Bridging the Barriers

Table of Contents

I. Summary 2

II. Introduction 8
Renal Rehabilitation: Definitions and Goals
Expectations vs. Reality: Changing Demographics
Goals and Purposes of Renal Rehabilitation
The Broad Spectrum of Renal Rehabilitation
Targeting Vocational Rehabilitation Resources to the Appropriate Recipients
Objectives of the Life Options Rehabilitation Program
Advisory Council Role

III. Participants in the Rehabilitation Process 14
The Patient
The Dialysis Facility
The Business Community
The Public Service and Professional Organizations
The Government

IV. Barriers to Renal Rehabilitation 29
Barriers in Patient and Professional Attitudes
Barriers at the Facility Level
Barriers in the Business Community
Barriers in Government Programs

V. Bridges to Renal Rehabilitation: The Five E’s 36
Encouragement (Patient and Staff Commitment)
Education of Patients and Staff
Exercise
Employment
Evaluation

VI. Case Report 51

VII. Appendix 54
Addendum A: ESRD Treatment Modalities
Addendum B: Demonstration Projects and Model Programs
Program 1: Florida Network 7
Program 2: Development of a Comprehensive Job Retention/Return Service Delivery System for People with Kidney Failure, New York, New York
Program 3: Renal Rehabilitation Assessment Center Pilot Project, Madison, Wisconsin
Program 4: Satellite Dialysis Centers Exercise Program, Northern California
Program 5: Rehabilitation Project, Cleveland, Ohio
Program 6: Springboard, Atlanta, Georgia
Program 7: Forward Bound, Jackson, Mississippi
Program 8: Career Workshop, Lansing, Michigan
Program 9: Vocational Rehabilitation for ESRD Patients, Austin, Texas
Program 10: Promise for Living, Hartford, Connecticut
Addendum C: Recommendations for Renal Rehabilitation Made in the Past 15 Years
Addendum D: Health Outcomes Assessment: Relevance for Renal Rehabilitation Research
Addendum E: Philosophy of U.S. Programs for the Disabled
Addendum F: Legislative History of ESRD Program
Addendum G: Patient Education Resources
Addendum H: State Kidney Disease Programs and State Vocational Rehabilitation Agencies
Addendum I: Glossary of Acronyms
Addendum J: Glossary of Renal Organizations

VIII. References  96
I. Summary

More than 100 individuals are diagnosed with end-stage renal disease in this country each day, 365 days a year. Whether these new patients will allow the illness to consume their hopes and dreams—or whether they will move beyond it to contribute to family and community life—depends largely on the interventions they receive early in the course of dialysis. For the individual dialysis patient, the difference between helplessness and hope may be a timely and effective rehabilitation program.

Rehabilitation means, literally, restoration. Today, the well-being of patients with kidney failure has been significantly improved by advances in technology and pharmacology. More efficient dialysis equipment and the development of the synthetic hormones erythropoietin and active vitamin D, for example, represent recent important breakthroughs. However, despite this improved potential for restoration, it is generally acknowledged that renal rehabilitation has not yet been addressed nationally in a sustained and integrated fashion.

A group of people who feel that renal rehabilitation should be addressed more systematically has formed an interdisciplinary council to research the field and make recommendations for change. This coalition, known as the Life Options Rehabilitation Advisory Council, includes patients and family members, providers, government representatives, researchers, and private business individuals.

This draft of Bridging the Barriers is the first step in the process of reviewing renal rehabilitation in the 90s. It contains some focused recommendations for integrating rehabilitation resources. The report is currently in draft form to enable interested parties to contact the Council with ideas or comments on any aspect of the report.

The recommendations exist in chart form in the companion publication summary, and in greater detail on pages 36-50 of the complete report. The recommendations constitute the Advisory Council’s vision of a national agenda in renal rehabilitation. The Council hopes to involve many organizations and individuals in a coordinated approach to implementation. Components of this agenda could be implemented by various entities, including patients, dialysis professionals, renal organizations, the business community, and government agencies including the Health Care Financing Administration, the Rehabilitation Services Administration, and the Social Security Administration.

To maintain a clear focus on a subject of extreme breadth and complexity, this report concentrates on the dialysis patient and an integrated program for rehabilitation using resources and systems available to the dialysis center. Many of the recommendations made in broad policy areas such as improving work incentives in Social Security disability programs, however, will benefit transplant patients as well.

According to the Life Options Advisory Council, the ideal process of rehabilitation for a dialysis patient is: a coordinated program of medical treatment, education, counseling, dietary and exercise regimens designed to maximize the vocational potential, functional
But process alone is not enough. Rehabilitation efforts must be tied to measurable outcomes that will guide medical practice and suggest new directions for research. The main outcome goals for rehabilitation of patients with kidney failure identified by the Advisory Council include:

- Employment for those who are able to work
- Enhanced fitness to improve physical functioning for all patients
- Improved understanding about adaptation and the options for living well with dialysis
- Increased control over the effects of kidney disease and dialysis
- Resumption of activities enjoyed prior to dialysis

The Council has identified five “bridges” to rehabilitation that have been shown to lead to the desired outcomes. For memorability, these bridges or core principles are identified as the “Five E’s”: education, encouragement, employment, exercise, and evaluation. These principles are the foundation of this report.

A Profile of the ESRD Population

The ESRD population has already more than doubled the initial projections of the Medicare ESRD program, and is still growing. There are a projected 179,000 patients with kidney failure in 1993 (Green Book, 1992). At the passage of the landmark 1972 legislation that extended Medicare coverage to kidney patients, many expectations about vocational rehabilitation were expressed. Examining the characteristics of this population as it exists today will demonstrate that some of these expectations must be amended as the profile of the ESRD patient has changed.

Although ESRD affects people of every age, race, and walk of life, the ESRD group does not mirror that of the US population in general. In 1992, 42 percent of the ESRD population was over the age of 60, up from 32 percent in 1978. In addition, several studies have indicated lower educational levels and lower income levels among dialysis patients than in the general population (Kutner, Brogan, and Fielding, 1991; Network 20 Study, 1987; Network 19 Study, 1985). Finally, at least one study showed that the proportion of people unemployed prior to dialysis was more than double that of the general population (Network 19 Study, 1985).

From a vocational rehabilitation perspective, it is clear that a substantial proportion of the ESRD population are unlikely candidates for employment, either due to advanced age, low educational levels and previous vocational achievements, or limited physical abilities. It is clearly beyond the scope of the Medicare ESRD Program to solve the generalized societal problems of poverty and lack of education.

However, approximately half of the ESRD population does fall within working age. Many of these individuals have at least a high school diploma as well as sufficient physical capacity to work. Research suggests that, while only ten to 20 percent of the
ESRD population is currently working, up to one third identify themselves as able to work. The number of working ESRD patients could be potentially doubled by targeting these individuals for vocational intervention at the onset of dialysis. Many kidney patients want to work and have important contributions to make. This nation cannot afford to waste the unique talents of this group.

**A Case for Stratification**

Vocational rehabilitation is a discrete and separate category of renal rehabilitation that must be approached far more systematically than in the past. It is an area in which outcomes can be readily measured and interventions structured accordingly.

The Life Options Advisory Council believes that stratification (dividing patients into groups based on their needs and capabilities) is the most viable strategy for encouraging each patient’s peak rehabilitative and vocational achievement. This strategy allocates resources in a focused way, targeted at the groups most likely to benefit from the interventions. The following groupings are recommended:

- **Currently in school or employed.** Once patients leave school or the work force, it is difficult to return. Those who are of working age and in relatively stable health may need minimal assistance to encourage continued education or employment, or to find a new job. Patient care staff should communicate the crucial message: “If you are currently in school or employed, let’s work on strategies to help keep you there.”

- **Not employed, but able to work.** This group of patients who are not working may need retraining, particularly if the jobs they held prior to the illness were physically demanding. For those who are able and willing to work, strategies would include appropriate VR referrals, communication with prospective employers, consideration of home dialysis options, and treatment schedule changes. The bulk of vocational rehabilitation resources would go to this group.

- **Not employed and unable to work.** These patients need an array of services including physical and occupational therapy to help improve their functional status and quality of life, and possibly literacy training or other education to improve their long-term prospects of employment.

The Advisory Council recommends that the renal community launch the development of a diagnostic assessment system for rehabilitation that would:

- Stratify the patient population in the manner described above
- Differentiate objectives for these different groups
- Specify interventions for the entire dialysis team based on appropriate targeting of resources

Rehabilitation objectives for each patient should be integrated into each patient’s care plan. Patients need to be re-evaluated periodically for employment eligibility, to ensure that they are not categorized inappropriately.
Beyond Vocational Rehabilitation
When it can be realistically accomplished, the Advisory Council believes that employment is a crucial goal for the rehabilitation of patients with kidney failure. However, as seen from the population demographics, to focus purely on vocational rehabilitation is to ignore the needs of a large segment of the dialysis population.

In addition to a more systematic approach to vocational rehabilitation, all renal patients share a need for educational, motivational, and life-enhancing rehabilitation options. Some patients need encouragement to become involved in recreational activities such as classes, hobbies, or travel. Physical and occupational therapy can help maximize endurance and strength to increase fitness. Counseling in peer groups or by professionals can facilitate the emotional adjustment to chronic disease.

Patients and their families require ongoing education, ideally starting pre-dialysis, to help them fully understand their disease, its modes of treatment, the diet they must follow, and the likely consequences for their personal and family lives. Education and improved physical functioning can be considered the universal goals for all patients with kidney failure.

Perceived Barriers to Rehabilitation
While the medical potential for rehabilitation of patients with kidney failure has never been greater, too often attitudinal and institutional barriers prevent patients from realizing their fullest potential.

New ESRD patients do not yet know what to expect from life on dialysis. The beginning of dialysis therapy is a window of opportunity during which the expectation of rehabilitation can be instilled. This is where the attitude of the professional dialysis staff is of paramount importance in helping patients shape a positive vision of the future.

Depressed themselves, and confronted with the generalized pessimistic perceptions of many dialysis caregivers, it is no wonder that many patients allow themselves to sink into apathy and learned helplessness. This dependence makes it difficult for patients to pursue independent, goal-oriented behavior such as job-seeking, exercise, or even pursuing a favorite activity.

Rehabilitation must also be predicated on adequate dialysis therapy. Three sessions of dialysis each week must substitute for the waste-removing action of the kidneys, which normally function 24 hours a day. Patients suffering the ill-effects of inadequate treatment will not have the energy to concern themselves with rehabilitation. The renal community must continue its efforts toward achieving consensus on standards for dialysis adequacy.

Lack of physical conditioning prevents some patients with kidney failure from fully enjoying life. Inactivity contributes to a generalized low work capacity level among ESRD patients that can be a barrier to rehabilitation.
Patients who quit their jobs and receive federal Social Security disability insurance (SSDI) benefits soon learn that the path to vocational rehabilitation is obstructed with roadblocks. Work incentives designed for SSDI recipients are actually disincentives: upon earning just $500 per month for nine months, the recipient is considered gainfully employed and loses the disability benefit abruptly. If health complications arise, it is extremely difficult to return to the disability program. This provision prevents many patients from attempting to work.

Even if patients successfully jump the financial hurdles of SSDI, they may have trouble obtaining vocational services to equip them for work. Nationally, data from the Rehabilitation Services Administration show that patients with kidney failure have a low rate of referral to state vocational rehabilitation (VR) agencies, and poor rehabilitation outcomes. In fact, VR success rates for patients with kidney failure are lower than those of any other disability group—even the spinal cord injured.

Removing these barriers to the successful rehabilitation of kidney patients requires educational and attitudinal change along with a well-considered reform of national disability and insurance policy.

**Bridges to Rehabilitation: The Five E’s**

The barriers to renal rehabilitation described above can be successfully addressed. The Life Options Advisory Council has identified five core objectives or “bridges” essential to the rehabilitation of ESRD patients. These interrelated objectives include encouragement, education, exercise, employment, and evaluation.

**Encouragement.** Patients with kidney failure and dialysis team members need encouragement to adopt a positive bias toward rehabilitation. For some, this will require a change in attitudes and perspectives. For rehabilitation efforts to succeed, patients must be committed, both psychologically and physically, to the concept of restoration. And there is a vital link between patient and staff attitudes. Staff members can profoundly affect patient expectations of what is possible.

Patients and their families are at a crossroads when dialysis begins: a point of extreme vulnerability. The quality of staff interventions at that time can influence whether a patient follows a course of self-determination—or of dependence. ESRD patients already have a chronic illness, but by cultivating a health care partnership between patients and dialysis providers, it may be possible to prevent further deterioration of health and function, which is costly both in dollars and in dreams.

**Education.** Renal patients and other disabled groups can make important contributions to society. To take advantage of this potential, patients, staff, vocational rehabilitation counselors, and employers require education about the positive life options of kidney patients.

Comprehensive pre-dialysis education, in particular, is essential for patients. When the kidneys fail, the resulting metabolic chaos sets off a chain of psychological and
physiological events that forever alter the lives of the individuals and families affected. Because the life changes associated with beginning dialysis are so profound, patients and their families need to be educated about strategies for successful adaptation to dialysis, about maximizing functional status, about employment options, and many other subjects. Patients must learn about their disease and the possibilities of life beyond it—and then expect to assume responsibility for their own health by complying with the treatment plan and participating actively in rehabilitation initiatives.

**Exercise.** All too often the need—and ability—of ESRD patients to lead physically active lives is underestimated. It is well understood in cardiac medicine that exercise is a critical bridge to rehabilitation. The same is true for renal patients. Part of ESRD patients’ gradual decline in muscle strength and endurance is due to inactivity. Patients need encouragement and counseling about exercise. There are many levels of activity to fit varying degrees of functional ability, from vigorous workouts for the otherwise healthy patient to stretching exercises for the chairbound. Anecdotal evidence as well as formal studies with dialysis patients (Goldberg et al, 1983) confirm the beneficial effects of exercise.

