime, arrangements are made prior to admission for purchase of equipment. While the patient is in the rehabilitation program at TIRR, both the patient and family members are provided training on the use and maintenance of the respiratory equipment. A full range of options is considered in managing high risk tetraplegic patients, including implantation of electrophrenic stimulators to augment respiratory function. TIRR is one of the few hospitals in the country providing this sophisticated rehabilitative service.

Another special service is the pediatric SCI program directed by Kathryn Zidek M.D., who

completed a combined residency program in physical medicine and rehabilitation and pediatrics. She currently holds Baylor College of Medicine and University of Texas Health Science Center-Houston faculty appointments in the departments of physical medicine and rehabilitation, as well as pediatrics. Dr. Zidek also directs the pediatric day hospital, providing for more comprehensive diagnostic and therapeutic services than can be provided through a typical outpatient program, while still avoiding much of the costs associated with traditional inpatient rehabilitation services. This program was developed in response to policy changes in Texas' Medicaid program whose policies in effect severely limit the number of inpatient rehabilitation days for children with disabilities. The direction of SCI rehabilitative services by highly trained physicians will continue to be standard practice in the TMSCIS.

Specialized medical services. In addition to comprehensive medical rehabilitation services directed by SCI physicians, specialized medical and surgical services are available as needed to address specific clinical problems of both inpatients and outpatients. Accessible onsite clinics with specialized equipment and trained nursing staff are designated for gynecology, obstetrics, optometry, plastic surgery, podiatry, proctology, sexuality and urology. Consultation services are readily available for dentistry, ENT, gastroenterology, infectious disease, orthopedics, neurosurgery, neuroradiology, pain medicine (algology), psychology, psychiatry and pulmonary medicine.

For each of these areas the clinical services are provided by board certified specialists who have obtained additional training in the special medical needs of persons with SCI. A brief summary of qualifications of specialty-area clinicians is provided under section (d) of this proposal entitled Quality of Key Personnel and biosketches are appended.

SCI nursing services. Persons with SCI requiring an inpatient admission are admitted to a specific geographically designated nursing unit at TIRR. Once admitted, these patients receive intensive nursing care directed by professional nursing staff with specialty training in rehabilitation nursing. In addition to specialty training obtained prior to employment at TIRR, every nurse assigned to SCI services undergoes a six-week orientation to SCI care and is monitored by an experienced TIRR SCI nursing supervisor during the probationary period to assure compliance with TIRR SCI nursing practices and procedures. The nurses on the SCI unit also assist the nursing staff caring for patients with SCI on Lifebridge with appropriate inservices and use of teaching manual.

For each of the therapeutic areas presented below, new staff assigned to work with patients with SCI are provided with initial training in TIRR SCI practices and procedures and are reviewed during the probationary employment period to assure compliance with TIRR SCI care standards. Thereafter, periodic staff development updates on SCI care are provided by TIRR clinical staff and outside consultants to assure adherence to state-of-the-art practices. In the interest of brevity, this stipulation is not repeated for each service described.

Physical therapy services. TIRR offers comprehensive physical therapy services provided by licensed physical therapists and certified physical therapy assistants using current practices and equipment. Physical therapy services focus on enhancing mobility, improving range of motion, maintaining optimal muscle tone and strength in affected and unaffected muscle groups, and providing specialized services such as pool therapy, functional electrical stimulation and hydrotherapy as a part of wound care. As mentioned, physical therapy staff also conduct a program called "Strength Unlimited" which is offered at no charge to persons with SCI living in the community. It provides opportunities for group exercise and encourages maintenance of optimal physical condition through a supervised exercise program. Exercise is promoted as an integral aspect of maintaining one's health. This in turn is a *sine qua non* for sustaining vocational goals.

Occupational therapy services. Occupational therapy services include traditional therapies such as self-care training provided by professional therapists and certified OT assistants in preparing patients with SCI for activities of daily living and for work-related activities. Occupational therapy staff is also responsible for assessing wheelchair needs of patients and for properly fitting wheelchairs and wheelchair cushions in accordance with physician prescriptions. This type of prescription writing is made easier by computer assisted technology, currently the Force Sensor Array soon to be replaced by the Xsensor. This technology is also used as a patient teaching tool to demonstrate to patients how easily pressure over bony surfaces can reach dangerous levels and how this pressure can be relieved. Driver education, available to both persons with paraplegia and tetraplegia, is also provided to patients with SCI through the occupational therapy department by contract. Transportation is a vital aspect in the pursuit of vocational goals therefore this activity is explored as part of each patients' vocational assessment.

Therapeutic recreation/Music therapy services. Therapeutic recreation is provided under

the direction of registered recreational therapists. Services provided include instruction in sports and recreational activities that can be pursued safely by persons with SCI, development of exercise programs to maintain fitness, and provision of information and training on adaptive equipment available to persons with SCI for recreational purposes. In addition to the vocational counseling provided to all patients, this service provides avocational counseling for leisure time activities appropriate to the disability.

Outings to supermarkets, shopping malls, airports, restaurants, and sporting events are organized by the therapeutic recreation department to help prepare inpatients with SCI, whether in wheelchairs or ambulatory with gait aids, for community re-integration.

After an ENT evaluation, music therapy is also used in some individuals with vocal cord paralysis or direct trauma to assist them in regaining the use of their vocal cords. Those patients who require ENT procedures (e.g. collagen injections) also find this beneficial. Every effort is made to treat and improve impairments of the voice as it is so important in occupations requiring good communications skills.

How about animal assisted therapy?? (Dr. Parsons)

Speech therapy services. Persons with SCI, particularly those with cervical lesions, may have speech or swallowing difficulties because of respiratory impairment, trauma to the neck and throat, or concomitant head injury. These problems are addressed by the speech therapist. Speech therapy services are very important in evaluating swallowing capabilities of patients with cervical spine injury. It is frequently necessary to do modified barium swallow fluoroscopic examinations to determine the extent of swallowing impairment in persons with high cervical SCI. This examination is important in some persons for evaluating the risks of aspiration and secondary respiratory infection. We are regularly reminded of this by admissions to TIRR of patients who received initial rehabilitation in other settings and who experienced lung complications due to aspiration associated with impaired swallowing. These patients have been treated successfully after diagnosing the problem, by a combined program of speech therapy, intensive respiratory therapy, appropriate antibiotic therapy, and weaning from oxygen. Barium swallows are now performed routinely on patients with high cervical spine injuries, and feeding programs are provided for patients with impaired swallowing so that the risk of aspiration is

minimized. The barium swallow also allows for evaluation of esophageal function, including gastro-esophageal reflux, to assess risk of esophageal inflammation.

Respiratory Care. TIRR offers a full range of respiratory evaluation and therapeutic services. These include pulmonary function testing, routine measurement of vital capacity and negative inspiratory force, mechanical ventilatory services, intermittent positive pressure breathing (IPPB) treatments, blood gas monitoring, intrapulmonic percussive ventilation (IPV), chest physiotherapy, postural drainage, tracheal suctioning and insufflator assistive coughing as may be required according to the patients' condition. They also provide instruction to the patient and family regarding ventilator management and suction equipment when these are required after discharge.

Social work. The job of the medical social worker begins during acute care, with information gathered from the patient and from family members and with discussions about the nature of the rehabilitation program and later community reintegration of the patient. The medical social worker also plays an important part in identifying financial sponsorship for the rehabilitation program by working closely with the admitting office and the case manager at the referring hospital and helps coordinate the transition from acute care to rehabilitation. Once the patient is admitted to TIRR, the medical social worker continues to provide one-on-one and group counseling and education services throughout the duration of the rehabilitation program. Some sessions are targeted to specific topics such as adjusting to disability, sexuality, substance abuse, attendant care management and family counseling. Other sessions are more open ended, allowing for patients to set the agenda. The medical social worker works closely with the family as well as with the patient throughout the rehabilitation program. They also assume lead roles in preparing patients for community re-entry as initial rehabilitation is finishing. They teach independent living skills including those mentioned above, using printed and media materials developed and refined previously at TIRR and elsewhere and they provide the contact with the TRC vocational counselor at the appropriate time – when the injured person is ready to consider his/her vocational options. The medical social worker continues to be involved in follow-up activities and inpatient and family counseling once the patient has been discharged from initial rehabilitation.

Medical social work services are complemented by psychological and psychiatric services of the TMSICIS. During the rehabilitation program, patients may experience a variety of

difficulties in the adjustment process. These may include denial, anger, and depression. Patients may express adjustment problems through a number of manifestations including hostility, withdrawal, or drug seeking behavior. Although the social work staff is very experienced in dealing with these problems and generally deals with them effectively, in some cases the patient may be referred for additional psychological or psychiatric services. TIRR has staff psychologists who provide counseling services and has two consultants on the active medical staff who provide psychiatric services as needed. The array of social work, psychology, and psychiatric services available through the TMSCIS assure that patients and family members receive adequate assistance in making the adjustment to disability and in coping with problems that arise in the process. Only when these problems are recognized and treated can otherwise effective vocational strategies be implemented.

Nurse Case Manager. The rise in the number of patients funded by managed care has created the need for an additional team member i.e., the case manager. These are persons with registered nursing backgrounds who are also knowledgeable in the needs of the managed care payer for information. They know how to provide that information so that the patient has the best chance of obtaining authorization for the hospital days needed, equipment required and personal assistance that will be needed when he/she returns home. These nurses fulfill the seemingly endless requests for justification from managed care providers. They spend much of their day on the phone, faxing information and obtaining letters of justification from physicians and therapists to send to managed care personnel. They also assist the patient in gathering necessary information such as medical history needed for TRC sponsorship and the prescriptions for therapy and durable medical equipment with letters of justification for payment by the third party, which may be TRC for some patients. In Texas TRC will cover these items and hospitalization in some cases (after appropriate means testing).

Orthotics. TIRR insures that needed orthotic equipment is provided by orthotists in the community. Often dictated by contracts between the orthotist and the managed care organizations, these orthotists measure, fit and fabricate the orthoses according to the surgeon's or physiatrist's prescription. For many persons with SCI, having the correct orthosis can mean the difference between ability and disability during the Rehabilitation 1 phase and later.

Pharmacy. TIRR operates a full-service pharmacy with 4 pharmacists to meet the pharmacotherapeutic needs of persons with SCI. In addition to stocking pharmacologic agents

needed in treating SCI-related problems, the pharmacy operates a computerized drug surveillance program. This program allows TIRR clinical staff to monitor drug usage by patients with SCI for the purposes of detecting both intentional and unintentional prescription drug abuse (this applies mostly to outpatients), to proactively identify potential allergic reactions to certain drugs, and to anticipate possible drug interactions that might have deleterious effects on the patient. The pharmacy staff also publishes the "Pharmacy Newsletter" informing current and former patients about pharmacological issues. They work closely with consulting pain specialists. They also assume responsibility for educating patients and family members concerning discharge medications, and they participate in the hyperalimentation program and the program on withdrawal from pain medication. They take particular effort to be sure that persons with SCI understand the effects of their medication and certain commonly used other medicines on one's cognitive function and how this important aspect relates to their vocational plans and future. Pharmacy services are available on both an in-patient and outpatient basis.

Nutrition. TIRR has three certified dieticians on staff. They advise all patients with SCI regarding their current caloric intake, need for dietary supplements, ideal body weight, how to choose from the menu and insure that patients are eating a nutritious diet. They ascertain that the diets that were ordered match any individual requirements e.g. diabetes and general requirements such as sufficient fiber to aid in evacuation of neurogenic bowels. They also consult on all patients receiving tube feedings and calculate for the physician the required formula and water required.

Radiology. TIRR has a fully staffed radiology department. It has equipment to perform standard radiography, plane tomography, and fluoroscopy. With this equipment, most diagnostic imaging procedures can be done in-house. Ultrasound imaging services are available to inpatients at their bedside. When CT scans and MRI services are needed, patients are sent to one of the acute care hospitals, usually Memorial Hermann since this is where most have received their acute care.