**Employment.** The primary employment goal for patients with kidney failure is to allow them to keep their current jobs, whenever possible. When this is not possible, vocational rehabilitation counseling should be used to help employable dialysis patients find employment. VR counselors require education about the unique needs of ESRD patients. Ideally, VR agencies could provide educational services at dialysis facilities. Targeting employment resources at patients who have identified themselves as able and willing to work could improve efficiency and reduce costs.

According to a study by Rasgon et al, “Findings . . . imply that patients who are beginning in-center hemodialysis could be aided in maintaining employment if they are provided with a pre-dialysis education program containing the following five key features: early referral to a social worker, psychosocial assessment, pre-dialysis education and counseling, dialysis center orientation, and multi-disciplinary follow-up.”

In the Rasgon study, 55 percent of the group who received the above interventions continued working after beginning dialysis; of the control group, who received no interventions, only 27.8 percent were working.

**Evaluation.** The potential value of systematic evaluation of rehabilitation outcomes is twofold. First, government policy decisions cannot be made in a vacuum—information on the present status of rehabilitation interventions and their outcomes is necessary to guide policy making. Second, renal professionals interested in improving the functioning of ESRD patients and enhancing their quality of life currently have few benchmarks by which to evaluate their progress. Clinicians need reliable predictors and outcome measures to identify which interventions work.

**Renal Rehabilitation: The Time Has Come**
Addressing renal rehabilitation in a systematic, coordinated way will require policy
changes based on prudently designed research studies. Resources must be devoted to
determine the most effective medical practices in rehabilitation, address the integration of
federal agency efforts, and educate the renal community about practical, effective
rehabilitation initiatives. Inevitably, these worthwhile efforts will require time and
expense.

Meanwhile, each day in this country there are over 100 chances to influence a new
dialysis patient’s life in a positive way—to start an individual on a path to rehabilitation
and maximize vitality and physical functioning. The renal community can take steps to
encourage rehabilitation for these patients even before a single additional dollar is
allocated.

It costs nothing to encourage patients to keep their existing jobs or remain in school. It
costs nothing to post examples of successful, active patients on bulletin boards at each
dialysis facility. It costs nothing to tell patients that remaining physically active and
participating in regular exercise can have positive implications for their overall health. It
costs nothing to suggest that patients join public service organizations because they have
an important contribution to make. It costs nothing to offer hope.

More than any other single factor, it is vital to intervene early in the course of kidney
failure. The time and money we invest in helping these patients to believe in their own
futures will be paid back in lives restored to productivity and promise.

II. Introduction
Renal Rehabilitation: Definitions and Goals

“Rehabilitation, like medical restoration, is a complex process that requires
concentrated, organized effort: an evaluation process, identification of problems, a
program of positive action, and follow-up with feedback.”
Samuel B. Chyatte, MD, Physician and Patient

In every healthy individual, two kidneys—each roughly the size of an adult fist—
maintain fluid levels, remove metabolic wastes, assure acid/base and bone mineral
balance, and control blood pressure. When the kidneys fail, the resulting metabolic chaos
can extend beyond the physical body and into the patient’s psychological life and self-
concept. All too often, failure of the kidneys translates into failure of the person to
participate in family and community life. The disease can be treated, but the resulting
disintegration of dreams, ambitions, and life goals has not yet been adequately addressed.

Kidney failure is a terminal illness with two possible treatments. A kidney transplant can
replace the damaged organs with a donor substitute. More commonly, dialysis is used to
cleanse the blood by filtering it through a membrane. Hemodialysis accomplishes this by
connecting the patient to an artificial kidney machine through a surgically enhanced
blood vessel called an access. Peritoneal dialysis uses the lining of the patient’s
abdomen, moving cleansing fluid in and out through a surgically implanted catheter, in a
process called an exchange.
The experience of permanent kidney failure, or end-stage renal disease (ESRD) is a turning point, at which timely intervention can turn the individual toward the path of rehabilitation. Failure to intervene with expectations of positive outcomes can lead to helplessness and depression. For dialysis patients, rehabilitation means restoring the mind and body to encourage the individual to maintain as full and active a life as possible. Recent innovations in medical technology and pharmacy have significantly improved the potential for rehabilitation of patients with kidney disease. Advances like more efficient dialyzer membranes and the synthesis of the hormone erythropoietin have improved many aspects of patient well-being.

Unfortunately, the percentage of renal patients who are rehabilitated is lower than it should be (Evans, et al 1985; Gutman, Stead, and Robinson, 1982A; Kutner and Brogan, 1985; Rubin, 1990; Vachon, 1992A). It is the view of the Life Options Advisory Council that the actual life options for people who experience kidney failure could have much greater richness and diversity if rehabilitation resources were integrated systematically and consistently, and made available to patients.

The Life Options Advisory Council has defined the ideal process of rehabilitation for a dialysis patient as: a coordinated program of medical treatment, education, counseling, dietary and exercise regimens designed to maximize the vocational potential, functional status, and quality of life of dialysis patients. Ideal outcomes for rehabilitation include employment for those who can work; enhanced physical fitness; increased individual control over the effects of kidney disease and dialysis; improved compliance with the dialysis regimen; improved communications with dialysis staff, family members, and employers; and resumption of activities enjoyed prior to dialysis.

The challenge for the renal community in the 1990s is the need to mount a realistic, effective rehabilitation effort in an environment where financial and staffing resources are diminishing and the patient population is growing rapidly and becoming ever more diverse.

**Expectations vs. Reality: Changing Demographics**

When the end-stage renal disease (ESRD) program was introduced in 1973, it was anticipated by many that its cost would be offset in part by patients’ participation in the work force (Rettig, 1980). Over the years unrealistic expectations have been promoted—as in Senator Hartke’s now famous assurance that enactment of the ESRD program would result in a wholesale return of dialysis patients to productive employment (cf. Hytner, 1993).

Unfortunately, various studies indicate that at this time, only 10 to 20 percent of working-age dialysis patients are employed (cf. Richardson, 1987; Evans, Blagg, and Bryan, 1981; Kutner, Brogan & Fielding, 1991), although researchers estimate that effective vocational rehabilitation of ESRD patients may be a realistic goal for one third or more of the patient population (cf. Kutner, Brogan and Fielding, 1991). This paper will explore possible reasons for the failure of rehabilitation to live up to its early expectations.
One of the dynamics affecting renal rehabilitation is the changing demographic profile of the ESRD population. In 1990 there were more than 195,000 patients enrolled in the Medicare ESRD program, a figure already more than double the early 70s projection of 90,000 patients in 1995 (Harris et al., 1993; cf. USRDS Annual Report, 1993). The population of ESRD patients today is increasingly comprised of elderly and minority patients, changes which were not anticipated when the program began.

The dialysis population is aging. Only two percent of treated patients reported to HCFA are under age 19. In 1978, 32 percent of all patients were 60 years or older; in 1992, that figure was 42 percent. Recently, the greatest increase in ESRD program participation has been in patients over 75 years of age, with the second greatest increase in patients aged 65 to 74 years (Green Book, 1993 [A compilation by the Committee on Ways and Means that describes the history and extent of all programs overseen by the Ways and Means Committee]). The median age of treated ESRD patients from 1987 to 1990 was 61 years old (USRDS, 1993). Rehabilitation goals must be age-appropriate; we cannot realistically expect more employment from this population than we would of the general population of retirees. Despite the aging trend, however, the majority of ESRD patients (54 percent) still fall between the ages of 20 and 64 years (USRDS, 1993).

Kidney failure affects more men (54.4 percent) than women (45.6 percent). Of the patients enrolled in the ESRD program, 68.2 percent are white, 1.9 percent are Asian, 1.3 percent are Native American, and 28.6 percent are black: a disproportionate number compared to 12.1 percent blacks in the general population. Educational attainment and employment levels of ESRD patients (in this case transplant patients) prior to kidney failure were below those of the general population (Florida ESRD Network 19, 1985).

Diabetes as a primary cause of ESRD has the largest rate of growth for persons entering treatment. (Overview of Entitlement Programs Green Book, 1992). This fact has far-reaching implications, since diabetic patients frequently have multiple health problems, which make the treatment of their renal disease and their rehabilitation more difficult and complex.

Thus, while there is a considerable portion of the population for whom vocational rehabilitation is potentially a realistic prospect, an ever increasing portion of the population is in need of rehabilitation services and programs designed to further their adjustment to their condition and help them resume life activities in their families and communities.

**Goals and Purposes of Renal Rehabilitation**

There have been many attempts by professionals in the field to develop definitions of renal rehabilitation that encompass more than vocational efforts. A focus on the broadest definition of the term, encouraging patient goal-setting, has been recommended (Diamond, 1989; Bower, 1989). According to Blagg and Fitts (1991), “Rehabilitation should encompass all aspects of the patient’s well-being and include vocational, physical, and medicinal therapies.”
Feinsmith (1989) concurs: “Rehabilitation is the whole idea of dialysis: physical, mental and economic rehabilitation; the opportunity to lead a normal life, to work full time for the psychological rewards as well as the ability to support oneself and one’s family; to have the ability to travel, socialize, eat, and play in as normal a manner as possible.” From this perspective, restoring chronically ill patients as closely as possible to “the level of activity they held before the onset of the disabling condition” (Kutner and Brogan, 1985) is perhaps the broadest definition in the literature, and the one that now seems to be the most meaningful.

Harada et al (1993) define rehabilitation as: “the application of medical procedures to restore the individual with disease or disability to optimal functioning in his or her own normal societal environment.” This medical definition has recently been expanded upon by the larger rehabilitation community, which has agreed to distinguish four conceptual levels affecting patients:

1. **Pathology** (the initial injury or underlying disease—e.g. ESRD).

2. **Functional limitations** (e.g. loss of sensation and motor control, or need for dialysis).

3. **Handicap** (e.g. need for assistive devices or post-dialysis fatigue).

4. **Disability** (e.g. inability to work—affects some, but not others with the same handicap).

According to this model, rehabilitation goals are to minimize escalation at each level, first by preventing secondary complications such as access infections, then by encouraging compensations and facilitating accommodations so that the remaining functional limitations do not necessarily lead to handicaps—or handicaps to disability. For ESRD patients, early intervention is essential to prevent a progression from dialysis to disability. Before rehabilitation can occur, patients must be educated about what rehabilitation possibilities exist, and what can realistically be expected from life after dialysis.

**The Broad Spectrum of Renal Rehabilitation**

Many renal professionals equate successful renal rehabilitation with employment, in part because employment can be readily measured and documented. The Life Options Advisory Council places a high priority on employment as a goal for patients who are able to continue with or return to work. However, while vocational rehabilitation is a relevant goal for many patients, as well as for American taxpayers who hold a financial stake in the ESRD program, it is insufficient to consider employment alone in a discussion of renal rehabilitation.

It is important to keep in mind the other relevant and worthwhile goals of renal rehabilitation: to enable patients to maintain as active a lifestyle as possible, to independently perform activities of daily living, to return to previously enjoyed activities, and to pursue individual life goals.
Comprehensive rehabilitation efforts can make the difference between quality life and mere existence. The improved overall health and outlook of successfully rehabilitated patients may have positive cost implications as well (Stewart et al, 1989). Patients who are rehabilitated to the point of employment are able to offset some of the costs of the Medicare ESRD program. Patients whose physical health improves to the point where they can manage self-care activities may allow an adult caregiver to re-enter the work force. Even patients who cannot care for themselves, but whose outlook and quality of life are improved, can experience positive health consequences that reduce costs; keeping patients at home rather than in nursing homes decreases the costs of their care as well. And costs notwithstanding, the achievement of these improvements in patient condition is inherently valuable.

**Targeting Vocational Rehabilitation Resources to the Appropriate Recipients**

In light of the fiscal constraints upon health care and rehabilitation as well as the demographics of the ESRD population, it is unrealistic to expect every patient to return to paid employment. Individuals in the ESRD program can be classified into three groups from an employment perspective. The first group of patients (10 - 20 percent, according to Evans, Blagg, and Bryan, 1981; and Kutner, Brogan & Fielding, 1991) continues to work. A much larger proportion of dialysis patients is not employed. Many patients are elderly or have comorbid conditions that render them genuinely disabled. A third group of dialysis patients is restored to a reasonable degree of well-being and would like to work, but cannot find employment due to obstacles discussed later in this paper.

The Advisory Council believes that patients who are not appropriate candidates for vocational rehabilitation could lead more active and productive lives if other rehabilitation interventions such as physical, occupational, and recreational therapy, counseling, and education were made available to them on a regular basis. Joint goal-setting between well-informed patients and their care providers assists this process (cf. Ellstrom Calder). This paper will explore some ways to make these services feasible for the facility that is hard pressed to deliver high quality dialysis treatment in a fiscally limited environment.

The Advisory Council emphasizes that, in addition to a more systematic approach to vocational rehabilitation, all renal patients share a need for educational, motivational, and life-enhancing rehabilitation options. Some need encouragement to become involved in recreational activities such as classes, hobbies, or travel. Physical and occupational therapy can help maximize endurance, strength, and physical function. These therapies can also help increase resistance to the otherwise progressive frailty resulting from periodic hospitalization, illness, and forced inactivity. Counseling in informal peer groups or by professionals can facilitate the emotional adjustment to chronic disease. Patients and their families require ongoing education, ideally starting pre-ESRD, to help them fully understand their disease, its modes of treatment, the diet they must follow, and the likely consequences for their personal and family lives.

**Objectives of the Life Options Rehabilitation Program**

Life Options: Rehabilitation for the Dialysis Patient is a multidisciplinary program whose
Amgen Inc. is sponsoring the Life Options program with an educational grant. Work on the Life Options project began in April 1993 with a meeting of the Life Options Advisory Council, a coalition of patients, providers, researchers, government, and private business. One Council activity is to identify, analyze, and make recommendations about the multiple dimensions of renal rehabilitation in the 1990s. This report is one facet of the Council’s work.

The recommendations herein constitute the Advisory Council’s vision of a national agenda in renal rehabilitation. Components of this agenda would be implemented by various entities, including patients, dialysis professionals, service organizations, the business community, and federal agencies including the Health Care Financing Administration, the Rehabilitation Services Administration, and the Social Security Administration.

The objectives of this report are:

• To identify several dimensions of rehabilitation and what these mean to the kidney patient.
• To identify barriers to rehabilitation and recommend actions/programs to surmount these obstacles.
• To suggest means for systematic integration of renal rehabilitation resources.
• To review valuable initiatives in renal rehabilitation at the facility and regional levels.
• To identify existing networks of national, state, and community resources that could assist patients in returning to a pre-ESRD lifestyle.
• To review and report on work currently in progress by private groups, service organizations, and government groups.
• To serve as a catalyst for local, regional, and national research, program, and policy efforts to assist renal patients to achieve their fullest potential.
• To identify rehabilitation program models and integrate them into useful tools to support rehabilitation

Target audiences for the report include individuals and groups who have a potential or an actual role in renal rehabilitation. These include:

• **Renal Community**
  - Kidney patients
  - Primary physicians
  - Dialysis staff
  - Nephrologists
  - Administrators
  - Nurses
  - Social workers
  - Technicians
- Dietitians
- Transplant facility staff
- ESRD public service organizations and readers of their publications
- Researchers

- **Extra-Renal Consultants**
  - Physical therapists
  - Occupational therapists
  - Recreational therapists
  - Educators of renal professionals
  - Psychiatrists
  - Physician rehabilitation specialists
  - Rehabilitation counselors
  - Internists

- **Government Entities (Local, State, Regional, Federal)**
  - Legislators, legislative committees
  - Social Security Administration
  - HCFA and Networks
  - Rehabilitation Services Administration
  - National Institutes of Health
  - United States Renal Data System
  - National Institute of Diabetes and Digestive and Kidney Diseases
  - State kidney programs
  - State DVR programs

- **Media**
  - Trade journals
  - Academic journals
  - General press
  - Related organizations

- **Private Industry**
  - Business owners/employers
  - Insurance companies

**Advisory Council Role**
The Advisory Council, working with the staff of the Medical Education Institute, which is administering the grant, has a number of roles:

**Liaison role:** Individual group members will form (or draw upon) liaisons with other groups whose influence and input could help shape programs and policy in renal rehabilitation. These entities include kidney patients, ESRD organizations, ESRD health care professionals, government representatives, rehabilitation specialists, key media people, and business executives. Liaisons with government agencies have been
established to address the following substantive issues:

- Social Security disability program disincentives to re-employment (specifically SSDI work disincentives)
- The role of the Networks in facilitating renal rehabilitation
- Integration of rehabilitation resources within HCFA, the Rehabilitation Services Administration, and the Social Security Administration

**Strategic recommendations**: The Advisory Council has developed a recommended national agenda in renal rehabilitation.

**Program development**: After a comprehensive review of best practices in renal rehabilitation throughout facilities in the country, the Advisory Council will advise on the design of a demonstration program that meets documented needs in renal rehabilitation. The dimension, design, scope and direction of the demonstration program will depend upon the Council’s recommendations.

The individuals working on the Life Options program hope to focus national attention on a problem that heretofore has seemed intractable, and to suggest strategies in the crucial areas of patient and staff commitment, education, physical rehabilitation, psychosocial rehabilitation, vocational rehabilitation, and rehabilitation research. The group has encountered, in the course of its work on this project, an encouraging climate of interest and receptivity on the part of patients, professionals, and government groups. There is a clear consensus that we must look at renal rehabilitation again in the context of health care in the 1990s.

**III. Participants in the Rehabilitation Process**

Kidney failure is a complex disease, and requires a variety of interconnected resources for treatment. These include such diverse groups as colleges and universities that educate renal professionals, equipment and pharmaceutical companies that produce the mechanisms and medications for patient treatment, and insurance companies that may provide health care for affected individuals and their families. The Advisory Council recognizes the valuable contributions of these participants. However, these participants will not be addressed directly in this paper. Generally, direct participants in the rehabilitation process fall into the following very broad categories:

- The patient
- The dialysis facility
- The business community
- The public service organization
- The government

Each of these participants has unique characteristics and a critical role to play. But, as Dr. Samuel Chyatte noted in the 1970s, the renal rehabilitation field is notable for its fragmentation. There are many untapped resources available to the dialysis patient, but until an integration of disciplines, systems, and agencies takes place, the potential of
these resources will not be realized. Before recommending ways to integrate resources, we must analyze the dynamics of each participant group.

Participants in Rehabilitation: The Patient

“Any significant rehabilitation and adjustment to chronic uremia requires a strong acceptance (by the patient) of responsibility for his physical, mental, and emotional health. This implies regaining or, in some cases, establishing for the first time substantial control and independence in living one’s life.”
John Newmann, PhD, Economist and Patient

“It seems to me that the disabled population is perhaps our nation’s most untapped economic resource.”
Bruce Lublin, Dialysis Patient for 23 Years

Despite the best efforts of everyone involved, unless patients are able and willing to participate in rehabilitative efforts, the likelihood of success is small. Coping with the physical, emotional, and financial implications of kidney failure can drain energy and personal resources that could otherwise be used for more productive pursuits—like employment; improved physical conditioning; or enjoyment of family, friends, life, and society’s activities. This section will discuss the impact of ESRD on various aspects of patients’ lives, the potentially disruptive effects of the disease on the process of rehabilitation, and the quality of life experienced by patients with ESRD.

End-Stage Renal Disease (ESRD)

End-stage renal disease is defined as the complete and irreversible loss of kidney function (Hura, 1991). Kidneys perform several vital functions in the body, including excretion of fluid and metabolic wastes, control of pH and blood pressure, control of calcium/phosphorus balance for healthy bones, and production of hormones needed to trigger the formation of red blood cells. Without treatment—dialysis or transplantation—ESRD is invariably fatal. During 1990, 45,153 patients were registered as starting ESRD therapy. (USRDS Annual Report, 1993) (Please refer to Addendum A for a discussion of treatments for ESRD.)

There are many types of renal disease which result in ESRD, including the number one cause: diabetes (34.2 percent), as well as hypertension (29.4 percent), glomerulonephritis (14.2 percent), polycystic kidney disease (3.4 percent), interstitial nephritis (3.4 percent), and other diseases (15.4 percent) (USRDS Annual Report, 1993). Other less common causes of renal failure include: drug toxicity (i.e., non-steroidal anti-inflammatory drugs, antibiotics and heroin), congenital anomalies or defects, lupus, AIDS, and sickle cell disease (Kammerer, et al., 1992).

Clinical Consequences of the Disease

“Chronic illness is characterized by the realization that there is no likely cure, that the patient will always have this disease. The trajectory of chronic illness is variable and typically unfolds over many years. In patients with chronic illness, the goal of
medicine therefore is to optimize health status rather than cure disease.”
Sylvestre Quevedo, MD

When the kidneys fail, the ability to regulate blood pressure, acid/base balance, fluid levels, bone formation, and red blood cell production is altered. Metabolic chaos ensues. Hemodialysis, peritoneal dialysis, or a kidney transplant are then needed to replace some of the kidney’s functions and sustain life. Healthy kidneys work 24 hours a day, while hemodialysis occurs for only six to 15 hours per week. Peritoneal dialysis can be done continuously. Kidney transplants have the advantage of replacing the hormonal functions of the kidneys as well as fluid removal. However, a life-long course of medications that suppress the immune system is necessary to prevent organ rejection.

ESRD patients experience a decline in their physical well-being. Fatigue, anemia, loss of bone minerals and hypertension are common consequences of ESRD. Other complications may include fluid buildup in tissues, loss of appetite, restlessness, shortness of breath, and a variety of other symptoms (Kammerer, et al., 1992). Dietary and fluid restrictions, the necessity of interrupting daily life for regular dialysis treatments, and the psychological impact of coping with a chronic illness renders some patients perpetually incumbent in the “sick” role. However, these physical and emotional symptoms can be minimized through appropriate treatment and counseling, and new dialysis technology has increased the likelihood that dialysis patients will lead healthier lives.

Emotional Adaptation to Kidney Failure
“The patient must provide the active effort and the health professional the supervision...the patient and his/her family cannot be ignored and, in fact, must be considered the main participants in the process.”
Samuel B. Chyatte, MD, Physician and Patient

Being diagnosed with a serious chronic illness is a life threatening event, which—depending upon the interventions at the time—can initiate positive or negative life changes. Adding to the complexity of an individual’s response to illness are the psychosocial implications—the interconnections between the disease process itself and the patient’s experience of the sick role, as well as the response of family members and other individuals important to the patient (Kleinman, 1988; Quevedo, 1991).

Regaining emotional equilibrium after a chronic disease can take time. One patient’s description of the feelings of a hypothetical patient upon being diagnosed with renal failure is bleak: “You’re sick...you’re disabled...you’re emotionally and physically weak, your friends don’t know what to say to you, people pity you, your security and self-esteem are gone, and you have no control over your life.” (Lublin, 1992). Added to the shock of the illness is an extended grieving process for the loss of kidney function, and the personal knowledge of mortality (Lundin, 1989).

John Newmann (1983) describes a three-stage process of adapting to life as a dialysis patient, which may overlap with the generally accepted model of emotional adaptation to
grief. **Stage one** occurs during the initiation of dialysis and the first several months of treatment. During this stage, a patient may feel, “scared, worried, resentful, angry, tired, weak, and in a hurry to get on and off that machine which is tying him down.” Learning self-care skills at this point may help the patient regain a sense of personal control; staff can facilitate adjustment by assuring patients that they can continue to enjoy active, productive lives—although there may be a temptation to give up and settle for being disabled.

During **stage two**, the transition to acceptance of the renal failure, a patient may begin to become accustomed to the treatment regimen, and fears may be reduced, although the patient may still experience fatigue, depression over his or her changed life, and problems adjusting to the restricted diet. Patient responsibility and control must be emphasized.

**Stage three** is acceptance of and adjustment to chronic renal failure. Patients in stage three can be classified into three groups: a well-adjusted, highly motivated consumer group of patients who know what they want and go after it; a poorly adjusted, non-compliant group that feels hopeless and helpless; and a third group which Newmann describes as “on the fence.”

It is this uncommitted, “on the fence” group which may be most amenable to timely intervention. In general, keeping the patient’s adaptation stage in mind when discussing rehabilitation options may be helpful, because the patient’s current state of mind may render him or her more or less receptive to learning. Some movement back and forth between stages may also occur, particularly if a patient’s equilibrium is upset by a medical crisis such as the need to change the type of dialysis, or problems with the access blood vessel used for hemodialysis.

**Role of Family Members**
The importance of the family members’ role in the rehabilitation of some patients cannot be underestimated. Family members, long-term friends, or non-married partners, while not prey to the disease process itself, are nonetheless subject to the uncertainty, the profound life changes, and the emotional adjustments required to adapt to life with kidney failure. Family members who are correctly educated and oriented to learning to live with dialysis can be extremely helpful in the rehabilitation process.

Aside from the practical matters of incorporating diet and scheduling and adapting family activities to a more limited scope, family members must learn many intangibles in order to provide the right type of support. They must learn not to promote the “sick” role; they must learn to provide help where it is needed and promote independence. The complexity of this balancing act is extreme; yet those family members who have the proper orientation and expectations can make a crucial contribution to restoring normalcy to family life.

**Financial Implications of ESRD**
Beyond the emotional issues, many patients are frozen into immobility due to fears about their financial status as an ESRD patient. Concerns about supporting dependents or
rapidly depleting family resources may contribute to a paralyzing depression and fear in new dialysis patients.

Once diagnosed with renal failure, the illness and any medical complications related to it may become “preexisting conditions” to many insurance carriers. This designation results in refusal of coverage for the very condition that necessitates the insurance; or forces patients into a series of increasingly more costly policies (with premiums increasing 65 to 90 percent) in a tactic referred to as a “death spiral” by Jane Bryant Quinn (Newsweek, 2/22/93).

Patients who are working fear losing their jobs, and lack of flexibility in dialysis scheduling may contribute to this fear. If they are not working, they fear they will never work again because employers are reluctant to hire ESRD patients (HCFA, 1981). If they are “disabled,” they fear their efforts to return to work will ultimately net them less than their monthly disability check (Oberley, May, 1991).

**Quality of Life of ESRD Patients**

In the past, quality of life was commonly defined solely in terms of happiness or satisfaction (Ferrans and Powers, 1985; Campbell, Converse & Rogers, 1976). Life satisfaction may be the most important domain of quality of life. This so-called “subjective” quality of life is in the eye of the beholder, and changes over time along with the patients perceptions of the illness and its effects on daily life.

More recently, researchers have recognized that there are at least four or five basic components or dimensions to individuals’ evaluations of quality of life. These include perceptions of physical status, emotional status, mental status (cognitive or intellectual status), social role functioning, and sense of well-being/satisfaction with life (cf. Quevedo, 1991; Simmons and Abress, 1990; Ferrans & Powers, 1992; Stewart and Ware, 1992).