Advanced Technology Services. TIRR's own rehabilitation-engineering department offers a variety of assessment, modification, and fabrication services relating to technology and devices for people with SCI. The types of devices that can be provided persons with SCI through the rehabilitation engineering department and advanced technology private vendors range from specialized wheelchair cushions and bed mattresses designed to avoid development of pressure

sores, to environmental control systems that allow persons with significant disabilities to operate temperature controls, electronic doors, entertainment equipment, and telecommunication devices from chairs or beds. The wheelchair clinics alluded to earlier where FSA's are conducted, provide the forum where therapists and engineers (and engineering students) can discuss and recommend the basic as well as the assistive technology elements of modern powered wheelchairs. These clinics provide engineering students with exposure to the kinds of problems encountered by people with disabilities who rely on technology and encourage them to pursue careers in this area. Other engineering services are provided upon request to meet special needs of persons with SCI. Staff collaborates with other rehabilitation technology programs in the Houston area and elsewhere in Texas, including the program operated by the Texas Rehabilitation Commission and the Texas Assistive Technology Partnership based at The University of Texas at Austin. The intent of the center and of collaborative efforts with other technology-related programs is to provide as wide a range of technological options as possible in addressing individual needs of persons with SCI.

Vocational services. Since a large percentage of TMSCIS patients will not be able to return to the vocational activities in which they were engaged prior to being injured, vocational services are an integral component of the proposed program. The TMSCIS will conduct initial vocational assessments with referrals being made to the Texas Rehabilitation Commission (TRC) and other vocational rehabilitation sources. TIRR provides office space for onsite TRC staff. The onsite TRC vocational counselor, Mr. Rodney Senigaur, insures that TIRR vocational services are carefully coordinated with the state vocational rehabilitation agency to assure continuity of services from inpatient rehabilitation through transition to community living and on to gainful activity (see letter of support in the Appendix). Vocational services begin during the acute rehabilitation process, Rehabilitation 1 or 3, and are continued through each phase of the rehabilitation program and during outpatient follow up. The TMSCIS—often under TRC sponsorship—will provide medical as well as vocational support services including physician and hospital services, fabrication of orthoses for functional enhancement, rehabilitation engineering assessment and provision of assistive devices, driver training and wheelchair fitting and modification to accommodate individual vocational needs. In all cases, the goal of vocational services is to assist patients in securing whatever services and technological devices are necessary to maximize the likelihood of resuming gainful activity.

Additional strengthening of the scope of vocational rehabilitation services is planned through the statewide technology-related program operated by TRC that involves the TMSCIS as a collaborating partner, along with other medical, vocational and community-based organizations, such as independent living centers. Also, through its relationship with the Texas Assistive Technology Partnership, services related to the use of technology in the home, job and other setting are made available to individual who have sustained spinal cord injuries. Lastly with regard to vocational services, the TMSCIS draws upon the resources of the Southwest Disability and Business Technical Assistance Center (DBTAC) operated by TIRR's ILRU Program. DBTAC services include providing information for persons with SCI, employers and others concerning rights and responsibilities under the Americans with Disabilities Act and other disability rights legislation, as well as onsite assistance to employers who are attempting to accommodate employees with SCI and other types of disabilities.

Persons requiring vocational services also have available to them the Functional Capacity Evaluation (FCE) and the work hardening program. Conducted through TIRR Outpatient Therapy Services, the FCE evaluates and documents the SCI person's physical abilities by measuring capacity for numerous different tasks. Based upon the results a plan is developed that helps steer the person towards one of the following paths. Return to school for remedial or higher education prior to job seeking; further training and preparation through a trade school for an occupation within that person's measured capacity; or enrollment in the work hardening program in order to improve their physical capacity. With consent of the patient, close collaboration between TRC, the person's insurance company, case manager and any other agency or person with a need to know is continued throughout these sessions

Community reintegration services. Training in independent living skills, including use of community services and developing contingency plans for dealing with personal assistance services and other similar problems, is provided through the social work department. As described above, other departments are also substantially involved in preparing patients for return to the community by emphasizing these concepts during inpatient and outpatient sessions. The outpatient nursing staff plays a significant role in assisting patients with re-entry to community living. These nurses' responsibilities begin prior to discharge of the patient through a series of formal patient/family educational programs. These programs involve staff of several departments and focus on important information needed by patients and family members on such

topics as ordering supplies and equipment, obtaining prescription refills, making and keeping clinic appointments, and the importance of participating in the follow-up program. Patients and family members are informed about the importance of having a family physician that is familiar with the patient's medical history and about how to deal with medical emergencies that might arise. They play an integral role in establishing home health services for outpatients, just as TIRR case managers do for patients being discharged. The clinic nurses assist the physicians in making referrals for medical therapy and psychological and vocational services. Further, the patient education series described earlier prepares the patient and family as thoroughly as possible for problems that may be encountered once the patient leaves the hospital.

The TMSCIS will continue to provide ongoing services to patients through its outpatient services department and will continue to make follow-up contacts with patients on a regular basis to determine if medical and support needs are being met. Patients typically are given follow-up clinic appointments one to two months after discharge from TIRR. Thereafter, clinic visits are scheduled as needed according to health and functional status. For patients whose health is being adequately maintained and who are not experiencing unusual medical, functional, psychosocial, or vocational problems, the frequency of visits to the clinic is reduced to one or two per year after the initial follow-up visit. Patients with particular medical problems are referred to specialized clinics listed above and described in section (d). The outpatient service component of the TMSCIS assures that patients with SCI have access to properly trained care providers who can address a wide range of problems that may occur after the patient leaves the rehabilitation program.

In summary, the range of services provided persons with SCI by the TMSCIS is comprehensive and includes an array of medical care, rehabilitation, community re-entry, and ongoing support services that address almost any SCI-related problem

(3) Service coordination and use of other appropriate community resources.

This topic has been dealt with in considerable detail in prior sections of this proposal. Close collaboration with a range of community agencies, including the Houston Center for Independent Living, the recently established Attendant Services of Houston, various public and private vocational rehabilitation providers, and the Client Assistance Program operated by Advocacy, Inc., will be continued. In light of trends in reimbursement of medical rehabilitation

services that have been in the direction of shorter stays and increasingly limited authorizations for follow-up services, the need for optimal use of community-based services are of increasing importance. Programs proposed for the TMSCIS are designed to make the best use of the full array of community resources to promote optimal independence of persons with SCI and to test new approaches for delivering clinical and non-clinical support services to people with SCI.

An important part of the community re-entry program for each patient involves working with other community agencies to be sure that support services are available to the patient upon leaving the hospital. In April 1990, the Texas Department of Human Services (TDHS) established a new Office of Services to Persons with Disabilities. The goals of this unit are to develop: (1) a comprehensive approach within TDHS to serve people with disabilities, and (2) interagency strategies for services to people with disabilities for the purpose of encouraging continuity in service delivery. Since its establishment in 1990, TIRR staff has worked with TDHS staff to help identify needs of persons with disabilities, as well as approaches for addressing those needs. TMSCIS staff and collaborators will continue to work with TDHS in identifying strategies for assuring adequate community support services for people with SCI. Particular attention will focus on assisting TDHS in its efforts to develop statewide personal assistance services (PAS). Collaboration with Texas ADAPT, and other community-based service and advocacy agencies will be critical in assuring that efforts are continued toward a program of comprehensive services for people with SCI.

Coordination of TMSCIS services with other community resources will continue to be a high priority throughout the proposed project period. Coordination with area emergency medical services will be maintained through continued close working relationships. Coordination with acute care hospitals that serve as partners in the TMSCIS will be maintained through the TMSCIS liaison program and through shared training programs between acute care and rehabilitation staffs. Coordination with vocational service providers will be maintained through the TRC vocational counselor in residence, and through training activities and information-sharing activities that involve TMSCIS staff and vocational rehabilitation staff. Community physicians and other health care providers who are knowledgeable concerning spinal cord injury and associated health care problems will continue to be identified and patients will be appropriately referred for health care problems.

TMSCIS staff will continue to work with staff of the Texas Department of Human

Services and its Office of Services to Persons with Disabilities to develop statewide support services for people with SCI. Long-standing collaborations with community-based agencies, such as the Houston Center for Independent Living, will be maintained, and support will be provided for organizations, such as Attendant Services of Houston, that are working to fill service gaps through development of consumer-directed community-based service programs. Developments of the last few years with regard to delivery of health care services (i.e., the trend toward managed care programs) and reimbursement policies (i.e., third-party negotiations with providers to obtain the lowest possible costs) reinforce the need for extensive and effective collaborative efforts to assure that persons with SCI are obtaining services necessary to live independently. Fostering such collaborations will constitute a high priority over the proposed five-year project period.

The goal of the proposed five-year efforts will be to enhance further coordination of services and linkages between service components, while at the same time developing new service strategies through research, service demonstrations, and advocacy efforts that involve numerous partner organizations in the Houston area and elsewhere in Texas and the nation. The remainder of this application provides additional information on how this will be accomplished.

(c) Plan of Operation

(1) Plan of operation and efficiency of administration.

The proposed model system incorporates an administrative structure that is designed to assure reasonable distribution of administrative responsibility. The distribution of administrative responsibilities is discussed below.

In addition to the internal administrative structure indicated, external accountability will be strengthened through the use of a Model System Consumer Advisory Committee. Consumer participation in all stages of research efforts purported to be designed to be of benefit to those consumers is an effective method for enhancing the likelihood that the research will (a) be relevant to their needs and (b) result in appropriate action being taken once the results are known (Cornwall et al., 1995; Graves, 1993). Committee functions will relate primarily to planning and evaluation and are discussed at greater length under the evaluation plan, section (h). The committee will be convened in months 2 and 3 of the first year of operation to provide input on

the overall research plan to evaluate models of disability. Members will be asked to suggest important life areas that should be included in the models but are not. The committee will meet in months 6, 7, and 8 to focus on the interrelation between specific measures/abilities and other constructs. The committee will be convened again for one or more meetings beginning in month 18. The Consumer Advisory Committee's primary function will be to help the research team develop models to be tested against objective data. The committee will take part in a layman's introduction to the concepts behind correlation, and modeling. Then the committee will be presented with scenarios developed from the research findings of various interim analyses of data collected as part of the TMSCIS, as well as data available in existing datasets (i.e., RRTC on Community Integration for Individuals with SCI, and the SCI database developed by the VA Center of Excellence on Healthy Aging with Disabilities), and asked to help explain the findings based on their own knowledge and experiences. The reason for asking consumers for their input is that it is possible to create very different models that will fit a particular dataset. Combining theory and experience is the best method of developing models that will not only statistically fit the data, but also be a reasonable approximation of reality. The committee will meet in months 36 and 48 to evaluate the progress of the research and further review model development. Finally, in month 56, the final results will be presented and again the committee members will be asked to aid with interpretation. Their suggestions will be reflected in the final report and dissemination efforts.

In terms of composition, the 7-member committee will include six men and women with SCI from various racial, ethnic, and cultural backgrounds who live in the vicinity of the TMSCIS. Selection criteria for these members will include (a) the ability to understand research when described in lay terms and (b) the ability to contribute to discussion of the consumer perspective with regard to research aims and results. The seventh member will be Dr. Glen White, who is not only a person with SCI but he is also currently conducting an intensive study of secondary complications that will provide invaluable information. His primary function will be to share his expertise on the theoretical underpinnings of the IOM model and help guide the development of models with the consumer groups. Dr. White's contribution will be especially valuable because he participated in the development of the IOM model. Although it may not be feasible for him to attend all of the meetings of the committee in person, Dr. White will at least attend the meetings in months 2, 8, 18, 36, 48, and 56. Other modes of communication such as

telephone calls, e-mail, mail, and fax will be utilized between visits to keep him abreast of the progress and to acquire his comments and suggestions.