Even when such comprehensive, multidimensional measures of quality of life have been used, patients with ESRD have reported enjoying a surprisingly good quality of life; in fact, only slightly less positive than that reported by the general population (Evans, et al., 1985). This indicates that rehabilitation to prevent deterioration and maximize functioning is indeed possible in this population.

It is conjectured that such patients might be favorably comparing their present life quality with a time when they were actually experiencing a more difficult course (i.e., transplant patients remembering pre-transplant life or dialysis patients recalling pre-dialysis states) (Quevedo, 1991). Whether or not that is the case, these patients did indeed report that the quality of life they were experiencing was more than acceptable.

Not surprisingly, older ESRD patients describe a less satisfactory quality of life than older non-patients, reporting lower levels of employment (Kutner, Brogan, and Fielding, 1991), greater functional limitations and a decreased ability to do the activities they enjoy (Kutner and Brogan, 1992), and a poorer health outlook (Kutner, Cardenas, and Bower,
1992). These results point out the need to target rehabilitation interventions that improve physical functioning and quality of life.

**Quality of Life and Treatment Modality**

Different treatment modalities appear to engender different levels of life quality. For example, it seems that the quality of life enjoyed by patients after a successful transplant cannot be duplicated with any other form of therapy for ESRD (Martino, 1987). Research under the auspices of the Battelle Human Affairs Research Centers has shown that among ESRD patients, successful transplant patients enjoy the highest average quality of life (Evans et al., 1985).

Forms of dialysis which can be done at home, including home hemodialysis and peritoneal dialysis, also have positive impacts on quality of life, compared to in-center hemodialysis. Home hemodialysis and peritoneal dialysis afford the patient control over the scheduling and setting, can be done in comfortable, familiar surroundings, and are generally perceived to be less disruptive to family and employment life than in-center hemodialysis (Blagg, 1989).

Home hemodialysis is a very positive modality for improving quality of life and rehabilitation potential, although, unfortunately, the number of patients participating is very small: Less than two percent of all U.S. dialysis patients are using home hemodialysis (USRDS, 1993), down from a peak of 42 percent in the early 1970s (Oberley et al, August, 1992). Evans et al (1985) have reported that the subjective and objective quality of life of home hemodialysis patients most closely resembled that of transplant patients.

The choice of modalities available to patients may vary regionally, and may also vary depending on the physician. This choice is a very personal one, with important implications for how patients live their daily lives and how likely they are to be rehabilitated to the highest possible level. To have optimal quality of life given this chronic illness, patients require education about each modality, and must have access to the widest array of treatment choices possible.

**Quality of Life and Medical Advances**

Recent medical advances which have the potential to positively affect ESRD patients’ quality of life include the introduction of more efficient hemodialyzers which allow reduction of treatment time required; more reliable hemodialysis machines; bioengineered erythropoietin, which alleviates anemia; and development of intravenous calcitriol, the active form of Vitamin D, which reduces bone disease associated with kidney failure and treatment. Research specifically relating these innovations to patients’ quality of life is not yet available.

**Effects of Erythropoietin**

Hemodialysis patients are typically anemic. A deficiency of the hormone erythropoietin (which triggers the production of blood cells) combined with vitamin deficiencies, blood losses from laboratory tests, and the dialysis process itself contribute to diminished
hematocrit (red blood cell) levels. While a healthy adult would normally have a hematocrit between 37 and 52 percent, a dialysis patient’s hematocrit might be as low as 15 to 25 percent (Kammerer, 1992), and are typically in the 20 to 24 percent range. Anemia results in fatigue, feelings of malaise, and low exercise capacity.

Until recently, the only treatment for the anemia of ESRD was blood transfusions. However, a bioengineered form of erythropoietin, introduced in 1989, alleviates the anemia of dialysis patients without drawing upon the nation’s blood supply, or subjecting patients to the risks of repeated exposure to donor blood.

Studies of patients receiving erythropoietin (EPO) have reported improvements in their aerobic exercise capacity (Mayer et al, 1988; Robertson et al, 1990) and muscle strength (Robertson et al, 1990). In addition, EPO patients reported a level of overall life satisfaction that exceeded that of patients on all ESRD treatment modalities. Another study (Levin, 1992), yielded similar results, with significant improvements in subjective and objective quality of life indicators for patients with improved hematocrit levels.

Evans (1991) examined the effect of administration of erythropoietin on the lives of ESRD patients. He was able to demonstrate that hemodialysis patients being treated with erythropoietin reported a significant improvement on all quality of life indicators except employment status.

The improved well-being reported by patients receiving erythropoietin has propelled the issue of rehabilitation of renal patients once again into the public eye. Unfortunately, the increased energy levels and feelings of well-being among patients taking the synthetic erythropoietin have not translated into higher rates of employment. This suggests that well-being alone is not sufficient to encourage vocational rehabilitation. The pervasive barriers against gainful employment must also be addressed.

Participants in Rehabilitation:
The Dialysis Facility

“Patients and dialysis professionals need to believe that it is possible to be on dialysis while living a close-to-normal life.”
Peter Lundin, MD, Nephrologist, Dialysis Patient, and Transplant Recipient

“It is vital that all of dialysis staff members work as a team. Rehabilitation of these complex patients is best accomplished in an atmosphere of shared information and integration of services between nephrologists, social workers, dietitians, technicians, and, most importantly, patients themselves.”
George Porter, MD, Nephrologist

“Patients have traditionally respected medical staff because in the past they came to you and you would cure them of their ills. Not so with kidney failure....The rules and outcomes are different with kidney failure and it is important for staff to understand this
“and share that understanding with patients.”
John Newmann, PhD, Economist, Patient

Dialysis facilities serve as hubs of activity and information for ESRD patients. The majority of dialysis patients receive in-center hemodialysis (USRDS, 1993), and even patients who perform hemodialysis or peritoneal dialysis at home receive services through the local dialysis facility. Because dialysis staff members have such a pervasive influence on a patient’s attitudes toward rehabilitation and restoration, it is important to explore trends and interactions in the dialysis facility as they relate to rehabilitation today.

Ideally, within the facility, an interdisciplinary team of staff members interacts to provide a variety of vital services to patients, including medical care, nutritional recommendations, and social work services. Physical and occupational therapy may also be provided directly or by referral.

In reality, a decline of 65 percent over the past two decades in real dollars spent by Medicare on each dialysis treatment (Green Book, 1992) has made the task of bringing an interdisciplinary focus to rehabilitation a major challenge.

**Rehabilitation in the Context of Medical Care**
Patients whose kidneys are failing typically visit a primary care physician, such as an internist, until the disease requires dialysis or a kidney transplant. At this point, or perhaps earlier, the patient is generally referred to a nephrologist, who specializes in disorders of the kidneys. As the first medical contacts with newly diagnosed ESRD patients, it is vital that the rehabilitation messages given to patients by primary care physicians and nephrologists be positive ones.

The physician’s words are regarded as gospel by the patient. “Once you go into kidney failure,” noted a participant in the Institute of Medicine ESRD Study focus groups, “the doctor holds the key to life. You can’t get life support without the doctor…” (Oberley, May, 1991). Staff expectations regarding rehabilitation may be driven by the attitudes of the physician; in facilities where physicians encourage self-management and a return to employment, these outcomes may be more likely to occur (Lundin, 1989). There is no question that the physician sets the tone and expectations for rehabilitation in the individual dialysis facility.

Nephrologists are responsible for explaining the medical condition and its treatments to the patient. If dialysis is chosen, the nephrologist then tailors a dialysis prescription to meet the patient’s individual needs. Registered nurses, licensed practical nurses, and dialysis technicians are then responsible for providing this care as it is prescribed. Each of these professionals has a role to play in encouraging the potential for rehabilitation among dialysis patients. For these reasons, after a discussion of treatment options with the nephrologist, the patient’s next contact should be with the dialysis facility.

Dialysis professionals with extensive patient contact are the logical sources of patient
information about the possibilities of life beyond dialysis. If these staff members maintain high expectations of the patient’s potential, provide appropriate education—pre-ESRD if possible—and a coordinated educational program when dialysis begins, as well as pointing out role models of patients who have succeeded in rebuilding their lives, patients receive a more positive picture of their future.

According to the 1990 Institute of Medicine study of the Medicare ESRD Program, given the limited dollars available for dialysis staffing, many facilities have replaced registered and licensed nursing positions with technician positions. The background, education, and training of dialysis technicians varies widely. Depending on state law and facility policy, technicians may have high school equivalency certificates or advanced degrees, and facility training programs for dialysis technicians may be more or less comprehensive. Some technicians advance their professional status through state-required or voluntary certification exams, while others receive no standardized training at all.

While many technicians are trained to deliver dialysis treatment with great proficiency, replacing nurses with technicians may result in reduced direct clinical supervision of patients, less clinical information about each patient made available to the nephrologist, reduced crisis management ability, and an increased probability of errors (Rettig and Levinsky, 1991). Errors and poor crisis management have high costs in terms of patient quality of life, time off work, and hospitalization.

Within the field of nephrology, the roles of the various dialysis professionals in patient rehabilitation are complicated by philosophical distinctions between the medical model for acute care and the lack of a distinct model for providing chronic care, including rehabilitation. In the traditional medical model applied to acute illness, a clear distinction is possible between the healthy and the ill. ESRD does not lend itself to such obvious delineations. Rather, fluctuations in health status occur.

The role of the patient is different between an acute and a chronic model as well. While acutely ill patients may passively accept the ministrations of a health care team, patients with chronic illness cannot be cured, and must take on a more active role in the redefining of their own lives. The dependence that tends to be fostered in a dialysis facility when all decisions are made by the medical personnel is harmful to patients’ motivation (Antonoff and Mallinger, 1991).

Patients may be caught in a perplexing dichotomy of compliance vs. independence (Oberley, 1990). On the one hand, they are expected to comply with an extremely restrictive regimen of diet, treatment, and medications; on the other hand, they need to be independent in order to have control over their lives. When dialysis begins, there is a window of opportunity for each patient to set a more independent course if encouraged to do so by the staff and other patient role models. The very strong influence the staff may have in setting patient expectations for the future and affecting the patient’s attitude is seldom constructively utilized.

End-stage renal disease cannot be cured. Instead, medical professionals have the
challenge of setting realistic rehabilitation goals for each patient, knowing that philosophical commitment on the part of patient and professional will be the primary key to a successful outcome.

**Social Work Staffing**

It is the dialysis facility social worker who is the most familiar with all aspects of the patient’s new lifestyle—from dialysis treatments to emotional adjustment to financial considerations. The social worker is responsible for counseling the patient and his or her family, performing crisis intervention, coordinating insurance and other benefits, and arranging for transportation and other community services (Rettig and Levinsky, 1991). It is the renal social worker who is most likely to connect the patient to various community resources, including vocational resources.

As dialysis budget belts are pulled tighter, however, there is insufficient time for supportive counseling and other interventions designed to help patients make a positive adjustment to their changing circumstances. Instead, over the past decade, social workers in many facilities have been forced by larger patient loads to spend the majority of their time on patients’ financial concerns (Rettig and Levinsky, 1991).

The average patient to social worker ratio in 1988 was 102 to one (Rettig and Levinsky, 1991). In a 40-hour work week, this figure allows less than 24 minutes per patient, per week. While research to establish benchmarks for sufficient weekly social worker time per patient is lacking, 24 minutes would seem to be insufficient to provide the type of education, counseling, or vocational encouragement necessary for rehabilitation. Several national dialysis chains have recently implemented policies that limit social workers and dietitians to only 30 minutes per patient per month.

**Dietitian Staffing**

Dietary management is a vital component of the treatment for end-stage renal disease. Because it is impossible to remove fluid and wastes that have built up over a week in 12 hours or less of dialysis, ESRD patients must also reduce their intake of fluids, protein, potassium, and phosphorus. This must be done while maintaining enough calories to prevent burning of muscle tissue for energy, which would create even more wastes. Clearly, the role of the dietitian in helping ESRD patients to understand the need for a restricted diet and to plan meals accordingly, is crucial.

Unfortunately, Rettig and Levinsky (1991) report that the scarce data available indicates patient to dietitian ratios of 140-200 to 1. In a 40-hour week, this allows only 12 to 17 minutes of dietitian time per patient. Again, while research has not yet been done to indicate how much weekly dietitian time per patient is optimal, it seems apparent that little detailed counseling can be done in such a limited time frame.

Failure to adhere to the renal diet can contribute to long term complications such as coronary artery disease and bone disease, as well as short-term difficulties with potassium levels, blood pressure control and complications during dialysis. Any of these conditions can lead to increased morbidity, lost time from work or other desired
activities, and higher rates of hospitalization—costly alternatives to adequate dialysis dietitian staffing. It is difficult to rehabilitate patients who are malnourished and fatigued, due in part to inadequate nutritional assistance.

**Participants in Rehabilitation:**

**The Business Community**

“*What I found out years later from the person who was my boss at the time is the insurance company came in and said, ‘We’ve spent $100,000 on this guy in the last quarter. If we can’t drop him off the policy, we’re going to drop your whole policy for 100 employees. So guess who left? I spent a year looking for a job after that and finally gave up.’*”

Patient, Irvine, California (IOM ESRD Study focus groups)

“*We want to do what’s right and humane, but when it comes down to it, the bottom line is money.*”

Employer (Interviewed by Friedman & Rogers, 1988)

Preparation, motivation, even education may be sufficient to produce successful vocational rehabilitation, but vocational rehabilitation alone may not be enough to assure that trained, motivated patients will be able to locate jobs. Employment is an important source of self-esteem and identity, as well as a source of income and, usually, health insurance and other benefits. Unfortunately, there are many obstacles in the business community to employing kidney patients, and it is important to explore them here.