Overall administration and direction of the service demonstration component of the TMSCIS. The plan of operation for the TMSCIS draws upon an administrative structure that has worked effectively over more than 20 years. It allocates responsibility for administrative activities in a manner that assures reasonable distribution of effort with back-up support when required. The overall TMSCIS will be directed by William H. Donovan, MD and co-directed by Kenneth C. Parsons, MD and Daniel E. Graves, M.Ed. These three individuals will be responsible for overall direction of system activities and for administrative decisions regarding aspects of both the service delivery and research missions. In addition to overall administration of the TMSCIS, Drs. Donovan and Parsons will share responsibilities in directing the service delivery program. Dr. Parsons will have primary responsibility for general oversight of the SCI program, coordinating day-to-day management of the SCI Core Group team members, making periodic evaluation of treatment strategies and clinical personnel in response to internal and external pressures and supervising follow-up activities. Dr. Donovan will have principal responsibility for coordinating with emergency medical service and acute care service providers, monitoring work of consulting physicians, directing research activities and in his capacity as TIRR Medical Director, will liaise with hospital administration, advocating for the SCI Program. Mr. Graves will have primary responsibility for directing the research efforts of TMSCIS, supervising and insuring compliance with data collection for the national database and directing personnel working on this grant while liaising with the TIRR department of Human Resources and departments of Payroll and Accounting. In addition to providing for reasonable distribution of work, this sharing of administrative responsibility assures that back up is available should any of the three directors be unavailable to deal on site with a problem that may arise.

Finally TIRR will bear the fiduciary responsibility for this grant, if this application is successful. Under the leadership of Ms. Louisa Adelung, President/CEO TIRR, TIRR has managed to survive in a market with a managed care penetration of nearly 35%. She and the TIRR Board of Directors are completely supportive of the TMSCIS, as its goals and mission are congruent with those of TIRR's. Ms. Adelung has been the driving force behind converting TIRR from a departmental structure to a programmatic structure, thereby insuring a sense of cohesiveness within the SCI team of professionals, giving them a sense of accomplishment as

they work together creatively to alter policies and procedures to accommodate shrinking reimbursement and accepting a greater number of charity patients while maintaining quality. This has not been easy but the staff at TIRR has pulled together, accepted the challenge and have come up with creative solutions rather than succumbing to "burn out". At the same time, the entire staff has avoided the pitfall of clique formation, pitting one program e.g. SCI against another e.g. Brain Injury. In fact all professionals will cross between programs when needed and some services are deliberately shared e.g. respiratory, vocational, recreational, music and animal assisted therapies.

Administration of the research component of the TMSCIS. The director and two co-directors will share direction of TMSCIS research, with Dr. Donovan and Mr. Graves having primary responsibility. Dr. Donovan--with assistance from Mr. Graves and Dr. Parsons and support from professional staff with expertise in research design, data collection methods, and analytic techniques--will monitor progress toward specific research goals and will meet regularly with the investigators responsible for the center specific research projects, concerning progress towards established deadlines, problems noted with research progress, facilitate that progress when necessary and deal with other matters that may influence the scope or quality of research efforts. In addition to conducting their own research under the TMSCIS, Dr. Donovan and Mr. Graves will be responsible for assuring that all research activities conducted through the model system meet with the highest research standards and that research efforts are of sufficient quality to merit dissemination through scholarly journals and through presentations at professional research-focused meetings, such as the annual meetings of the American Spinal Injury Association, the American Congress of Rehabilitation Medicine and other professional meetings.

Administration of educational and dissemination activities. Responsibility for overseeing planning and offering of TMSCIS education and training activities will rest with Karen Hart, PhD, TIRR vice president for education and director of the Baylor College of Medicine and University of Texas-Houston Physical Medicine and Rehabilitation Alliance. Dr. Hart will direct staff of the TIRR education division in the development and participation in training programs in prevention, emergency medical services, acute care of SCI, rehabilitation of patients with SCI, ongoing medical, psychosocial and vocational services and community re-entry services for those patients. These training programs will be targeted to staff of partner institutions and organizations of the TMSCIS, such as the acute care hospitals mentioned earlier and independent

living centers. The programs will also be directed to TMSCIS staff at various levels to assure that they remain current on care issues and research related to SCI and its management. Dr. Hart's division has responsibility for both staff development and continuing education activities for all TIRR programs, including SCI programs, and for assurance that education and training activities pursued under the auspices of the TMSCIS meet quality standards.

Dr. Hart's division also will work with TIRR clinical staff in refining existing resources or developing new educational materials to be used with persons with SCI and family members. These include instructional materials on self-care, health promotion, resource listings, and a variety of other informational materials that are designed to provide easy-to-use information to patients and families during and after their medical care and rehabilitation programs. The TIRR education division has established procedures for developing and field-testing instructional materials and will follow these procedures in preparing new materials for the field. Once field-testing and refinement of materials have been completed, selected materials will be disseminated to state, regional, and national audiences using appropriate promotional strategies, including exhibits at SCI professional meetings, presentations before consumer groups, and announcements in TIRR's own and other newsletters and journals. Dr. Hart will also oversee the production and distribution of patient and family-focused newsletters and flyers that are sent out from TIRR regularly. These newsletters and flyers inform patients and families about issues involving health, safety, rehabilitative care in SCI, ongoing research towards a cure of SCI, new or modified services at TIRR, and national, state, and local actions relating to SCI and disability issues. One exciting activity at TIRR frequently mentioned in the above publications that has drawn a great deal of consumer interest is *Mission Connect*. Created to financially support collaborative investigative work in the area of spinal cord regeneration, *Mission Connect* has raised seven million dollars towards the \$33 million capital and endowment campaign goal. Reported in TIRR's newsletter several times, *Mission Connect* is a TIRR led consortium that includes the neurosurgery/neuroscience departments of three area medical institutions, the University of Texas Medical School – Houston (UTMS-H), Baylor College of Medicine (BCM) and the University of Texas Medical Branch in Galveston (UTMB). Grants of \$100,000 were made in 1999 to UTMB to aid in research to identify the mechanisms that cause chronic pain in SCI that may affect function and to BCM for research in applying gene therapy to the repair of SCI.

Direction of component SCI services. In addition to the administrative structure indicated above, professionals serve the components of the TMSCIS with appropriate certification in their respective disciplines and with specialized training and/or experience in SCI. Each service component has clearly identified administrative lines of authority and these facilitate adherence to high quality service delivery. Tables of organization for the TMSCIS service delivery and research components are provided in the appendix. These tables indicate reporting relationships for the TMSCIS and identify persons responsible for directing each component.

(2) Use of resources and personnel.

The detailed service descriptions provided previously and the additional detail on administrative arrangements in the immediately preceding section offer clear evidence of effective use of resources and personnel. For relatively modest grant support, the TMSCIS will provide a comprehensive service delivery system, the scope of which spans the service continuum from initial trauma through acute care, rehabilitation, community re-entry, and ongoing follow-up and community support. To achieve this comprehensive service system an array of resources has been marshaled, most of which will not be supported by the requested grant funds. In addition, the TMSCIS will conduct an ambitious research program that will contribute significantly to understanding clinical and support factors and measurements that influence outcomes in the management of SCI. The TMSCIS, based at TIRR, is in a strategically favorable position to align with local EMS and acute care providers as well as consumer groups to capture the majority of persons with SCI in Houston and the surrounding areas either immediately after injury or for follow up medical services. In addition to the greater Houston area, TIRR receives many patients from central and east Texas and western Louisiana. Such is TIRR's reputation that even HMO's in the Houston market who are not contracted with TIRR (very few) will agree to "out of contract" TIRR admissions for acute rehabilitation. (Acute rehabilitation includes medical management, initial mobility and self care training, patient and family education on medical, psychosocial and vocational issues and prescription of durable medical equipment.) The word has gotten out that mistakes and/or omissions in these areas early on can prove costly later on, so even though they will insist on daily accountability, the HMO's in the market will usually approve admission to TIRR for at least Rehabilitation 1.

As regards personnel use in the proposed TMSCIS, the previous description of

administrative plans for the system indicate an approach that capitalizes on the specific knowledge, skills, and experiences of a highly qualified core project staff, augmented by use of selected experts in various clinical, support service, and research fields. As in the case of resource usage, personnel plans reflect a deliberate attempt to deploy limited funding to secure the very best personnel to direct various activities of the TMSCIS and to serve in key staff and consulting positions relating to specific operations of the model system. It should be emphasized that only a very small percentage of personnel costs associated with operating the model system will actually be borne by grant funds requested for this project.

(3) Effectiveness of inter-institutional collaborations.

Inter-institutional collaborations have been discussed in considerable detail prior to this. As indicated by the earlier discussion of service comprehensiveness, the proposed model system relies heavily on inter-institutional collaboration. Fortunately, the TMSCIS has a lengthy history of effective collaborative endeavors from which to draw for the proposed project. TIRR has been involved in spinal cord injury care for more than 35 years and has established a reputation for excellence in delivery of SCI services. This reputation facilitates establishment and maintenance of collaborations with sister institutions in the Houston area and elsewhere in the country. Local collaborations that will be maintained by the TMSCIS/TIRR over the proposed project period include:

- Baylor College of Medicine
- The University of Texas Health Science Center at Houston
- Houston Fire Department Emergency Medical Services
- Ben Taub Hospital/Memorial Hermann Hospital/The Methodist Hospital/St. Luke's Hospital
- Harris County Hospital District
- Texas Rehabilitation Commission (vocational rehabilitation)
- Houston Center for Independent Living
- Attendant Services of Houston
- ILRU Research and Training Center on Independent Living at TIRR
- The University of Texas Dental Branch

- University of Houston School of Pharmacy
- Texas Women's University

(4) Participation in the National SCI Database

Other inter-institutional collaborations that extend outside the immediate geographic area include collaborations with partners in the National Spinal Cord Injury Database (NSCIDB). The TMSCIS has been a participating member in the NSCIDB since its inception. After the April 7, 2000 data submission, the NSCIDB contains data on 1,539 TMSCIS patients. Actual forms submitted include 1,338 Form I's which provide extensive data on the patients' status at the time of SCI and document events occurring during the initial acute care and rehabilitation hospitalization as well as post-discharge rehabilitation information and death data. There are Registry forms on an additional 190 patients. These are patients that did not qualify for Form I data collection. TMSCIS Form II's submitted number 6,816. These are annual follow up forms that document events occurring during specified anniversary years post-injury. Seventy-three of these Form II's document events occurring during patients' 20th through 25th year post injury.

The TMSCIS also hopes to participate with other Model Systems and possibly other SCI care providers e.g., the Veterans' Administration when collaborative research and funding proposals are announced later this year by NIDRR.

Coordination of data collection and reporting activities. As indicated throughout this proposal, there will be a substantial number data collection and reporting activities carried out over the duration of the project period. Ms. Francine Mechoulam and Mr. Glen Baker will coordinate data collection efforts of the TMSCIS. Working under the direction of the director and co-directors, Ms. Mechoulam and Mr. Baker will review current data collection methods and materials, make revisions in data collection instruments and procedures as deemed necessary by the project directors, and monitor data collection and data entry, communicate regularly with National SCI Statistical Center and provide assistance in data retrieval for use in service monitoring and research projects of the TMSCIS. A summary of data previously collected by the TMSCIS is shown in Table 3. Ms. Mechoulam and Mr. Baker will ensure that data collection activities of the TMSCIS are conducted in a manner that meets the standards of the National SCI Database and of any collaborative research projects. The To Be Named (TBN) Data Collector will assist Ms. Mechoulam and Mr. Baker in these activities and will be

responsible for NSCIDB Form I data collection and aid in data collection for the center specific research projects. Currently a research analyst, who will be leaving TMSCIS in August, carries out these responsibilities.

(5) Inclusion of traditionally underrepresented persons.