The spectrum of employers is so widespread that it is difficult to reach them with education or other interventions that might change their attitudes about hiring the disabled in general, and ESRD patients in particular. Still, it is vital to consider employers as targets for education. Possible avenues of self-employment for motivated dialysis patients should also be assessed.

**ESRD Patients and Employers**

Employers are in business to provide a product or service in exchange for profits. When they employ ESRD patients, as with any other employees, they tend to choose the best candidate for the job. Better educated and more experienced white collar workers are most likely to be employed after a diagnosis of end-stage renal disease (Friedman and Rogers, 1988; Antonoff and Mallinger, 1991).

A study of 283 ESRD patients aged 18-59 by Kutner, Brogan, and Fielding (1991) found age, race, educational level, health status, physical ability to perform job tasks, recent work experience, and interest in working to be related to reported ability to work.

Recent work experience is particularly important, indicating the need for timely intervention to help patients maintain their current employment. Fully half of the 284 patients studied by Friedman and Rogers (1988) had resumed work. The majority did so immediately after renal failure (within 2 months), or never stopped working.
In order to become more employable, ESRD patients (particularly less educated or blue collar workers) may require job retraining, basic job skills and/or job hunting skills (HCFA, 1981)—factors within the purview of vocational rehabilitation agencies.

The jobs may need to be adapted to the patients’ skills as well. Friedman and Rogers (1988) found that two-thirds of the employed patients in their study had work adjustments made for them by employers, such as shortening the work day, allowing more breaks, changing work schedules, and modifying the nature of tasks.

Employers interviewed in this study preferred to rehire a previous employee with renal failure than hire an unknown patient—which may have had an impact on their willingness to make the above mentioned adjustments. Clearly early intervention to help ESRD patients keep their current jobs is essential. The Americans with Disabilities Act requires employers to make reasonable accommodations for disabled employees, such as altered work schedules, more frequent breaks, or a clean, sanitary place to perform a peritoneal dialysis exchange.

**Americans with Disabilities Act**

As the most important law affecting the disabled since the Rehabilitation Act of 1973, the Americans with Disabilities Act (ADA) effective July 26, 1992, symbolizes a mandate for national change in cultural values toward the disabled (Albrecht, 1992).

Simply stated, the ADA attempts to broaden the access of disabled individuals to public transportation, schools, stores, libraries, recreational facilities, and public and private employment. Employers are required by this law to make “reasonable accommodations” to enable disabled individuals to work if they are capable of performing the job tasks.

The types of accommodations required by renal patients would generally extend to flexible scheduling (the ability to leave early on some days to perform hemodialysis, and make up the time on other days, for example), more frequent breaks to compensate for reduced stamina, or a clean, private place to perform sterile peritoneal dialysis exchanges. These types of low-cost accommodations have been found to be very important to the employment success of many dialysis patients (Friedman and Rogers, 1988).

While the spectrum of accommodations required of employers may be determined in the courtroom rather than the boardroom, the ADA has the potential to be a valuable asset to renal patients seeking entry into the workplace.

**Participants in Rehabilitation:**

**The Public Service and Professional Organizations**

There are several public service organizations which have arisen to serve the needs of the ESRD community for education and legislative advocacy to assure the future of the Medicare ESRD program. In recent years, several renal public service organizations
have turned their efforts toward activities relevant to the rehabilitation of ESRD patients, and their efforts can be combined with those of facilities, government, and patients themselves, to create a coherent rehabilitation environment.

One significant recent development on the part of the public service organizations has been a recognition that the definition of rehabilitation in the context of an aging, diverse, and functionally debilitated renal population must embrace more than the notion of “return to work.” Rehabilitation is also acknowledged to encompass restoration of the individual’s self-esteem, revival of life-affirming goals set prior to the onset of renal disease, and renewed enthusiasm for participating in daily family and community activities.

It is clear that the renal public service organizations have begun to exhibit a new level of awareness in dealing with the varied and complex issues associated with attempts to encourage and sustain patient rehabilitation efforts. Educational materials, in particular, have become more relevant, more comprehensive, and more widely distributed than in the past.

The fact that these organizations have become increasingly active suggests that they might be willing (under the right circumstances) to embrace joint efforts to support and carry out the necessary research and participate in the design and implementation of strategies and programs.

The renal public service organizations have moved beyond their previously almost exclusive concern with “advocacy” (preservation of government support for the ESRD program) to focus on issues of rehabilitation—what it means in a practical sense for patients and their families; what attitudinal changes are required among patients and professionals and how they can be brought about; what kinds of research are necessary; what kinds of rehabilitation programs and practices are feasible and how they can be successfully implemented.

**American Association for Kidney Patients**

The American Association for Kidney Patients (AAKP) has assigned a preeminent role among its organization objectives to the analysis of rehabilitation and the improvement of patient understanding of the importance of rehabilitation—whatever their medical condition or life goals—to their continued survival and personal well-being.

Among the initiatives recently launched by the organization is the publication and widespread distribution of a brochure “Americans With Disabilities Act of 1990”; the publication of its magazine, *Renal Life*; and the publication of the AAKP Bulletin, a new quarterly newsletter providing current information on legislative developments in the area of rehabilitation. It includes information on the availability of private/public insurance programs for the disabled, VR projects around the country, employment opportunities, and stories of individual patients in a variety of settings who have successfully adjusted to their circumstances and reconstructed their lives.
AAKP has also sought to address an issue of fundamental underlying importance to the whole question of rehabilitation—the adequacy of dialysis. It is universally recognized that the essential ingredient in any patient’s effort to rebuild his life and pursue his goals is optimum dialysis treatment. Without such treatment and all that it entails—the feeling of well-being, a sense of personal control and the energy to become engaged—all else pales into insignificance.

Consequently, in an effort to educate the patient and professional communities about the need to focus on this vital issue, AAKP has published an “AdvisoryÓ designed to give adequacy of dialysis the broad attention it deserves and to enable patients to work more knowledgeably with their caregivers to achieve an optimum level of treatment.

**American Kidney Fund (AKF)**

Each year the American Kidney Fund presents a topic of current interest to the nephrology community across the country. In 1993, the topic, “An Inter-disciplinary Approach to Managing Depression in ESRD”, was presented in five cities. While the theme was developed at a national level, each region adapts the program for its own community and utilizes local speakers.

The AKF is currently researching the topic of “Overcoming Barriers to Rehabilitation of Renal Patients” for its 1994 conference series. In addition to the conferences, they are planning to publish one or two corresponding newsletters that would include clinical articles, resources and a bibliography related to the 1994 theme.

**American Nephrology Nurses Association**

Information has been requested.

**National Association of Nephrology Technologists**

Information has been requested.

**National Kidney Foundation**

The National Kidney Foundation (NKF) has approached renal rehabilitation on several levels. The organization has produced a number of educational brochures for patients designed to emphasize the availability and value of rehabilitation programs and to combat the debilitating mindset (prevalent among patients as well as professionals) that kidney patients are unable to work or resume their former lifestyles, or play a role in the management of their own treatment and daily lives.

The NKF launched Family Focus magazine, dedicated to providing information and encouragement for patients to regain control of their lives. A large quantity of Family Focus magazines is sent to every dialysis unit in the nation—with the potential result that every dialysis patient in the country may have access to the publication.

The National Kidney Foundation has also produced a series of videotapes called “People Like Us.” These videos, designed to encourage positive attitudes among ESRD patients, depict the lives of positive role models. Each video features an individual on dialysis
who has had a successful rehabilitation outcome and is leading an active, productive life.

At the same time, NKF has instituted, as part of its regular clinical meetings, a program session devoted to the analysis of issues related to rehabilitation, encouraging research and the exploration of alternative approaches to implementing effective programs. The Foundation’s Patient Services Committee has undertaken an extensive investigation and evaluation of the various types of barriers patients face in initiating or carrying on “rehabilitation efforts.”

Finally, a number of NKF state-affiliates have pursued a range of local projects designed to educate patients about rehabilitation, stimulate their participation and improve access to state and local rehabilitation programs. (Please refer to Demonstration Projects and Other Programs in Addendum B).

Renal Physicians Association
Information has been requested.

Participants in Rehabilitation:
The Government

End-stage renal disease is the only single disease category which has its own federal medical support program, backed up by coordinating Networks. In addition to the medical care mandated by the federal government, many ESRD patients receive disability support as well. A number of federal government programs were intended to provide an income floor for the disabled, supporting individuals who cannot work, and providing assistance to help those who can return to the work force. Because of a lack of coordination between these two program levels, support and maintenance of the disabled has been far more adequately addressed than vocational rehabilitation.

Within state vocational rehabilitation agencies and at the federal level, vocational counselors typically are not familiar with the special situations of ESRD patients. This may, in part, account for the dismal vocational rehabilitation (VR) statistics among dialysis patients in most states, and the low numbers of VR referrals. In other states, such as California, counselors may be more familiar with the needs of this population, but choose to be minimally involved.

What stands out in the following brief review of government disability policy is the existence of a commitment to address both income maintenance and other rehabilitative needs of the disabled population, and the simultaneous failure of existing government programs to provide incentives for the disabled to return to productive employment.

Health Care Financing Administration
Medicare ESRD Program

Rehabilitation can be a concern for patients with kidney failure only because since 1972 they have been able to survive their illness without the major burden of the crushing costs
of their own care. Prior to the Medicare ESRD program, the availability of dialysis was limited, and only those patients deemed most worthy received the life-saving therapy. Today, ninety-three percent of ESRD patients are eligible for coverage under the ESRD program, which pays for 80 percent of the allowable charges for outpatient dialysis treatment under Medicare part B. Coverage by the ESRD program is no small benefit. In 1989, it cost the program $29,476 per year to pay 80 percent of the dialysis costs and other covered benefits (such as EPO) for each dialysis patient (Green Book, 1992).

Kidney transplants—a treatment modality highly associated with favorable quality of life—are also paid for by the Medicare ESRD program. However, one year after a successful transplant Medicare ceases payment for the costly immunosuppressive medications necessary to keep the new organ functioning, and three years after a successful transplant, Medicare eligibility ceases entirely for non-disabled patients (Rettig & Levinsky, 1991). This policy leaves transplant patients with annual medication costs of $6,000 - $8,000 per year—a figure high enough to dissuade some patients from attempting a transplant, and which may cause other patients to jeopardize their safety and risk losing the transplanted organ when they cannot afford the medication (Rettig & Levinsky, 1991; Coutts, 1992).

This situation will be partly remedied by the 1993 federal budget. Coverage for immunosuppressant medications will increase from 12 months to 36 months in six month increments from January 1, 1995 to January 1, 1998. However, coverage will still end after 36 months, leaving patients with the same high costs at the end of the three year period. Yet kidney transplantation is less costly to the government than dialysis in the long run. In 1989, it cost the ESRD program $78,506 per successful kidney transplant—but thereafter the cost per year to maintain a kidney transplant patient was only $6,653 (Green Book, 1992).

The Medicare ESRD program is responsible for saving the lives of many patients with renal failure who would not otherwise have had access to dialysis treatment. However, funds allocated to the program have not kept pace with the rising cost of medical care. Although the number of patients enrolled in the Medicare ESRD program continues to rise, the reimbursement rate in real dollars has fallen substantially since the ESRD program began. Dialysis reimbursement rates, adjusted for inflation, were nearly 65 percent lower in 1991 than in 1974 (Green Book, 1992), a factor which has contributed to changes in dialysis facility staffing patterns, an increase in multiple use of dialyzers (instead of single use), and, possibly, increased mortality among United States dialysis patients (Rettig and Levinsky, 1991).

**ESRD Networks**

The portion of the Medicare ESRD program specifically designed to coordinate the provision of care to ESRD patients is a national system of regional oversight organizations called the ESRD Networks.

In 1972, Congress enacted the Medicare ESRD program. At that time, the broad array of professionals and facilities required to treat persons with irreversible kidney failure
indicated the need for coordination of care. On June 3, 1976 the Secretary of Health, Education, and Welfare published final regulations that included provisions for implementing ESRD Networks.

Initially, the Networks served as resources to ESRD facilities and patients to help assure access to ESRD care; assisted states with the development of their statewide health plans for kidney disease; served as technical advisors to the states’ Certificate of Need Program staff; and collected and validated data on the incidence, prevalence, and treatment of end-stage renal disease.

On April 7, 1986, Congress enacted the Consolidated Omnibus Budget Reconciliation Act (COBRA) which included provisions that mandate the ESRD Networks to:

- Encourage the use of treatment settings most compatible with successful rehabilitation and encourage the participation of patients, providers and facilities in vocational rehabilitation programs
- Develop criteria and standards relating to the quality and appropriateness of patient care
- Submit an annual report to the Secretary including a full statement of the Network’s goal and data on the Network’s performance in meeting its goal

In implementing the legislation, the Health Care Financing Administration adopted the policy of allowing each Network to define and develop its own strategies. Networks have pursued a variety of activities ranging from special studies and surveys, to development of educational materials for patients and VR counselors, to pilot projects involving employer groups.

While it appears that there are some innovative and effective VR programs being conducted by the ESRD Networks, there is currently little uniformity among the Networks in carrying out the statutory mandate to “encourage” facilities and others to participate in patient vocational rehabilitation efforts. Part of the problem is, undoubtedly, the difficulty involved in determining what kinds of Network activities would produce the desired encouragement, and how such activities could be documented and evaluated. The ideal is to institute measurable rehabilitation approaches with concrete beneficial effects that could be implemented with the full commitment of the participants, but without imposing undue burdens.