The proposed project will involve persons from traditionally underrepresented groups in a number of roles. TIRR, Baylor College of Medicine and the University of Texas Medical School-Houston (which is part of the Health Science Center) are equal opportunity employers and have in place plans designed to assure that persons belonging to a disadvantaged minority e.g., women, African Americans, Latin Americans, Native Americans, Asian Americans, persons with disabilities and the elderly, who have traditionally experienced discrimination in employment, service access or other aspects of life will have a full and equal opportunity to participate in all TMSCIS/TIRR activities. TIRR has always been particularly interested in enhancing opportunities for persons with disabilities, including SCI, and employs people with disabilities in all types of roles, from upper level administration through support staff levels. TIRR also has a large cadre of volunteers many of whom have disabilities and/or are elderly. The director of volunteers, a salaried position, is herself a ventilator dependent tetraplegic and a senior citizen. TIRR's in-house legal counsel is also a woman who has ventilator dependent tetraplegia.

In an effort to accommodate its many Spanish speaking admissions, TIRR has offered free of charge to its employees, onsite Spanish classes for academic credit by Houston Community College instructors.

For the proposed project, an aggressive approach to involving people from racial and ethnic minority groups, as well as persons with disabilities, in all aspects of model system activities will be pursued. Evaluation data on persons served through the TMSCIS and on persons involved in the TMSCIS, as staff or consultants will reflect significant involvement of individuals from groups that have historically been significantly underrepresented in various aspects of community life.

(d) Quality of Key Personnel

In addition to the brief summaries provided in this section, reviewers are referred to the appendix

containing biosketches for additional detail on each key staff person.

(1) Training and experience of project director and key staff. Primary Texas Model Spinal Cord Injury System (TMSCIS) Administrative Staff.

William H. Donovan, M.D. is director of the TMSCIS. He is professor and chairman of the Department of Physical Medicine and Rehabilitation (PM&R) at the University of Texas Medical School-Houston. He is also adjunct professor of PM&R at Baylor College of Medicine. Dr. Donovan has been on the staff of the SCI program at TIRR since 1980 and is currently TIRR vice president for medical affairs. Prior to that he worked at the Regional Spinal Injury Center in Perth, Australia under the supervision of Sir George Bedbrook, physician-in-charge. He is a past president of the American Spinal Injury Association (ASIA) and still chairs two liaison committees: The Model Spinal Cord Injury and The International Medical Society of Paraplegia (IMSOP). He also serves on the IMSOP Board of Councilors. He has published more than 60 articles in peer reviewed journals, book chapters, and other materials on SCI. His responsibilities for the proposed model system include direction of the acute care hospital liaison program, supervision of SCI medical staff, networking with consulting physicians, and overseeing collaborative research projects to be conducted over the proposed five-year project period. He spends roughly 65% of his time doing clinical work and will dedicate 10% of his time to this grant.

Kenneth C. Parsons, M.D., Will act as co-director of the TMSCIS for SCI services the, he is director of TIRR's SCI program. He is also director of the University of Texas Medical School-Houston PM&R residency program. He is an assistant professor of PM&R at the University of Texas Medical School-Houston and an adjunct assistant professor of PM&R at Baylor College of Medicine. He has extensive experience in management of SCI, having worked at Craig Rehabilitation Hospital in Colorado and SCI units in California and Michigan hospitals. He spends roughly 75% of his time doing clinical work and will devote 6.5% of his time to this grant.

Daniel E. Graves, M.Ed. Will act as co-director of the TMSCIS as Director of Research, since 1996 he has acted as Director of Spinal Cord Injury Research for The Institute for Rehabilitation and Research (TIRR) and an Assistant Professor of Physical Medicine and Rehabilitation, Baylor College of Medicine. He holds a Master's Degree (1997), and is currently a Doctorial Candidate in Statistics and Measurement at the University of Houston. Mr. Graves

will direct all data collection and research activities associated with TMSCIS. He will devote 80% time to grant activities.

Kathryn Zidek, M.D., joined the TIRR staff in 1997 to assume direction of the pediatric rehabilitation program. Dr. Zidek completed her residency program in pediatrics and physical medicine at the Baylor College of Medicine prior to joining TIRR and the faculty of Baylor College of Medicine, where she holds appointments as assistant professor in the departments of Pediatrics and PM&R. She is board-certified in both pediatrics and physical medicine and rehabilitation. For the proposed TMSCIS, she will have principal responsibility for directing the care of pediatric patients with SCI.

Karen Hart, Ph.D., will have responsibility for oversight and support of the numerous education, training, and dissemination activities to be carried out through the TMSCIS. She is vice president for education at TIRR and previously served as director of training for the Rehabilitation Research and Training Center on Community Integration for Individuals with Spinal Cord Injury. She has authored numerous journal articles, book chapters, and other materials on disability and on SCI. She will devote 5% of her time to the grant.

Diana Rintala, Ph.D., will serve as senior researcher for the TMSCIS. Dr. Rintala is an Associate Professor in the Department of Physical Medicine and Rehabilitation and directs TIRR's Rehabilitation Research Program. She also serves as director of research for TIRR's NIDRR-funded research and training center on spinal cord injury. Her research interests are primarily in the area of factors that influence effective reintegration of persons following SCI, with particular attention to access to health services as it affects outcomes. Dr. Rintala will oversee recruiting persons with spinal cord injury for the consumer advisory panel. She will facilitate focus sessions in which the panel will participate to assure the activities of the model system will be relevant to the needs of the persons it is designed to serve.

Francine Mechoulam, B.A. In addition to data collection responsibilities, Ms. Mechoulam will monitor all budget activities. Ms. Mechoulam has been responsible for these functions for fifteen years and is very familiar with the accounting practices of TIRR.

Glen Baker, B.A. Mr. Baker is currently the NSCIDB Follow Up Coordinator for TMSCIS. Mr. Baker is a former TIRR patient; he is a C6 tetraplegic as a result of a diving injury in 1971. He is currently responsible for conducting the NSCIDB annual interviews and their data entry. TMSCIS anticipates expanding his responsibilities to include, database

programming, website creation and maintenance and programming in visual languages. These specific high-technology skills will be necessary for the efficient conduct of research and dissemination of results. Mr. Baker is committed to improving his skills through formal education and training to meet these requirements.

Vanessa Southard, L.M.S.W., A.C.P. Has recently joined the Staff of TIRR as Director of Social Work Services. She was formerly employed by The Methodist Hospital and a social services supervisor at Memorial Hermann Hospital. SCI social workers are Kristy Davidson, Worth Whiteside and Anna Patrick (bilingual, English-Spanish speaking).

Lourdes Cuellar, R.Ph., has been director of the TIRR pharmacy since 1979. She developed the clinical pharmacy training program at TIRR and implemented the pharmacologic surveillance program that will be an integral clinical service component of the TMSCIS.

Marilyn Emerich, P.T., M.S., was formerly director of physical therapy and is currently TIRR SCI program administrator. She is responsible for assisting with coordination of services for patients with SCI admitted to TIRR and for planning and direction of programmatic services specific to the needs of patients with SCI. Ms. Emerich's change in responsibilities reflects a change in TIRR organization away from departmentally organized services and toward services organized under functional programs. This change occurred in 1995 and has been very successful in the TMSCIS's ability to coordinate services of all the required disciplines. This type of change reflects TIRR's efforts to respond to a changing health environment.

Physical and Occupational Therapy Manager, The position of physical and occupational therapy manager is currently unfilled. The position has been advertised and resumes are being gathered. OT/PT manager's responsibilities include supervision of both clinical services and research activities conducted by therapy staff who are assigned to specific functional programs i.e., brain injury, spinal cord injury, amputee etc.

Joyce Bylund, R.N., and **Donna Ferreri, R.N.**, serve as liaison nurses for TIRR's SCI program. Each has more than ten years clinical experience in nursing, and both were provided specialized training in SCI rehabilitation prior to assuming the role of liaison nurse. In the liaison nurse role, Ms. Bylund and Ms. Ferreri are responsible for working closely with staff of acute care hospitals that participate in model system activities. This involves reviewing trauma cases to determine which might be considered for admission to TIRR, facilitating communication between acute care and rehabilitation physicians attending patients with SCI, and

assisting in the transfer process from acute care to rehabilitation. The liaison nurses also participate in training of acute care facility nursing staff on SCI management.

Terri Hudler-Hull, M.S. is coordinator of the TIRR SCI and TBI prevention program. In this role, she is responsible for developing and implementing programs designed to decrease the incidence of SCI in the targeted area. She is responsible for the previously cited school-based program and for various other prevention activities that will be conducted through the TMSCIS. She will continue to direct activities designed around primary prevention of SCI.

Cindy Bukauskas, M.A. is director of the TIRR speech language-pathology department. Her specific areas of clinical interest are in swallowing problems of high tetraplegic patients and in evaluation and management of aspiration problems in ventilator-dependent tetraplegics. She will provide speech-language pathology services for the TMSCIS, including assistance in evaluation of swallowing capabilities and risks of aspiration in persons with SCI.

Carlos Ortiz, R.R.T., is manager of respiratory therapy. He and his staff ensure that all persons requiring respiratory treatments are managed appropriately. He serves as an instructor for the other therapists and inpatients as well. He is particularly involved with the ventilator dependent inpatients. For those patients that will require ventilatory equipment after discharge, he aids the physicians in ordering equipment.

Regina White, R.N. is head nurse on the TIRR spinal cord injury unit. In this role she supervises nursing services provided to inpatients with SCI at TIRR. She will continue in this supervisory role for the proposed TMSCIS.

Donna Smith, R.N., is the internal case manager for inpatients with SCI in the TMSCIS. She acts as liaison between the inpatient team and the admitting office – preparing for admission so that the SCI person's needs can be met as soon as they arrive. She also acts as liaison between the team and the external case managers for purposes of obtaining approval for the estimated length of stay and durable medical equipment.

Lalita Thompson, R.N., is coordinator of our intrathecal baclofen service. She schedules patients for intrathecal baclofen trial and pump implants, which are performed by Richard Simpson, M.D. Ms. Thompson performs pump refills in outpatient clinic and also schedules appointments for botox injections used for the management of spasticity.

Pamela McCracken, R.N., is surgical liaison nurse. She schedules outpatient appointments and books cases for Drs. Shenaq and Pickard in the operating room. Ms.

McCracken follows up on all post operative patients on a daily basis.

Margaret Rogers, R.N., is the urologic liaison nurse. She assists Dr. Del Terzo in urology clinic, video urodynamic studies and books urologic cases in the operating room.

Donna Stultz, R.N., is manager of TIRR's outpatient clinic. She provides general oversight for activities of the clinic, including scheduling and conduct of SCI clinics and various specialty clinics to which persons with SCI are referred (e.g., urology clinic, plastic and reconstructive surgery clinic). She has 21 years experience in rehabilitation nursing, most of that with patients with SCI.

Theresa Gregorio-Torres, O.T.R., is senior SCI staff occupational therapist and is in charge of scheduling Forced Sensory Array (FSA) testing for the purpose of prescribing appropriate wheelchair cushions and seating surfaces. She acts as a senior mentor to all of the therapists working at the TMSCIS and supervises the recommendations therapists make to the physicians for patients' durable medical equipment.

Sibyl Anderson, O.T.R., is a senior staff and is in charge of outpatient therapy services. She insures that the transition from inpatient to outpatient is as seamless as possible. She organizes the team rounds for Drs. Donovan and Parsons.

Margaret Nosek, Ph.D., is director of Baylor College of Medicine's Center for Research on Women with Disabilities and director of research for TIRR's ILRU Program, as well as associate professor of physical medicine and rehabilitation at Baylor College of Medicine. She has done seminal research on the definition of independence for people with severe disability. Her current research, funded through the National Center on Medical Rehabilitation Research, focuses on psychosocial behaviors in women with disabilities, with particular attention to sexuality behaviors. She has and will continue to work closely with the TMSCIS, many of whose female patients have worked with her and have participated in her many research projects. She will in turn continue to act as a liaison between the TMSCIS and the SCI community, help it to apply itself in an advocacy role and reminding us to continually monitor our consumer friendliness. Her letter of support can be found in the appendix.