Social Security Administration
Disability Programs

“One renal patient, always a renal patient—you never get cured. I worked seven years straight this last time, then developed amyloidosis. SSA said, ‘you’ve been working over five years, you’ve proved you could overcome your disability.’ I had to document a new disability. Patients are forced to fight with the system at the very point when they are least able to, when they are distraught.”

Bruce Lublin, Patient
It is the federal disability system, particularly the Social Security Disability Insurance program, that makes it difficult for many patients to return to work. The conflict between a program designed to help the permanently and totally disabled, and a population of disabled individuals who are increasingly able to be helped to lead more normal lives has not been settled.

Compared to the limited work incentive provisions of SSDI, SSI heralds an era of more comprehensive programs to help the disabled survive while also encouraging them to seek paid employment when possible.

**Social Security Disability Insurance (SSDI)**

Beginning in 1956, the Social Security Administration has provided cash benefits based on previous income to disabled individuals under age 64 who are eligible for Social Security (Green Book, 1992). To be declared disabled, an individual must be unable to perform “Substantial Gainful Activity (SGA),” defined as work that pays more than a predetermined amount monthly. Since 1990, that amount has been $500 per month, or $880 per month for the blind. (Green Book, 1993). The disability must be medically determined and expected to last for 12 months or more or to result in death.

End-stage renal disease is a “listed” impairment, meaning that for ESRD patients who meet the criteria, the process of being declared disabled is streamlined. As of 1991, there were 4.5 million SSDI beneficiaries receiving a total of $2.2 billion annually (Green Book, 1992). Many disabled ESRD patients receive benefits under SSDI, and thus are affected by the SSDI work incentives.

While SSDI was designed for patients who would never work again, the lines of disability have become blurred in this era of rapidly advancing medical, pharmaceutical, prosthetic, and assistive technology. Recognizing that many impairments are no longer permanent, the Social Security Administration created work incentives in an effort to encourage patients to return to the work force. With vocational rehabilitation services to improve job skills, beneficiaries are entitled to a nine-month trial work period during any five-year period of disability. The nine months do not have to be consecutive. During the trial work months, patients are allowed to earn as much as they can without losing their benefit check. Any month in which over $200 is earned counts as a trial work month.

If an evaluation after the nine trial work months shows an ability to earn at the $500 level (substantial gainful activity), cash benefits cease after three more checks. During the three years after the trial work period, the individual can still receive a check for any month where earnings are below $500.

The Social Security Act requires that individuals applying for Disability Determination be “promptly referred to State vocational rehabilitation agencies for necessary rehabilitation services” (Green Book, 1992). Unfortunately, vocational rehabilitation services for ESRD patients who receive SSDI are problematic. Dialysis patients may be erroneously considered “too disabled” and transplant patients “not disabled enough” to receive VR services.
Prompt referrals to VR agencies have not always occurred for renal patients, perhaps due, in part, to a provision of PL 97-35, which eliminated payment from the Social Security Trust Fund to State VR agencies unless the services resulted in the client’s earning income at the SGA amount for a continuous period of nine months (Green Book, 1992).

**Supplemental Security Income (SSI)**

Supplemental Security Income, or SSI, is an income replacement program for low-income disabled persons. Recipients must meet the same disability criteria as for Social Security Disability, but may or may not qualify for SSDI. Up to a third of the disabled receive benefits from both programs. To receive SSI, recipients must have countable financial resources of less than $2,000; or less than $3,000 for married couples. While this sounds quite stringent, assets such as a home (of any value), household goods, personal effects, automobile, and burial plots are not counted (Green Book, 1992). SSI served 5.1 million recipients in 1991, at a cost of $18.5 billion (Green Book, 1992).

SSI used to offer the same package of work incentives used by SSDI. However, recognizing that loss of the cash benefit upon earning $500 per month was a substantial disincentive to working, in 1980, section 1619 was instituted, creating a comprehensive package of work incentives for SSI.

Section 1619 allows cash benefits to be reduced on a sliding scale as earned income increases. The first $85 earned per month and half of any additional earnings is not counted when calculating the sliding scale benefit. Thus, in one of the nine states with no supplementation, a recipient can earn up to $953 per month in 1993 before losing the cash benefit completely—nearly double the substantial gainful activity amount. Recipients in states that supplement SSI can earn even more. Income-related work expenses can also be excluded from income.

In 31 states (accounting for 79 percent of the program enrollment) SSI beneficiaries are automatically entitled to Medicaid (Green Book, 1992). This provision can be quite an advantage for ESRD patients, because Medicaid pays for the 20 percent of treatment costs not covered by the Medicare ESRD program. Under 1619 (b), individuals can continue to be eligible for Medicaid even if their earnings lead to loss of the cash benefit—as long as they continue to be disabled and to meet other requirements for SSI eligibility, require the Medicaid coverage to be able to work, and don’t earn enough to purchase the coverage. States limit the amount of money that can be earned while retaining Medicaid coverage (Green Book, 1992).

SSI recipients can also “set aside” earned income toward a predetermined vocational goal as part of a PASS (Plan to Achieve Self Support). PASS funds can be used for tuition, tools, an automobile to drive to work, or for other work-related goals. The SSI benefit amount is increased to cover the amount set aside in the PASS.

If these more comprehensive and humane SSI provisions were made available to ESRD patients, who are predominantly SSDI beneficiaries, they could enhance the likelihood that more individuals with ESRD would be able to return to productive employment.
Rehabilitation Services Administration (RSA)

Although the major thrust of U.S. disability policy centers on income support to disabled workers through SSDI and SSI, there is also a long history of government involvement in rehabilitative programs. These programs, administered by the Rehabilitation Services Administration, are designed to increase the productive activity and earning capacity of the disabled, and to alter the economic environment in which they function.

RSA is a federal agency charged with providing oversight of rehabilitative services for the mentally and physically disabled. The RSA oversees each state’s vocational rehabilitation agencies, or, in certain cases, private contractors of vocational services. At the federal level, the Rehabilitation Services Administration provides funding, assistance with program development and implementation, ongoing monitoring, and regulation of State VR agencies—subject to agency interpretation. State VR agencies are responsible for determining eligibility for services, and providing the services needed. The actual array of services offered to clients varies from state to state.

While expenditures on direct services to disabled workers through the RSA represent a small fraction of total disability expenditures in the United States, this by no means reflects the extent of the public sector commitment to the goal of rehabilitation and employment. From its inception in 1920, the Rehabilitation Services Administration, established by the Vocational Rehabilitation Act, has undergone numerous changes. Over the years the RSA has expanded from a provider of strictly vocationally-related services for clients likely to find employment in the labor force, to a program offering multiple vocational and counseling services to individuals who are disabled—and from individual state plans with little federal oversight to an integrated system under federal regulation. Currently three separate RSA programs must be addressed by agencies in each state:

- Vocational rehabilitation, which assists eligible persons with disabilities to find and maintain employment
- Supported employment, which helps persons with severe disabilities who require ongoing services
- Independent living, which helps people with severe disabilities live in the community

Once determined eligible for one of the programs, individuals referred for services work with a counselor to develop a plan, called an individualized written rehabilitation program (IWRP). Under the plan, services available may include:

- Medical, psychological, and other assessments to determine functional strengths and weaknesses
- Referral to other necessary services
- Restoration services to correct or improve a physical or mental condition
- Vocational and other training, which may include work site training or education; and placement services
- Rehabilitation technology services
- Post-employment services necessary to maintain a job or find another position
Also included in RSA services are “equal access” programs which combine “affirmative action” with mandated changes in the work environment to increase jobs for disabled workers.

According to the Social Security Act, any patient applying for disability status must be promptly referred to a State VR agency to receive services; patients who refuse the referral can be denied Social Security Disability Insurance or SSI benefits. However, for several reasons, VR services have not traditionally been extended to large numbers of ESRD patients.

After 1973, dialysis treatment became available to a wider group of patients, some of whom were less amenable to vocational rehabilitation interventions than previous patients who were selected for treatment on the basis of continued employability. Potential clients at State VR agencies must have a disability which creates a barrier to employment—as well as a reasonable expectation that VR services will enhance their employment potential. VR counselors unfamiliar with ESRD patients may underestimate this potential. This perception, combined with provisions of PL 97-35 which eliminated federal payment for a client’s services unless the client earns at the SGA level for nine consecutive months, and a caseload of 200 to 300 clients, may make the ESRD population appear unappealing from a VR perspective.

It is likely that a lack of coordination of services between the Medicare ESRD program, the Social Security Administration, and the Rehabilitation Services Administration has also contributed to the lack of VR services available to the ESRD population. Fortunately, there are beginning signs of change. In the past year, meetings have been held by these three federal agencies to examine coordinated efforts to increase the rehabilitation of this disability population.

### IV. Barriers to Renal Rehabilitation

As enumerated by experts in the field for the past two decades or more, there are a number of factors that act as barriers to renal rehabilitation at all levels, and particularly to vocational rehabilitation. Several of these barriers include inadequate dialysis, underestimation of the rehabilitation potential of ESRD patients, limited opportunities to dialyze during traditional non-work hours, employer reluctance to hire ESRD patients, inadequate vocational rehabilitation interventions, patient physical limitations, and dependence or lack of incentive created by federal disability programs.

Each barrier is a formidable challenge to the possibility of vocational rehabilitation: a weak link in the return-to-work chain. Viewed together, these barriers form a convoluted web of obstacles. If one barrier does not prevent a patient from seeking or obtaining work, the next one very well might. This dysfunctional system drains hope and energy from ESRD patients, and minimizes the chance of success.

**Barriers in Patient and Professional Attitudes**

**Underestimating the Rehabilitation Potential of Dialysis Patients**
“In 1991 we invited dialysis patients to participate in the California Transplant Olympics. The first two places in the mile were won by dialysis patients. This demonstrated to me that patients are able to do more—perhaps our expectations for dialysis patients are very low.”
Patricia Painter, PhD, Renal Exercise Physiologist

Patients present with a set of backgrounds that predict how they will respond to renal failure and its treatment. Many patients do not believe in the possibility of a full, rich life on dialysis, nor do many dialysis facility staff members (HCFA, 1981). In the face of a chronic disease that is fatal without treatment, (unfortunately named end-stage renal disease by legislation) and without positive role models to show what can realistically be accomplished, patients may succumb to apathy, hopelessness, and an inappropriate level of “dis-ability.”

Patient dependence on staff is fostered in many facilities according to a medical model of disease. According to this model, knowledgeable health care professionals care for passive, subordinate patients (Albrecht, 1992). This dependence engenders apathy and makes it difficult for patients to pursue independent, goal-oriented behavior such as job-seeking (Antonoff & Mallinger, 1991). Before patients and staff can believe in the rehabilitative potential of dialysis patients, it may be necessary to replace this traditional model with one appropriate for a chronic disease like ESRD; such as those used by rheumatologists, cardiologists, and physical and occupational therapists.

There are a number of ways in which underestimation of patient potential could be significantly minimized. For example, there is widespread agreement that providing patients with a clearer and more hopeful understanding of what life will be like with dialysis before the patient begins dialysis would be immensely helpful. Similarly, considerable progress might be made in generating patient interest in rehabilitation if the education of renal professionals included attention to the rehabilitative aspects of patient care, and the benefits to be derived by staff support of rehabilitation.

Friedman and Rogers (1988) have reported that physician assessments of patient functioning were considerably more negative than the patients’ own assessments. Further research is needed to determine whether negative physician or staff attitudes about the rehabilitation potential of this population do, in fact, have a negative impact on patients’ own attitudes, or on their desire to work. One would expect such negative professional staff attitudes toward patient rehabilitation diminishes the effort dialysis physicians and staff may provide toward patient rehabilitation. Perhaps a requirement that physicians document reasons why patients are not back to their usual and customary activities would help encourage a higher estimation of rehabilitation among renal professionals.

Patients must learn to be active partners in their own medical care as well. They must take some responsibility for overseeing each dialysis procedure as well as their overall care. Such partnerships could help patients to be viewed by themselves and by dialysis professionals in a more positive light: a light which could also illuminate their rehabilitation potential.
Barriers at the Facility Level
Inadequate Dialysis

“Given the absence of a well-defined and accepted medical definition of adequate dialysis, let me suggest it include, in addition to acceptable blood chemistries, a stable and well-functioning mind and body during and between treatments.”
John Newmann, PhD, Economist and Patient

Adequate—and preferably optimal—dialysis is a fundamental element of renal rehabilitation. Any efforts at rehabilitation must be predicated on dialysis therapy that allows patients to function at their peak of well-being. However, despite the fact that long-term dialysis was first performed in 1960, there are still aspects of the physiology of renal disease that are not fully understood by the medical profession. “Adequacy” of dialysis has been determined by trial and error over the years, with attempts to measure adequacy becoming increasingly sophisticated in recent years.

There are several additional factors affecting the delivery of adequate dialysis to patients in this nation. The relatively higher rates of mortality among U.S. dialysis patients (compared to patients in Japan and Europe) may be due to differences in dollars spent for each dialysis treatment between countries, differences in patients accepted for dialysis, completeness of the patient registry information, patient compliance, and/or differences in the adequacy of treatment (Rettig and Levinsky, 1991).

The 1991 Institute of Medicine study of the Medicare ESRD Program suggested that the 65 percent decrease in real dollars spent for dialysis between 1974 and 1991 has indirectly affected dialysis adequacy by changing staffing patterns in the dialysis facility. Lower reimbursement rates have directly affected the ratios of staff to patients in dialysis units, the ratios of licensed nursing staff to unlicensed patient care staff, and have resulted in shorter (and potentially less than adequate) treatment times for patients (Rettig and Levinsky, 1991). Patient preference for shorter treatments may have also contributed to the reduction in treatment time; clearly a certain level of patient education is required simply to help patients understand the need for adequate dialysis therapy.

Fiscal concerns of dialysis facilities may play a role in reducing the adequacy of dialysis treatment offered to American dialysis patients. Diamond (1989) points out that it has not always been in the best financial interests of the dialysis facility owner to try to assure quality. According to a study of 527 dialysis patients by Jones (1992), the reason may be that improved care costs more. In the Jones study, 287 patients dialyzed at hospital-based units (which are reimbursed at a higher rate) were more likely to receive individualized dialysis prescriptions, special dialysate solutions and dialyzers, and individual dialysate delivery—factors that may result in more individualized and effective therapy—than 240 patients at freestanding, often for-profit, dialysis centers. According to Lundin (1989), the dialysis facility represents the business place for “the forefront of profit-making medicine in this country.”

The Jones findings were corroborated by the work of Delmez and Windus (1992). In
their study of 617 dialysis patients representing 75 percent of the dialysis population of the metropolitan St. Louis area, they found that nearly half of patients failed to attain what the study considered to be a minimum level of dialysis adequacy (Kt/V > 1.0). Patients who dialyzed in non-profit facilities had a significantly higher level of dialysis adequacy than patients in for-profit units. More than half of the low-adequacy patients had not been prescribed an adequate amount of dialysis by their nephrologists. The remainder did not receive the full amount of dialysis that had been prescribed.

Patients who do not receive adequate dialysis may be more likely to be hospitalized (Rettig and Levinsky, 1991), and less likely to hold paid employment. Research is needed to determine whether this intuitive connection is, in fact, the case. Held and colleagues (1990) have shown a powerful statistical association between time spent on conventional dialysis and the relative risk of death: The longer one dialyzes, with a required minimum of 3 1/2 hours of delivered dialysis, the lower the relative risk of death, and vice versa. Adequate or better dialysis is essential to the willingness and ability of patients to successfully sustain a rehabilitation effort.

Given the detrimental effects of uremia caused by insufficient dialysis: weakness, lethargy, weight loss, loss of appetite, poor nutrition, compromised mental state, we cannot expect patients to commit themselves to serious rehabilitation efforts if they live with these symptoms as a result of being underdialyzed. It is essential for any renal rehabilitation program to include a serious effort to assure delivered, adequate dialysis.

The issue of adequacy of dialysis is a major topic of concern and discussion within the renal community. The National Institutes of Health held a consensus conference regarding mortality and morbidity of dialysis during the first three days of November of 1993. Beginning in January of 1994, a seven-year NIH Dialysis Morbidity and Mortality study of 900 patients will ensue.

**Barriers at the Facility Level**

**Limited Evening Dialysis**

“In the early days, the nurses had to work eight hours anyway and dialysis was 4-5 hours, so if you wanted to dialyze later they were a little flexible. As the patient population increased, flexibility decreased. Dialysis units are set up for the convenience of staff—not patients.”

Bruce Lublin, Patient

“If you want to be trained to go home [home hemodialysis], they tell you they have a shortage of nurses and only one nurse handles it, and that nurse has been out for three months and you have to wait until that nurse comes back.”

Patient, Washington, D.C. (IOM ESRD Study focus groups)

If patients could dialyze in the evenings and then go to sleep, the disruptive effects of hemodialysis on physiology and lifestyle could be minimized (Lublin, 1993A). Without the ability to dialyze during non-work hours, either with peritoneal dialysis, home
hemodialysis, or an evening shift in the dialysis facility; the ability of patients to work full-time is severely restricted (HCFA, 1981; Feinsmith, 1989). The ability to care for children, perform volunteer duties, pursue social activities, or attend school may also be compromised. Research data are needed to quantify the effects of dialysis scheduling.

Unfortunately, the present composite reimbursement rate does not typically provide facilities with financial incentives to offset the cost of evening shift differentials (Witten, 1993). An informal telephone survey of dialysis facilities located in Networks 6 and 11 and several other facilities revealed beliefs that staffing overlaps required by an evening dialysis shift are inefficient, per-patient costs may be higher due to lower utilization, staff recruitment and retention for an evening shift can be difficult, and transportation may be problematic, as many areas reduce evening transportation service (Lublin, 1993B). Security problems in some areas may increase cost by necessitating extra personnel or “hazard” pay for an evening shift. The survey also revealed that even when an “evening” shift is offered it typically runs from 3:00 p.m. to 7:00 p.m., which still requires that the patient have flexibility in work scheduling or cut the dialysis treatment short—which can adversely affect health (Lublin, 1993B).

Fewer staff people may be needed to serve a shift of experienced and knowledgeable self-care dialysis patients. These patients can actually perform some of their own dialysis care, either in or outside of the dialysis facility. They may weigh themselves, take their own blood pressure, insert their own needles, and monitor the treatment. According to Dr. Peter Lundin (1989), knowledgeable patients who ask questions and take responsibility for their own care may actually reduce the burden on staff, while at the same time enhancing behavior and attitudes that are correlated with extended patient survival.

Other options for dialyzing during non-work hours include home dialysis. Both hemodialysis and peritoneal dialysis can be done at home, allowing the patient the flexibility to integrate the dialysis treatment into his or her other routine life activities—such as employment. Many patients who attempt CAPD (continuous ambulatory peritoneal dialysis) leave the modality due to infection or unhappiness with the changes in body image caused by the permanent abdominal catheter. Home hemodialysis requires several weeks of startup training and ongoing telephone backup, and has the side benefit of encouraging patients who are knowledgeable about their disease and its treatment to make more choices in diet and lifestyle that will enhance their health (cf. Oberley et al, September, 1992, October, 1992). Staff assisted home dialysis may also be an option for some patients. Unfortunately, home hemodialysis in any form was offered by only 1.9 percent of facilities in 1990, down from a peak of almost seven percent in 1985 (USRDS 1993).

In general, patients who take an active role in their treatments by hemodialyzing at home, performing peritoneal dialysis exchanges, or performing self-care dialysis in the facility may be less dependent and better able to work (Kutner & Brogan, 1985; Antonoff & Mallinger, 1991).
Meanwhile, until dialysis is made more available during non-work hours, it would be sensible to use some of the captive patient hours profitably by offering educational coursework in the facility. Vocational rehabilitation counselors, literacy training, physical fitness, and other interventions could be an attractive alternative to repetitive television viewing. Improving patient skills and quality of life are worthwhile endeavors that can occur anywhere—including in the facilities themselves.

**Barriers in the Business Community**

**Employer Discrimination**

“Not one employer that we spoke with actually conducted any sort of comparison of absenteeism among the chronically ill and the regular employee population. Still, they believe that dialysands lose time because of their illness, and this, in turn, creates a barrier to employment.”

Friedman and Rogers, 1988

Patients who have reported difficulty locating employment after a diagnosis of ESRD are by no means imagining their situation. A study by Ferrans and Powers (1985) of employed and unemployed dialysis patients found that five percent of the employed group had been prevented from advancing in their current jobs due to their renal failure, while 25 percent of the unemployed group had been turned down for jobs and another 10 percent had been fired or forced to resign. Thirty-five percent of the unemployed group reported a complete loss of life goals.

There is a persistent belief among employers that ESRD patients are poor producers with high absenteeism, requiring costly accommodations (Witten, 1993B). However, there is no evidence that ESRD patients are any more likely to be absent than any other group of workers (Friedman and Rogers, 1988). The cost of employer-paid health insurance—which may rise substantially due to the rating given when an ESRD patient is a group member—is an additional concern for employers.

Research needs to be conducted regarding the on-the-job characteristics of employed ESRD patients, and employers who are likely to consider employing ESRD patients should be identified and educated about how ESRD affects the ability to hold and perform a job, including the types of accommodations that would be required under the Americans with Disabilities Act. Employers will also require education about how to obtain assistance in providing accommodations such as maintaining a sanitary location for peritoneal dialysis exchanges.

**Barriers in the Business Community**

**Employer Insurance as Primary Payor**

Contributing to employer reluctance to hire or retain ESRD patients is a change in federal policy extending the period private that insurers must pay for ESRD treatment. Since 1981, employer group health insurance has been required to be the primary payor (paying
80 percent of treatment costs) for the first 12 months of ESRD treatment. OBRA 1990 extended this period to 18 months. For dialysis patients, this 18-month obligation for an employer’s health insurance, costing upwards of $44,218 per patient annually, can and has been enough to result in dismissal from employment (GAO, December, 1992).

It is claimed that this policy change saved the federal government approximately $56 million annually. However, renal patients and their spouses bear the brunt of this “savings,” when they find it more difficult to find and hold private sector jobs, according to an independent analysis of a 1992 GAO study surveying 1,306 ESRD-only patients and 1,443 disabled non-ESRD controls (Witten, 1993A). Two thirds of the kidney transplant recipients and one third of the dialysis patients were covered by employer health insurance; either their own (34 percent) or that of a spouse, a parent, or as a retirement benefit. (GAO, December, 1992). Of the 21 percent of ESRD-only patients who were employed with health insurance, nine percent were fired or forced to resign. An additional 10 percent faced insurance cancellation, encouragement or pay-off by the employer to drop coverage, or a change in insurance policies to exclude them (GAO, December, 1992).

The primary payor requirement appears to have an impact on the spouses of ESRD patients as well. Nearly three times as many spouses of ESRD-only patients had to seek new employment compared to spouses of patients with primary coverage. (GAO, 1992).

Fortunately, the federal budget passed by Congress and signed by President Clinton in August, 1993 did not extend private payor obligation to 24 months as was proposed by Senate members. In what appears to be a compromise, however, the 18-month private payor provision (which was due to expire soon) has been extended to 1998 by OBRA 1993.

Other parts of the new budget included the following that may affect renal patients:

- Coverage for immunosuppressants for transplant patients, now 12 months, will increase over a five-year period to 36 months in 1998. This was coupled with a $1 per 1000 unit dose reduction in EPO reimbursement that starts January 1, 1994.
- Payments to dialysis centers for antibiotics for patients with peritonitis, currently covered separately as a non-routine cost, will be folded into the composite rate, which remained as it currently stands. This change could have implications for rehabilitation by requiring hospitalization more often than home treatment for this infection, in order to assure coverage. Repeated hospitalization might affect the patient’s employment status.

**Barriers in Government Programs**

**Inadequate Vocational Rehabilitation Referrals and Outcomes**

“As it is, patients must be pioneers, finding information in the wilderness.”

Patient, Irvine, CA (IOM ESRD Study focus groups)
“Although employment is only one dimension of rehabilitation, it does have important implications for the individual’s self-esteem.”
Nancy Kutner, PhD, Rehabilitation Researcher

There is currently no allowance in the dialysis composite rate to pay for rehabilitation services, and ESRD patients’ rate of participation in the work force has been generally low. Most studies report that approximately 20 percent of working-age ESRD patients are employed (cf. Richardson, 1987; Evans et al., 1981). However, Kutner, Brogan and Fielding (1991) found only 11 percent of their study population to be employed—although 33 percent of the non-employed patients would be able to work, according to self and physician evaluations. These results emphasize the obvious potential for vocational rehabilitation that exists among unemployed ESRD patients.

Another factor in work force participation is the selection of younger, healthier patients for kidney transplant, which leaves a perhaps less work-ready dialysis population behind. In a study of 498 patients, Porter et al (1985) reported that, while up to 80 percent of the urban patients begin their dialytic career on in-center hemodialysis (60 percent of rural patients did so), younger patients were more frequently given transplants.

Nationally, Rehabilitation Services Administration (RSA) data show that ESRD patients have a low rate of referral, and poor rehabilitation outcomes; in fact the lowest success rates of any group of disabled individuals (Witten, 1993). This is a complex problem with many causes, including patient and professional indifference, overburdened State VR agencies, and federal government—HCFA and the Social Security Administration—failure to insist on compliance with the referral provisions of current law. Lack of education about ESRD on the part of vocational counselors is an additional factor.

A survey sent to the directors of state vocational rehabilitation agencies in all 50 states revealed the lack of direct services and specific training for VR counselors in the essentials of helping ESRD patients to reenter the work force (Kruse, 1993). Although the State VR agencies will consider all referrals for VR services, of the 33 responses received:

- 29 states offered no services specifically targeted at ESRD patients
- 17 states reported that no training was offered in the special needs of this population
- 25 or more states had no ongoing working relationship with public service organizations that support ESRD patients
- 13 states could provide no figures for the number of ESRD patients served in the previous calendar year.

Informed and enhanced cooperation on the part of local and national rehabilitation agencies is necessary to assist patients who require retraining, work accommodations, supported employment, independent living services, or job placement to succeed in employment options.
Barriers in Government Programs
Dependency On Federal Disability

“If only I could make at least two-thirds of what I’ll be receiving from Social Security and disability insurance, I would like to work.”
Patient, Washington, D.C. (IOM ESRD Study focus groups)

“I mean, if I make $100, let them take $50 away from me so that I can come out with $50 more than I had. But instead, they want to take away $125 if I make $100, which just makes it ridiculous. They don’t give you any incentive to go out and try to become a working part of society.”
Patient, Irvine, CA (IOM ESRD Study focus groups)

Many patients can continue working while on dialysis. When this is not possible, patients may qualify for Social Security Disability Insurance (SSDI) and possibly Supplemental Security Income (SSI).

SSDI work incentives were designed as an income floor to enable people with disabilities to test their ability to do substantial work. However, these provisions have had a paradoxical effect. Fear of the loss of disability benefits is a concern that prevents some patients from seeking employment (Kutner and Brogan, 1985; Oberley, May, 1991).