Bernie Silver, Ph.D., will serve as psychologist for the TMSCIS. He has been on the staff of the Department of Psychology and Neuropsychology at TIRR for twelve years having served as Department Manager for the last three years. During his tenure at TIRR, Dr. Silver has been actively involved in providing clinical services to the Spinal Cord Injury, Brain Injury, and

Pediatric Programs. He is particularly interested in school re-entry issues regarding students with spinal cord injuries. Dr. Silver will co-direct the project on outcomes after spinal cord injury in children and adolescents.

Rodney Senigaur, M.S., is the vocational counselor assigned by the Texas Rehabilitation Commission (TRC) to the TMSCIS. He provides formal and informal vocational counseling to both inpatients and outpatients. He regularly attends team rounds and provides liaison between TRC and the TMSCIS.

Consulting Professionals from Participant Institutions of the TMSCIS

John Bertini, M.D., will serve as urologic consultant for all issues of sexuality and fertility. He will work closely with **Hammill Hunter, M.D.**, obstetric and gynecologic consultant for all women followed at the TMSCIS.

Guy Clifton, M.D., is a professor and chairman of the department of neurosurgery at The University of Texas Health Science Center - Houston and is chief of neurosurgery at Memorial Hermann Hospital. He has worked closely with Dr. Donovan and other staff of the SCI model system in several research projects and in assuring optimal coordination of services for persons with SCI receiving acute care at Memorial Hermann Hospital. He will continue to serve as the primary professional contact person at Hermann Hospital for the proposed TMSCIS. His letter of commitment can be found in the appendix.

Michael Del Terzo, M.D., is an associate professor of the department of surgery (urology) at The University of Texas Medical School. The department provides urologic consultation services to the SCI program at TIRR and supervises urologic diagnostic and treatment services provided to patients with SCI. Dr. Del Terzo also collaborates with Dr. Donovan on a number of research projects related to urologic function in persons with SCI.

Bruce Ennis, M.D. and **Salem Sakeli, M.D.**, will serve as consultants in cardiology. They are certified by the American Board of Cardiovascular Diseases and the American Board of Internal Medicine.

Michael Kaldis, M.D., is a member of the orthopedics clinical faculties at both The University of Texas Medical School and Baylor College of Medicine. He provides orthopedic consultation to patients with SCI and will continue to provide such services during the proposed project period.

Michael Kaplan, M.D., will serve as ENT consultant. He is a clinical assistant professor

at Baylor College of Medicine and consults frequently on ventilator dependent patients and others with tracheostomies.

Brent King, M.D., is a professor of Emergency Medicine at the University of Texas – Houston and director of the department of Emergency Medicine at the, American College of Surgeons (ACS) approved, Memorial Hermann Hospital level one trauma center. The trauma center is a brand new 55,000 square foot facility that opened earlier this year (2000).

Thomas Krouskop, Ph.D., will serve as senior consultant in rehabilitation engineering for the TMSCIS. He is a professor of rehabilitation at Baylor College of Medicine and is the director of rehabilitation engineering services at TIRR. He also holds appointments to the staff of the Houston Veterans Administration Hospital and to the faculty of Texas Woman's University. Dr. Krouskop's major research interests are in tissue pressure management and development of robotics.

Jonathan S. Malev, M.D. and **Ruth Netchen, M.D.**, will serve as consultants in psychiatry to the TMSCIS. They has been very active in providing psychiatric services when needed to patients at TIRR.

Kenneth Mattox, M.D., is a professor of surgery at Baylor College of Medicine and is director of trauma services at Ben Taub Hospital. As his letter of commitment to the TMSCIS in the appendix indicates, he will continue to be actively involved in assuring optimal coordination of SCI services between the Level 1 trauma center at Ben Taub General Hospital and the spinal cord injury service at TIRR. Dr. Mattox has been committed to the TIRR philosophy of rehabilitative care since he participated in an elective rotation at TIRR as a medical student.

Fred Moore, M.D., is a professor of surgery at the University of Texas Medical School, medical director and chief trauma surgeon at Memorial Hermann Hospital's level one trauma center and medical director of the hospital's "Life Flight" helicopter service. He works closely with James "Red" Duke, M.D. (see letter of support in the appendix), and he will continue to work with TIRR staff in assuring that SCI trauma services provided by Memorial Hermann Hospital and its affiliated programs are provided in accordance with best management practices

Tina P. Oliver, D.P.M., will serve as podiatric consultant for the TMSCIS. She is a clinical instructor at The University of Texas Medical Branch in Galveston and has been providing both inpatient and outpatient podiatric services to patients at TIRR over the past few years.

Laurens Pickard, M.D., assistant professor in the Baylor College of Medicine department of surgery, will provide surgical consultation services for the TMSCIS. Dr. Pickard is a staff physician at The Methodist and Ben Taub Hospitals.

David Persse, M.D., directs all surface ambulance transport and care from the scene of the accident to one of the two level-one trauma centers in the Houston area. His letter of commitment to the TMSCIS can be found in the appendix.

Toby Samo, M.D., is chief consultant in infectious disease

Reziu Saquer, M.D., is the anesthesiologist who performs all anesthesia for surgical cases done at TIRR and is consultant for pain management.

Saleh Shenaq, M.D., is a professor in the division of plastic surgery at Baylor College of Medicine and along with Drs. Jay Shenaq and Tue Dihn will serve as plastic surgery consultants for both inpatients and outpatients receiving SCI services through the model system. Dr. Saleh Shenaq also serves as chief of surgical services at TIRR. The major clinical interests of these surgeons, in addition to reconstructive surgery for persons with SCI who experience serious skin breakdowns and decubitus ulcers, are in the areas of reconstructive hand surgery, restorative microsurgery and revision of residual limbs of amputees.

Richard Simpson, M.D., is an assistant professor of neurosurgery at Baylor College of Medicine and works closely with Drs. Donovan and Parsons. He performs Baclofen pump implants at TIRR. He will continue to provide such services for the proposed TMSCIS. His letter of commitment can be found in the appendix.

Alex Stadnyk, M.D., and **Thomas Solis, M.D.**, will continue to serve as respiratory medicine consultants for the TMSCIS. Both are associate professors in the Baylor College of Medicine's department of medicine - pulmonary section, and both have been actively involved in providing consultation services on respiratory problems of patients with SCI at TIRR.

Alex Valadka, M.D., is an assistant professor of neurosurgery at Baylor College of Medicine and chief of neurosurgery at Ben Taub General Hospital and works closely with Drs. Donovan and Parsons directing persons with SCI to the TMSCIS. His letter of support may be found in the appendix.

Alfred B. Watson, M.D., is director of radiology services at TIRR. He is Professor of Radiology at Baylor College of Medicine. He supervises three full time radiographers and Baylor College of Medicine residents who rotate through TIRR. He reads all of the x-rays

produced in TIRR's radiology department.

In addition to the consultants specifically mentioned, consultants of numerous other specialties will continue to be available to the primary SCI physiatrists, Drs. Donovan and Parsons.

(2) Familiarity with pertinent literature and methods.

That the key personnel indicated above are intimately familiar with pertinent literature and methods related to SCI service delivery and research is easily discernible through a review of the biosketches provided with this application. These biosketches, although abbreviated in the interest of reducing the volume of the application and out of consideration for reviewers, indicate that the key staff of this project have specialized training in their respective disciplines and areas of interest, are substantively engaged in professional activities (such as serving in leadership roles in professional societies) that mandate currency with findings and techniques relative to management of spinal cord injury. Perhaps the best evidence of familiarity with pertinent literature is provided through the lists of publications of key project people. The individuals serving in key roles for the TMSCIS publish regularly in the clinical and research literature. For their work to be accepted in peer-reviewed journals, these individuals must demonstrate familiarity with current literature and must be able to relate the findings of such literature to their own work. This familiarity and relational ability is demonstrated in publications listed on their biosketches (see appendix).

As regards familiarity with current methods, evidence of this is provided through both the publication listings of the principals in the proposed TMSCIS and through their continued contributions to the fields of SCI service delivery and research. A number of methods in use today for management of SCI were developed and/or refined through work of TIRR physicians and staff. Included in these accomplishments are treatment methods for use with high risk tetraplegic patients, improved methods for controlling spasticity, refined approaches for assessing swallowing capabilities of high tetraplegics and for managing aspiration-initiated pulmonary infections, management of the neurogenic bladder, enhanced orthotic services to improve functional capabilities for persons with SCI, and pioneering research on service relationships between clinically oriented SCI model systems and community-based non-clinical support service organizations. The available evidence supports the notion that key staff of the TMSCIS are not only familiar with current methods in treatment of SCI, but that they also

contribute significantly to the development and refinement of new service and research methods.

(3) Involvement of personnel necessary to establish a multidisciplinary team.

Disciplines represented in the proposed TMSCIS are diverse and appropriate to the activities proposed. In addition to physiatry, many other medical specialty areas (including internal medicine, neurosurgery, nuclear medicine, orthopedic surgery, plastic and reconstructive surgery, podiatry, psychiatry, pulmonary medicine, radiology, surgery, trauma medicine and urology) are represented through project staff or consultants to be substantially involved in the project. Other clinical disciplines represented in TMSCIS activities include, nursing, occupational therapy, orthotics, pharmacy, physical therapy, psychology, rehabilitation engineering, respiratory care, social work, speech therapy, and therapeutic recreation. Non-clinical disciplines significantly represented in system activities include biomedical research, biostatistics, education and training, independent living, and vocational rehabilitation. The mix of disciplines represented in the proposed work assures that expertise will be available to address the service and research priorities of the model system effectively.

(4) Commitments of staff time to the project.

Staff time commitments indicated for the TMSCIS are conservatively but adequately projected. There are several reasons why the proposed TMSCIS, with its comprehensive service scope and array of research activities, can be successfully operationalized without more extensive staff commitments. First, TIRR is a primary clinical affiliate of Baylor College of Medicine and The University of Texas -- Houston Medical School, both major clinical research and teaching institutions that require their faculty to be actively engaged in research, teaching, and scholarly activities. The key staff of the proposed TMSCIS, as senior faculty, are committed to research and scholarly activities as part of their faculty commitments. Scholarly activities are not viewed by the principals of the proposed model system as secondary responsibilities, but rather as integral to their every day jobs. Second, TIRR is the site of the ILRU Research and Training Center on Independent Living that is engaged in community-based service research that complements work proposed for the TMSCIS and that will be drawn upon substantially in the service demonstration component as well as in the research proposed for the TMSCIS. Third, the proposed TMSCIS is headquartered in the Texas Medical Center, the largest medical center

in the world, one that is characterized by institutions and individuals committed to improving health care services across all areas. This commitment provides access to an array of resources that benefit both the service and research components of this project at little or no cost to the funding agency. Fourth, TIRR is a well-established referral center for spinal cord injury and has admitted patients from all over the U.S. and from abroad. It averages **??? SCI admissions per year and since 1973, and since 1973, TIRR's first year as a Model System has treated ???,000 persons with SCI. TIRR sees ??? outpatients in its Outpatient Clinic annually.** TIRR is therefore well positioned to continue to serve as Model System center.

Key staff time commitments are as follow:

William H. Donovan, MD - 10%

Kenneth Parsons, MD - 6.5%

Daniel E. Graves, MEd - 80%

R. Frankiewicz, PhD - 5%

Karen Hart, PhD - 5%

Diana Rintala, PhD - 10%

Francine Mechoulam, BA - 100%

Glen Baker, BA - 87.5%

Barbara Markwardt - 10%

To Be Named Data Collector - 100%

It should be noted that only two of the listed positions will be drawing 100% support from the TMSCIS. These positions involve activities related solely to the work of the TMSCIS for which full-time staff commitment is critical to the success of the project. All other staff requests reflect the shared responsibilities of the proposed staff and make optimal use of the resources previously cited that contribute in a synergistic fashion to the proposed efforts of the TMSCIS. It should also be re-emphasized here that many persons who will be significantly involved in TMSCIS activities--such as Lex Frieden, TIRR senior vice president, will not receive any salary support from model systems grant funds. Salary support for many individuals involved with the TMSCIS is provided through other sources and represents a substantial in-kind contribution to

the TMSCIS.

(5) Nondiscrimination in employment and encouragement of representation.

Baylor College of Medicine, The University of Texas, and TIRR are equal opportunity employers which have in place affirmative action plans designed to enhance employment opportunities for persons from groups that have, in the past, experienced discrimination in employment. Adherence to the spirit of affirmative action will be maintained in all activities of the TMSCIS, and qualified persons from racial and ethnic minority groups, as well as persons with disabilities, will be encouraged to apply for employment and will be given full consideration in the selection process to fill any employment vacancies. Copies of Baylor College of Medicine, The University of Texas, and TIRR affirmative action plans can be made available for review by interested parties.

(i) Members of racial and ethnic minority groups. Although minority persons and persons from other groups underrepresented in education and employment are represented in the proposed activities, better representation is a goal of all three primary collaborating institutions. All three have proactive plans in place to attract and retain more qualified minority faculty or senior staff. The goal of increasing minority participation in key project roles will be pursued over all five-project years. As reflected in the letters appended to this application, involvement with groups having significant connections with minority community members (e.g., LULAC, The Urban League) will be increased with the intent of substantially increasing minority involvement in all phases of project activities.

(ii) Women. Women are very well represented in project activities. Women will fill 4 of the 10 positions for which funding is requested. Efforts to recruit qualified women candidates into senior project positions will be continued throughout the project period.

(iii) Persons with disabilities. One project staff member for whom funding is requested is a person with significant disability. In addition, TIRR employs many persons with disabilities in positions ranging from the level of vice president to support staff positions. TIRR has endeavored to become a model for employment of people with disabilities and will continue to be aggressive in seeking out individuals with disabilities who have the talents and skills to contribute to the TIRR's mission of promoting full community integration of persons with disabilities.

(iv) Elderly persons. All three primary collaborating institutions recruit and hire individuals without regard to age or other factors unrelated to qualifications to perform in the job. This practice will be continued, and efforts will be made identify qualified older persons for job openings and other project-related functions over the duration of the project. Affirmative actions will be pursued with regard to age, as they will with regard to other protected groups.

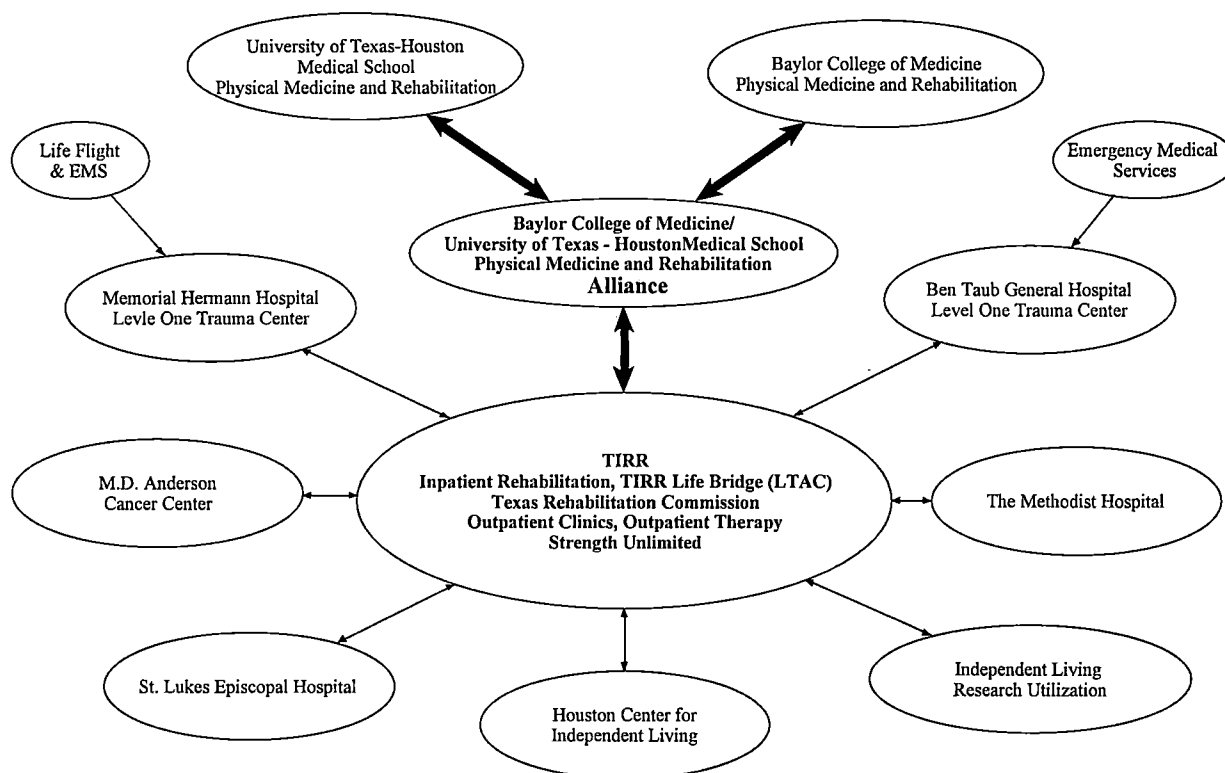
(e) Adequacy of Resources

(1) Facilities to be used.

The primary site for proposed Texas Model Spinal Cord Injury System (TMSCIS) activities is The Institute for Rehabilitation and Research (TIRR), a facility located in the heart of the Texas Medical Center (TMC). In addition to being a center for comprehensive rehabilitation of persons with physical disabilities, TIRR serves as the clinical home for both Baylor College of Medicine's and the University of Texas Medical School-Houston's departments of Physical Medicine and Rehabilitation (PM&R). The PM&R departments have formed an alliance so that PM&R faculty from both schools essentially function as one with regard to resident education, research projects and physician night and weekend coverage.

TIRR is one of the longest-established comprehensive rehabilitation centers in the country, having begun as the Southwestern Poliomyelitis Respiratory Center in 1959 and its Spinal Cord Injury Center in 1961. Today TIRR is a private, not-for-profit, non-tax supported rehabilitation hospital that is accredited by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and by the Commission on Accreditation of Rehabilitation Facilities (CARF). In this regard, it should be noted that TIRR provides the full array of services, both diagnostic and therapeutic, mandated under conditions for accreditation by the two bodies cited. TIRR acts as the hub for care of patients with SCI as shown in the accompanying diagram. Services not provided at TIRR, such as CTs or MRIs are provided at one of the TMC hospitals described below.

Figure 1 Diagram of Texas Model Spinal Cord Injury System and Affiliated



TIRR currently has 66 inpatient beds, approximately 40 to 45 percent of which are usually devoted to patients with SCI, while its sister long term acute care facility, TIRR Lifebridge has 38 inpatient beds. The rehabilitation services provided to patients with SCI include medical rehabilitation by specially trained SCI physicians. These physicians are primarily physiatrists but also include other specialists i.e., general, thoracic, urologic, plastic, orthopedic and neurologic surgery, pulmonology, gastroenterology, neurology, psychiatry, infectious disease and obstetrics and gynecology. Other rehabilitation services provided include, rehabilitative nursing care, a full range of therapies, orthotic services, psychosocial adjustment services, assistive technology services, vocational services, and community re-entry services. In addition, a comprehensive outpatient service program is offered that provides SCI medical follow-up and specialized clinical care as described in section (d).

In 1991, TIRR replaced its antiquated multi-bed wards with modern private and semi-private patient suites housed in a six story, technologically current inpatient facility. Opening of

the patient tower is part of an ongoing phased rebuilding program designed to assure that patients obtaining rehabilitative services through TIRR have access to current rehabilitation technology in a fully accessible environment that facilitates effective service delivery. Other significant modifications to the physical plant were completed in 1996 when the entire entrance and entry courtyard were remodeled. Further modification of the clinic and physician offices are planned within the next year.

In addition to TIRR, which is the hub of all SCI activities, the TMSCIS will draw upon an array of resources available through the other partners that are involved. Among these resources are:

The Houston Fire Department emergency medical service which operates 44 rescue units, 27 of which are equipped with advanced life support equipment and staffed by an emergency medical technician (EMT) and a paramedic and 17 of which are equipped with basic life support equipment and staffed by two EMTs. These units respond to nearly 200,000 requests for assistance annually, with an average response time of eight minutes. Using centralized telemetric communications equipment based at the Ben Taub Hospital, EMT crews provide on-the-scene trauma care and transport patients, with monitoring by medical staff at Ben Taub Hospital. Based upon the type of trauma, patients' conditions, and estimated transit time to various hospitals the EMT crews are directed to Ben Taub, Memorial Hermann or to various other hospitals. As indicated in the letter of commitment in the appendix from David Persse, M.D., director of the service, this critical resource will continue to be a part of the proposed service system. Similarly, EMT staff and flight nurses are available at all times at the 4 Life Flight emergency helicopter locations around the city for transport to Memorial Hermann Hospital.

Ben Taub General Hospital is a city/county acute care general hospital operated by the Harris County Hospital District. It operates one of two Level 1 trauma centers (as determined using criteria developed by the state of Texas and the American College of Surgeons (ACS) Committee on Trauma) in the Houston area. It has received many of the critically injured patients in Houston and Harris County since 1963. In 1990, Ben Taub Hospital moved into a new facility located less than one block from TIRR that was constructed to address the need for additional room and new technology that were not available in the facility vacated in February 1990. The new facility has 550 inpatient beds, complete and modern trauma care capabilities,

and up-to-date diagnostic and therapeutic technology to address the needs of critically injured patients, including patients with SCI. Medical staffing for Ben Taub Hospital is provided under contract between the Harris County Hospital District and Baylor College of Medicine, with the hospital serving as a major teaching and clinical research site for Baylor. Ben Taub will continue in its important role as one of the two trauma care facilities for patients of the TMSCIS, and a letter of commitment from Dr. Kenneth Mattox, Director of Trauma Services for Ben Taub can be found in the appendix.

Memorial Hermann Hospital, the second local Level 1 trauma center certified by the state of Texas and the ACS, is a major provider of trauma services in the Houston area. Hermann continues to receive and provide care to persons who experience traumatic injury. In addition to receiving admissions via surface ambulance, it operates a "Life Flight" emergency transport service from four locations around Houston and Galveston, that includes four life-support and telemetry-equipped helicopters and a fixed-wing jet aircraft for transport of patients within and beyond a 150 mile radius of Houston, respectively. Most of the persons with traumatic SCI are brought to Memorial Hermann for acute care via these vehicles. Memorial Hermann Hospital, a 500 bed facility has just completed a new wing which houses a new ultra modern 55,000 square foot emergency center with a new helipad on the roof. Elevators dedicated to incoming trauma deliver patients directly from the helipad to the emergency center. Staffing for Memorial Hermann is provided in large part by the faculty of the University of Texas Health Science Center-Houston. Advanced trauma capabilities are available at all times, day or night. Memorial Hermann Hospital will continue to be a full partner in the TMSCIS and a letter of continued participation from Dr. James "Red" Duke of the neurotrauma service at Memorial Hermann, is included in the appendix.

The Methodist Hospital has assumed an overflow role in trauma services in the Houston area, with increasing demands on Ben Taub and Memorial Hermann Hospitals' trauma services. The Methodist Hospital is a 1,228 bed primary teaching affiliate of Baylor College of Medicine and provides comprehensive services across a variety of clinical disciplines including neurosurgery, provided through an 85-bed neurosurgical unit. A letter of support from Alex Valadka, M.D., associate professor of neurosurgery at Baylor College of Medicine and The Methodist Hospital, is included in the appendix.

Another clinical facility that will be participating in the TMSCIS is St. Luke's Episcopal

Hospital. St. Luke's offers a full range of medical services and is a teaching affiliate of both Baylor College of Medicine and the University of Texas Medical School-Houston. The role of this hospital, as well as of other hospitals in the Houston area, will be primarily one of referring patients to the TMSCIS. Some of these referrals are persons with traumatic SCI but the majority is atraumatic. Being in close proximity to TIRR, both Methodist and St. Luke's will be included in TIRR's regular SCI liaison program and both will be sites at which rounds are conducted by TIRR SCI staff. The local Veterans' Administration Hospital will collaborate with the TMSCIS in research.

In addition to these clinical services located at referring collaborating hospitals, resources that will be regularly drawn upon by TMSCIS activities include vocational services provided through the Texas Rehabilitation Commission (TRC) and community reentry services provided through the Houston Center for Independent Living (HCIL). TRC services include comprehensive vocational evaluation, training, and work adjustment services that are facilitated through maintenance of a TRC office at TIRR. HCIL is a community-based, non-profit, consumer controlled service agency that supplies the core services of information and referral, peer counseling, independent living skills training, and individual and community advocacy on behalf of persons with disabilities. Starting in 1990, with support provided through TIRR's ILRU Program with funding from a Rehabilitation Services Administration grant, HCIL undertook a series of activities designed to expand the scope of services provided to people with disabilities in Houston's African American and Hispanic communities. As a result, HCIL increased the number and proportion of minority consumers in its service base significantly. The increased linkages with minority individuals and organizations that have been developed by HCIL will be an important resource that can be accessed in TMSCIS outreach efforts.

Access to consumer-controlled, community-based personal assistance services (PAS) is essential if many persons with SCI are to live independently and pursue life options that persons without disabilities take for granted. TMSCIS staff will work closely with staff and volunteers engaged in the important work of creating a PAS program that addresses the needs of persons with SCI in the service area. These efforts will include not only participation in training of consumers and providers of PAS services, but also active support of advocacy efforts designed to secure funding and other support needed to create an effective service program. Collaboration with other consumer controlled organizations--including Texas ADAPT, the Coalition of Texans

with Disabilities, and HCIL--engaged in similar activities will also be ongoing over the project period.

A large array of other resources, including comprehensive medical library services and research support are available through the Texas Medical Center and its affiliate institutions. These resources, including both medical schools, allow for collaboration across medical school lines, departmental lines and along the post injury continuum. The resources described in this section and other resources in the Houston and surrounding areas will be drawn upon as necessary to complete the work described in this proposal.

(2) Equipment and supplies to be used.

All equipment required to conduct the proposed model service system is available. This includes an extensive array of clinical service equipment with a value of several million dollars, as well as data and information processing equipment that will be used by clinicians, researchers, educators, and others with a value in the hundreds of thousands of dollars. TIRR and its partner institutions provide state-of-the-art rehabilitative services requiring extensive technological resources. This technology is available to support proposed activities.

With regard to supplies, a modest request of \$8,372 is included in the first-year budget. This request will cover only portion of the cost of consumable supplies that will be used in activities of the magnitude proposed. Similar modest supply requests are included in subsequent year budgets. By far, the largest share of costs for consumable supplies will be borne by TIRR and its partners, with the funds requested used to augment funds available through other sources to carry out the proposed work. Other funding is requested to support a portion of costs to be incurred for long-distance telephone service \$1,500. The largest expense item (\$18,000), other than personnel and fringe benefits, is for travel that is required to carry out research and dissemination activities proposed.

(3) Commitment to provide administrative and other necessary support.

The commitment of the applicants to provide support for the proposed TMSCIS can be seen throughout this proposal and the accompanying budget materials. With the exception of the two individuals who are involved in overall coordination of data collection, analyses, and reporting for the model system, there are no full-time staff committed to the project, and time

commitments of staff at all levels reflects significant in-kind contributions of time and effort to TMSCIS activities. The clinical staff of the various TIRR departments involved in the TMSCIS, with few project-related exceptions, will receive no support from the model systems grant. The commitments of time and effort by clinicians, particularly for specialists in fields such as neurosurgery, orthopedics and plastic surgery, and others in partner institutions of the TMSCIS are also not reimbursed by the grant and far exceed the personnel funding requested for the project. The commitment of sophisticated equipment by TIRR and other institutions to TMSCIS-related activities represents another kind of major contribution. In summary, the commitment of TIRR, Baylor College of Medicine, The University of Texas, and other institutional partners to this project is very substantial and is evident throughout the descriptions of the service demonstration and research projects, as well as in the letters of support and collaboration included with this application.

(f) Budget/Cost Effectiveness

(1) Adequacy of proposed budget.

(2) Reasonableness of costs in relation to project objectives.

The costs of this project are modest in relation to the objectives presented for the two components of the Texas Model Spinal Cord Injury System (TMSCIS). This project draws upon an array of resources that is in place and funded through a variety of sources, and that contribute to SCI service and research in substantive ways. In effect, the funding requested for this project will produce results that go well beyond what might be realized if the entire range of project activities was borne by funds available through the model systems grant alone. The proposed work compliments other ongoing activities of TIRR and its partners, allowing for a degree of cost effectiveness that would be unattainable otherwise. This is evidenced by the extensive utilization of existing data sources for achieving the research objectives as mentioned in the research design of this project.

(3) Reasonableness and adequacy of subcontract budgets.

The budget includes \$2,000 per year total for subcontracts. Bilingual personnel are paid a

premium. We have found it more cost effective to subcontract obtaining informed consents and follow up interviews from Spanish speaking only research participants. A portion of this \$2,000 may also be used to employ a part time data collector should the need arise.

There is also \$2,000 budgeted for consultant services. We propose to engage Glen White, he served on the committee that developed the IOM model discussed in section c, to advise us regarding our research models and to interact with the Consumer Advisory Committee, helping us explain to consumers the models and their significance. The amount budgeted is to defray his travel expenses and provide a nominal honorarium.

(g) Dissemination/Utilization

(1) Plan for dissemination and utilization of findings.

There are two components to the dissemination plan for the proposed model system. The first component focuses on dissemination to the individuals in the clinical, research, educational and insurance fields involved in SCI service and research. The second component involves dissemination to non-professional audiences, including the general public, regarding prevention of SCI, persons with SCI and their families, and employers and other members of communities in which persons with SCI live.

Dissemination to clinical, research, educational and insurance professionals. A multifaceted dissemination approach will be used. One of its most important aspects relates to publications in the professional literature, such as the Archives of Physical Medicine and Rehabilitation, Topics in Spinal Cord Injury Rehabilitation, Journal of Spinal Cord Medicine, American Journal of Physical Medicine and Rehabilitation, and Nursing Case Management *Journal*. Publication is given prominence in dissemination efforts because it assures that relevant research and clinical findings will be provided to professionals who can best use such information, and because it requires a commitment to quality in research design, methods, and analyses that will withstand the critical review of peers.

Another method that will be used frequently in disseminating outcomes to the clinical, research, and insurance professionals will be through presentations at professional meetings. By means of platform presentations, poster sessions, panel discussions, and workshops offered at professional meetings such as the annual meetings of the American Spinal Injury Association,

International Medical Society of Paraplegia, American Paraplegia Society, American Association of Orthopedic Surgeons, American Congress of Rehabilitation Medicine, and Academy of Physical Medicine and Rehabilitation, research and clinical findings will be presented to other professionals for review and comment. Abstracts of presentations are published by each of these organizations and are disseminated to the field. A subject classified listing of more than 200 presentations by members of the TSCIMS from 1995-1999 is included in the appendix. Subjects are classified as SCI Overview, Medical and Nursing Management and Medical Complications, Therapeutic Rehabilitation Management of SCI, Psycho-Social-Vocational Management of SCI, Sexuality and SCI, Life Long Issues, Research in SCI, and Special SCI Issues.

Additional presentations are offered specifically for case managers and insurance personnel through a series of programs by the TSCIMS entitled "Rehab Solutions". Attendees are awarded continuing education units (CEUs) and learn about specific cases and outcomes as a result of the collaborative efforts of payers and providers of rehabilitation services. The Insurance Rehabilitation Study Group (IRSG), the annual meeting of insurance representatives, is attended by invitation only and Dr. Parsons has presented at this conference on topics related to SCI and wound care as recently as April, 2000.

Through an array of related project activities, dissemination efforts will be targeted to professionals in other rehabilitation and related fields, including physical and occupational therapy, rehabilitation nursing, rehabilitation engineering, vocational rehabilitation/rehabilitation counseling, medical social work, orthotics, and independent living. A monthly seminar is held at TIRR entitled "Third Tuesday" and the entire SCI Program staff including nurse case managers, therapists, rehabilitation nurses, social workers, psychologists and residents and fellows attend this conference. Topics related to the latest developments in SCI are presented. A weekly research seminar is held in which research projects are presented at various stages in their development. The audience offers constructive input and revisions are made by researchers as appropriate until the final results are presented. In this manner, the relevance of the research is substantiated and the dissemination process begins at the conception of the research efforts.

A review of the credentials and professional accomplishments of key individuals involved in TMSICIS efforts reflects very active involvement in an array of dissemination activities, including professional publications, scientific presentations, and participation in

forums, seminars, and other activities that are effective in disseminating process and outcome information to professionals involved in the rehabilitation of persons with SCI. Reviewers are referred to TMSCIS staff biosketches and other attachments to get a sense of the range of activities targeted to professionals statewide, regionally, nationally, and internationally. Dissemination to professionals using an array of mechanisms will continue to be a high priority for personnel involved in the TMSCIS.

Other dissemination efforts targeted to professional audiences will be carried out locally and will include workshops and seminars on SCI for professionals from elsewhere in the country and those working at TIRR and its affiliates, SCI rounds conducted at TIRR and affiliated acute care hospitals by SCI physicians and other professional staff of the TMSCIS, special training sessions conducted for emergency medical personnel and trauma center staff, and participation in invited lectures and discussion groups at local hospitals and health-related facilities in the Houston area. Also, students from a variety of programs, including medicine, nursing, the rehabilitation therapies, and other health-related fields will continue to participate in preceptorships, residencies, and clinical practica at TIRR and will obtain information on current practices in spinal cord injury services and research. In addition, physical and occupational therapy students from Texas Woman's University (TWU) and nursing students from TWU rotate regularly through TIRR. Local dissemination efforts will focus on creating a cadre of professionals and support personnel who have the best possible skills in managing SCI at all points of the service continuum.

It is worth noting that the physician training program of the Baylor College of Medicine/University of Texas-Houston Medical School (BCM/UTHMS) Physical Medicine and Rehabilitation Alliance shares with one other institution the title of being the largest such training program in the nation. There are a total of 40 residents in the PM&R training program from many different states of the United States and from around the world. Each of them spends separate two-month rotations with (1) Dr. Donovan or (2) Dr. Parsons, (3) the SCI Service at the Veterans Affairs Medical Center in Houston, (4) Hermann Hospital acute SCI rehabilitation and clinics, (5) Ben Taub County Hospital acute consultations in SCI, and (6) Quentin Meese County Hospital for Harris County rehabilitation services. Each year PM&R residents across the nation participate in the SAE examinations as a preparation for their PM&R Board examinations. For the past several years, the #1 scoring area in for the residents in the BCM/UT PM&R Alliance

has been in the area of spinal cord injury. This reflects the excellent training and education that these many resident physicians receive at the TSCIMS program. This dissemination activity alone has a huge impact on the kind of medical care that is received by people with SCI in the United States and around the world. In addition, the Alliance has a large fellowship training program with 11 fellows annually. The Alliance is one of only six programs in the country that have a Accreditation Council for Graduate Medical Education (ACGME) accredited SCI fellowship. The 11 fellowships include the fellowship in SCI as well as other clinical and research fellowships. MDs, PhD.s and DO.s fill these fellowships as appropriate. Dr. Diana Rintala, PhD, one of the key TSCIMS researchers, is a product of these fellowships.

Dissemination to non-professional audiences. During the proposed five-year funding cycle, major dissemination efforts will be targeted to persons with SCI and their family members, as well as to the general public. Dissemination to people with spinal cord injury will be done largely through the TMSCIS's website (www.bcm.tmc.edu/pm&r/sci/research/modelsystem). In addition publications will be submitted to journals that are targeted specifically to people with SCI and their families such as *Paraplegia News* and *Mainstream*. The TMSCIS's consumer panel will also augment the dissemination activities through their work in sharing with others results of the research and suggestions for how relevant information can be communicated most effectively to others. Dissemination efforts targeted to the general public will focus primarily on two areas related to spinal cord injury: prevention of injury and reintegration of the spinal cord injured person into the community. Prevention efforts, using the "Think First" approach developed by the American Association of Neurological Surgeons and Congress of Neurological Surgeons, as well as other awareness heightening strategies, are designed to let people know about risk factors associated with SCI and about ways to reduce risks. Included in these activities will be (1) preparation of printed materials that can be provided to school groups and civic organizations that discuss risks associated with not using automotive restraints, with diving accidents, and with sports activities; (2) presentations by TMSCIS staff to school groups, community organizations, church groups, and others concerning risks for SCI, ways of reducing risks, and resources available in undertaking risk reduction efforts. These activities will continue to be documented as part of the evaluation of the TMSCIS. Since 1995, 397 injury prevention presentations have been made reaching 29,203 individuals in elementary, middle and high schools, community organizations such as the Junior League,

churches, and employees at major industries such as Exxon. (See appendix for itemized presentation list).

Public information on reintegration of persons with SCI into the community will focus on promoting a positive image of the contributions that can be made by persons with SCI and on the importance that equal opportunity plays for persons with SCI as regards housing, employment, transportation, and social activities. In order for persons with SCI to attain their full potential in the community, it is critical that the various sectors of the public have accurate information regarding disability and its implications for the person with SCI as well as for the community in which the person with SCI lives. Dissemination activities targeted to the general public are intended to provide such information in an appropriate and accurate manner. The primary means of conveying these messages to the community will be through presentations at meetings of groups such as the Chamber of Commerce, the Jaycees, Rotary, and other organizations. Dissemination activities related to community reintegration of and equal opportunity for persons with SCI will be carried out in conjunction with other entities whose missions and goals are consistent with those of the TMSCIS with regard to full participation of people with SCI and other disabilities in community life. Entities with which the TMSCIS will collaborate in this regard include the Region VI Disability and Business Technical Assistance Center (operated by TIRR's ILRU Program), the Client Assistance Program (operated by Advocacy, Inc.), and the activities of the Houston Center for Independent Living, the Coalition of Texans with Disabilities, the Texas Paralyzed Veterans, Houston Veterans Administration Medical Center for Healthy Aging with Disability (operated by faculty in PM&R at Baylor College of Medicine) and other groups involved in information and advocacy efforts.

In summarizing planned dissemination efforts, it should be emphasized that personnel of the TMSCIS will continue to address the needs of health care professionals, related professionals, people with spinal cord injury and their families, and the public using a range of dissemination activities that are known to be effective and with which staff of TIRR and its partners are very familiar and adept--as evidenced by their contributions to literature and meetings of their respective professions.

(2) Likelihood of availability of research results to others in the field.

The above discussion of dissemination and utilization methods to be employed by the

TMSCIS clearly indicates a strong likelihood that research results will reach all fields involved with SCI service delivery and research as well as rehabilitation educators and people with SCI. This likelihood is enhanced by the fact that the project director and each of the key staff members have been extensively involved with professional activities focusing on SCI for a number of years. Both Drs. Donovan and Parsons have served as presidents of the American Spinal Injury Association (ASIA), have made presentations to various professional groups on a regular basis, and both continue to be actively involved in professional organizations dealing with SCI. Dr. Hart is the first and only Ph.D. member of the ASIA Board of Directors and she has chaired the ASIA Education Committee for the past six years. Dr. Hart is also a past president of the American Congress of Rehabilitation Medicine, current President of the National Association of Rehabilitation Research and Training Centers, and on the editorial board of Topics of Spinal Cord Injury. Ms. Emerich is on the Program Committee of the American Spinal Injury Association and Dr. Rintala is a member of the Research Committee of the Association of Spinal Cord Injury Psychologists and Social Workers. These connections with the field facilitate efforts to disseminate information effectively.

Just as importantly, plans have been developed to address effectively the information needs of persons with SCI, their family members, and others affected by SCI. These plans involve both innovative approaches to information delivery using available technology and use of community organizations and service agencies to address the needs of individuals with SCI. In short, given the array of dissemination options available to the TMSCIS and the knowledge and prior experience of key project staff regarding access to various professional fields and outreach to individuals with SCI, there is every reason to expect that research results will reach individuals who can use them effectively in addressing their own needs or in designing and implementing services that promote attainment of optimal independence by people with SCI.

(3) Disseminating and promoting use by others.

Various means for disseminating and promoting use by others have been discussed to throughout the previous paragraphs on dissemination/utilization. Briefly these means include but are not limited to:

- enlisting the involvement of advocacy organizations at local, state, and national levels which can assist in dissemination efforts targeted to people with disabilities, their family

- members, and others working toward equal opportunity for all;
- publishing findings in professional clinical and research journals;
 - publishing findings in journals targeted toward individuals with SCI and their families
 - presenting at professional meetings, workshops, and other forums;
 - participating in activities of professional societies;
 - providing information and findings via the internet on the TMSCIS's web page and through links with other Model System Centers and relevant SCI consumer groups and networks;
 - providing training to professionals (e.g., physicians, therapists, nurses, etc.) in current management of SCI;
 - distributing special announcements on resource materials to targeted professional and non-professional audiences;
 - scheduling tours and visits to TIRR by professional and non-professional individuals and groups interested in SCI;
 - presenting to consumer groups and civic and community groups regarding various aspects of SCI;
 - following-up aggressively with patients to keep them informed of new findings and innovative services;
 - collaborating with ILRU in disseminating information on community re-entry services and independent living; and
 - participating in the National Spinal Cord Injury Data Base, allowing for comparison of TMSCIS performance with performance of other model centers in selected aspects of SCI service delivery.

(4) Likelihood of utilization approach addressing defined need.

The utilization approach addresses the defined need in that it is (1) comprehensive in covering a broad array of service delivery and research activities related to SCI, (2) multidisciplinary in focus, targeting dissemination efforts to a variety of professional personnel, as well as to people with SCI, family members, and the general public. (3) relevant to the needs of special populations both with regard to innovative approaches to be tested and the

involvement of groups and individuals who can facilitate implementation of targeted activities, (4) both process and outcome oriented for the purposes of assessing benefits that accrue from specific interventions and comparing benefits with costs of SCI services, and (5) designed to yield data that can be incorporated into national studies of SCI. The utilization approaches described throughout this section were formulated with the express intent of addressing identified needs.

(h) Evaluation Plan

(1) Mechanism to evaluate plans, progress, and results.

The mechanisms for evaluating plans, progress, and results are diverse and call upon several evaluation methods that examine both process and outcomes of TMSCIS efforts. Operational plans for the TMSCIS will be evaluated using both an internal review process and an external review process. The internal review process will involve ongoing monitoring of planning efforts by key administrative staff of the TMSCIS. Operational plans for the service demonstration and research components of the model system will be reviewed regularly by Dr. Donovan and Daniel Graves along with selected other clinicians and researchers at TIRR and cooperating institutions who have expertise in the area(s) under planning consideration. Dr. Hart, TMSCIS training coordinator, will review operational plans for education, training, and dissemination activities. This division of responsibility for internal review of planning efforts is designed to make optimal use of the expertise of individual TMSCIS staff.

In addition to internal review by the key staff mentioned, the TMSCIS will make use of a core group of clinicians that are experienced in delivery of clinical services to persons with SCI. The core group is composed of the project co-directors, plus selected staff of nursing, occupational therapy, physical therapy, pharmacy, respiratory therapy, social work, and speech therapy. These individuals have been meeting regularly since 1992 to review clinical policies and practices and to assess these policies and practices in light of current state of diagnostic and therapeutic services and with attention to the realities of third-party reimbursement issues that face rehabilitation service providers. It was this core group which made substantial revisions in the rehabilitation admission programs, as well as in treatment categories, taking into account the trend toward shorter lengths of stay, reduced rehabilitation benefits provided by many third-party payers, and the complications associated with the increasing enrollments in managed care programs which may restrict medical care options available to people with SCI. The revised

admission programs and therapeutic categories were developed with the intent of streamlining the rehabilitation process and emphasizing the need for persons with SCI and their family members to understand as thoroughly as possible how to reduce risks of secondary complications and make optimal use of service systems available through the public and private sectors. In addition to revisions in TIRR's rehabilitative programs, the SCI Core Group has worked to develop consumer-focused materials that assist persons with SCI in dealing with SCI-related problems that they may encounter in their everyday lives. An example of these materials is a laminated card with information in plain English about what to do if a person with SCI should experience autonomic dysreflexia, pressure ulcerations, or respiratory distress. These cards can be folded to fit in a shirt pocket or wallet so that they are easily retrievable should unexpected problems occur. The Core Group will continue to meet regularly over the five-year project period to review policies and procedures and recommend revisions in response to a continually changing health care environment. This represents an important ongoing evaluative function.

Internal evaluation efforts will be complemented by external oversight to be provided through the efforts of the Model System Consumer Advisory Committee described in Section (c), Plan of Operation, of this application. Model System Consumer Advisory Committee members will be provided with all planning materials relevant to the TMSCIS, as well as progress reports, research results, and other TMSCIS products. All meetings will be held in fully accessible settings in locations convenient to committee members. Any transportation costs incurred by committee members will be reimbursed, as will costs for childcare or other direct costs associated with members' participation on the committee. Accommodation of members with disabilities (e.g., provision of note takers, sign language interpreting, other personal assistance) will be provided.

Recommendations and comments of Committee members will be recorded and included in periodic progress reports, along with summary statements concerning actions to be taken in response to specific recommendations or comments of the Committee and any rationale for actions not taken. In addition to their reactive role in reviewing progress of projects underway, the Consumer Advisory Committee will be used more proactively in assisting TMSCIS in identifying problems that might be amenable to solutions through a model systems approach or through advocacy efforts in which TIRR and its partner institutions participate actively or take a

lead role. Advisory Committee members will be asked regularly to characterize problems that they experience with health care, employment, transportation, personal assistance services, and other issues that affect their abilities to lead full and productive lives. They will also participate with administrative staff of the TMSCIS in setting priorities regarding issues that should be addressed by the TMSCIS and in identifying resources, including those within the community as well as those of TIRR and its partners in the TMSCIS, that might be committed to addressing priorities in an orderly fashion.

In addition to the procedures mentioned above, TMSCIS is committed to the quantitative evaluation of research and clinical activities. Most recently, the TMSCIS lead a five-year Collaborative Program Evaluation Project, MSPE (Graves et al., 1999). There is a possibility that the reorganization of the National database will allow for the continuation of the indices and analyses developed in this project for all Model Systems. Regardless, the development of the indices of therapy intensity and intensity will be continued as a part of the proposed project. These indices will allow for the investigation of the process of rehabilitation as well as the outcome.

(2) Likelihood of producing quantifiable data.

(3) Likelihood of evaluation results being assessed in service settings.

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