It may be difficult for many patients to earn (particularly with part-time work) as much money as they receive in SSDI benefits. On average, workers who earned at 150 percent of the national average wage would have received $995 per month in non-taxable SSDI benefits in 1991. Workers who had earned the federal minimum wage would have received $505.50 per month. Beneficiaries who earned at the national average wage would have received $779 per month, and would be subject to termination of SSDI cash payments because they can work consistently at above the substantial gainful activity level of $500 per month (Green Book, 1992).

An individual who works full time at the 1993 federal minimum wage ($4.25 per hour) and has no deductions would earn between $557.67 and $627.07 (depending on whether state income tax is owed)—before paying for work-related expenses such as travel, work clothes, tools, licenses, or convenience foods. More to the point, many ESRD patients have advances skills that will enable them to earn above the minimum wage, but the number of hours on dialysis and periodic physical fluctuations in their health may only allow them to work part time. This skilled group may still earn above the $500 limit, but many of them severely restrict their earnings because it would be uneconomical to risk their secure SSDI benefits for wages only slightly above the benefit level.

It is clearly unrealistic to expect beneficiaries to work and pay taxes in order to live on scarcely more money than their SSDI check would bring. The SGA amount serves as one of the most powerful disincentives for some ESRD patients to return to employment once they have succeeded in having themselves determined to be “permanently and completely disabled.”
V. Bridges to Renal Rehabilitation: Toward an Integrated Program

“It is the essence of the rehabilitation process that all its parts be integrated...it is the integration of all the parts into a system that has been most notably neglected.”
Samuel B. Chyatte, MD, Physician and Patient

The Life Options Advisory Council has identified several core objectives or “bridges” which it believes to be essential to rehabilitation of ESRD patients. These interrelated core objectives address the barriers outlined in the last section and include five fundamental principles presented for simplicity as the “Five E’s.” These include Encouragement (patient and staff commitment), Education, Employment, Exercise, and Evaluation. These core principles constitute a national agenda for enhancing renal rehabilitation, and can be implemented by all the participants in renal rehabilitation as identified in Chapter III.

Integration of resources by the various participants—from patients, staff, employers, public service organizations, and government—is essential for the development of an organized program of rehabilitation for renal patients or any other group. Coordination of services avoids duplication and maximizes personnel time and dollars available for rehabilitative ventures. The Life Options program goal and core objectives follow.

Renal rehabilitation goal:

Provide patients the resources and opportunities to participate in desired and beneficial life activities.

Bridges to Rehabilitation: Encouragement

“Medical staff tend to present dialysis as a horrific burden that has to be ‘accepted,’ since, ‘there is nothing you can do about it.’ ...Encourage patients, don’t discourage them. Offer them hope, not despair. Expect them to do well, enjoy life, and be happy, and they probably will.”
Frank Brown, Patient, from NKF Family Focus

Patient Commitment

Rehabilitation cannot be “done to” the patient. Active patient participation in rehabilitation is key to the success of any rehabilitation venture. Increased emphasis on patient responsibility for undertaking and carrying through on an individual rehabilitation program is the missing ingredient in most discussions of rehabilitation. Participation in rehabilitation programs must be understood by patients as critical to their well-being, ongoing treatment, and attainment of a successful adjustment to their condition. The patient’s responsibility to participate in this area is no less essential and compelling than his compliance with any other aspect of his physician’s prescription and the management of his care.
Conveying (by professionals) and understanding (by patients) this sense of the vital nature of rehabilitation in its broadest meaning is what has generally been lacking—neither patients nor professionals have focused on this element of care. To overcome this deficiency several things must take place, such as: the explicit inclusion of rehabilitation in the physician’s prescription; the presentation of the responsibility to participate in rehabilitation programs to patients and their families during meetings with staff; the inclusion of this responsibility in patient educational materials, exposure to other patients who have successfully engaged in rehabilitation; and the establishment of facility patient support groups focusing on rehabilitation activities.

An important starting place for patient commitment is involvement in the dialysis treatment. There is perhaps no other single intervention that could do more to provide patients on dialysis with a sense of control over their own lives and the power of advocacy for their own medical care than encouraging self-care forms of dialysis (Kutner, 1993). Participating in their own treatment can help patients maintain a sense of control over their own lives—while a diminished sense of personal control is associated with reduced participation in the work force (Antonoff and Mallinger, 1991).

Encouraging patients to be as responsible as possible for their treatment may also help reduce the burden on facility staff, diminish the probability of medication errors (if knowledgeable patients check the accuracy of the dosage given to them), and encourage compliance with fluid and dietary restrictions necessary for successful treatment. Active patient involvement in dialysis treatment may also allow better nurse-to-technician staffing ratios and more time for individualized patient care. Whether through educational intervention or self-care, the importance of rehabilitation as part of the treatment and recovery process must be conveyed as forcefully as possible so that patients routinely come to recognize it as a personal commitment and benefit to themselves.

**Staff Commitment**

Who can predict how much difference it would make to patients to have rehabilitation approached by dialysis facility staff not as an improbable mountain to climb, but as a series of smaller, achievable steps? The importance of a positive staff attitude is indisputable. In order to help patients in a constructive way toward rehabilitation, staff members could help patients to identify activities they enjoyed and valued prior to renal disease which could be resumed. “To do this, all medical staff must reflect and exude a respectable and powerful bias toward rehabilitation” (Newmann, 1982).

It is not sufficient merely to provide information about rehabilitation to patients. Rather, the essential role of rehabilitation in the treatment and recovery process—both physical and emotional, as well as economic in many cases—must be continuously conveyed to patients and their families.

For rehabilitation to be possible for renal patients, facility staff must believe it to be so, in order that patients can, in time, believe it themselves. In particular, teaching patients about the consequences of renal failure and encouraging self-care options can enhance
their self-esteem and independence (Oberley, April, 1991). A philosophical commitment to making the most of the bridges to rehabilitation while working to diminish the barriers could go a long way toward motivating patients.

The realm of psychosocial rehabilitation encompasses an array of issues, problems and solutions. Individuals with ESRD must adapt to the new lifestyle of dialysis, modify finances and insurance, cope with family stress, develop new work and leisure patterns around the dialysis schedule, and examine life anew in light of chronic illness.

At the initiation of dialysis or transplantation, the patient “is at a crossroads” (Oberley, April, 1991). During this critical period, dialysis social workers facilitate adjustment to the personal issues of ESRD by counseling, coordinating services and benefits, initiating peer support groups, and educating patients about rehabilitation resources. But access to social work staff, who each typically have more than 100 patients to serve (Rettig and Levinsky, 1991), is often limited. Adequate staffing of dialysis units by qualified social workers is imperative.

The entire medical team plays a critical role in supporting, advising, and measuring patients’ rehabilitative efforts. Not merely important, this team approach is “vital,” according to George Porter, MD, nephrologist. In a unified approach, the team must reinforce, as well as measure, outcomes to rehabilitation interventions.

Advisory Council Recommendations

Encourage patient and staff commitment. (Suggested participants are in italics. A list of renal organizations can be found in Addendum J.)

1. Use a primary/team care approach in the dialysis facility to enhance rehabilitation goals and outcomes. Facility staff
   - Train staff and patients on the teamwork approach.
   - Renal organizations, facility staff, publications in the renal field
   - Add patient rehabilitation goals to the short- and long-term care plans and include:
     - Definition of rehabilitation
     - Potential for rehabilitation
     - Principles of rehabilitation
     - Counseling and psychosocial support
     - Resource availability
     - Patient well-being/quality of life
     - Cost benefit analysis of patient rehabilitation

2. Encourage patients to learn about all aspects of dialysis. Facility staff, renal organizations, Advisory Council, Networks
Provide patients with wide range of educational materials, particularly during the critically formative first 90 days of dialysis. Introduce patients to the following concepts:

- Optimal dialysis
- Self-care
- Modality choice
- Functional and vocational rehabilitation
- Physical fitness.
- Methods of dealing with Medicare and insurance

3. **Foster patient and staff commitment to rehabilitation.** Renal organizations, publications
   - Offer professional incentives for promoting and supporting rehabilitation.
   - Establish annual rehabilitation awards for renal professionals
   - Promote rehabilitation concepts in professional publications
   - Add a rehabilitation component to professional certification exams
   - Use case histories and role models with both patients and staff to demonstrate the potential for rehabilitation. Facility staff, renal organizations, Advisory Council
   - Support establishment of peer counseling and support groups. Facility staff, patients, renal organizations
   - Encourage patients and staff to join voluntary service groups (local community organizations, national renal organizations).

4. **Encourage working patients to retain employment.**
   - Foster the concept that continuing or returning to work is possible and preferable. Facility staff, renal organizations, Networks
   - Allow flexible dialysis scheduling to maximize employment possibilities. Facility staff, VR counselors, renal organizations
   - Establish early contacts with state VR agencies where necessary for supported employment and job retraining.

5. **Encourage exercise and fitness among renal patients.** Facility staff
   - Provide educational literature about exercise and guidance about community resources that can enhance fitness. Facility staff, renal organizations, Advisory Council
   - Create supportive atmosphere within the facility for pursuing fitness activities.

6. **Develop and use each health care professional’s knowledge and skills appropriately to maximize his/her contribution to rehabilitation goals.** Physicians, professional associations
   - Develop a clinical practice model for physicians which emphasizes setting realistic rehabilitation expectations with patients, and using appropriate methodology to measure outcomes.
   - Develop model “clerkships” or “preceptorships” in rehabilitation for both the fellowship level and practicing MD level -- similar to “internship in Washington”
programs. **Physicians, professional associations**

- Develop coursework on rehabilitation through Network medical review boards (using a rehabilitation educational model for physicians and other members of the treatment team), and integrate into rehabilitation continuous quality improvement plan. **Physicians, professional associations**
- Include rehabilitation issues in the new clinical indicators for nephrology social work. **Social workers, professional organizations**
- Develop incentives to promote and support rehabilitation goals in clinical practice.
- Social workers, professional associations
- Include articles on rehabilitation in publications.
- Encourage CNSW chapters to provide rehabilitation training for rehabilitation counselors.
- Assure ESRD patients access to appropriately staffed (numbers/job description) qualified social workers with clinical expertise who provide social work services to help maximize rehabilitation potential.
- Develop clinical practice guidelines on rehabilitation. **Nurses, dietitians, technicians, professional associations**
- Develop rehabilitation as part of advanced practice.
- Develop incentives to promote and support rehabilitation goals in clinical practice.
- Provide chapter programming on rehabilitation.
- Develop a rehabilitation Special Interest Group (SIG).
- Add a certification exam section on rehabilitation.

**Bridges to Rehabilitation:**

**Education of Patients and Staff**

“*Knowledge can dissipate fear. When you know where you stand, when you know what your options are, when you know what choices you can make, then you can develop your sense of self to know what you’re doing.*” Patient, Irvine, CA. (IOM ESRD Study focus groups)

“There were a lot of things (about dialysis) that I found out later that I wished I had known before. Whether I would have been in a frame of mind to have made decisions, I do not know. But I do think it would have been helpful to have at least known more.” Patient, St. Louis, MO (IOM ESRD Study focus groups)

The point of realization that one’s kidneys have failed irreversibly and dialysis or transplantation will be required is a point at which effective patient education is needed. The shock of coping with a chronic disease can be overwhelming, making it difficult to fully understand the treatment options and how they will affect the quality of daily life (Newmann, 1983, Oberley, April, 1991). Clear, accurate information must be presented in small doses to prevent information “overload,” preferably on several occasions, using several different approaches (brochures, video, books, a visit to the dialysis or transplant
facility, sessions with peers).

“The patient with kidney failure is at a crossroads when renal replacement therapy is finally indicated. When the patient reaches that crux of requiring dialysis or transplantation, the quality of staff intervention and interaction can be a factor that determines whether the patient will follow a road of passivity and dependence, or choose a course of self-determination.” (Oberley, April, 1991).

John Newmann, economist, dialysis patient, and former president of the American Association of Kidney Patients, holds a similar view:

“This initial period of introducing dialysis appears to be critical in determining the quality of life to be enjoyed or regained by the new dialysis consumer. I view the first few months with the same importance as many ascribe to the first year of marriage. New patterns are set and attitudes developed which strongly influence the future.” (Newmann, 1983).

Particularly with respect to vocational rehabilitation, it is clear that the patients who are most likely to work are those patients who never stopped working even though they had begun dialysis or had a transplant (Friedman and Rogers, 1988). Some patients, then, learn that dialysis and employment can be compatible. A second group of patients are, for reasons of age, lack of education, diminished physical work capacity, or other illness, not likely to work again once on dialysis. A third group of patients has been described as being, “on the fence.” (John Newmann, 1983). Not knowing what to expect, they may or may not continue their jobs or pursue new employment—depending on the messages they receive.

Education at the beginning of treatment for end-stage renal disease must provide the necessary facts for patients to make a considered choice of treatment modality—and it must also instill hope that life with a chronic disease does not have to be limited to “disability” status.

Advisory Council Recommendations
Provide education to patients and staff about rehabilitation.
(Suggested participants are in italics. A list of renal organizations can be found in Addendum J.)

1. Provide education about adequacy of treatment (optimal dialysis) to the renal community.
   - Distribute AAKP advisory on adequacy to patients and professionals. Renal organizations, Networks, publications
   - Distribute RPA guidelines on adequacy to professionals and patients. Renal organizations, publications
   - Publish information about adequacy in patient and professional periodicals.

2. Promote early (pre-dialysis where possible) education among prospective/new
patients, family members, referring physicians, and the dialysis community.

- Establish effective system for distributing existing educational materials to patients. *Renal organizations, Advisory Council*
- Where needed, develop videos/curricula for patients including:
  - What to expect on dialysis; treatment options
  - Successful role models
  - The importance of exercise
  - Available VR services
  - Dealing with employers
  - Understanding the federal benefits system
  - Relevant ADA (Americans with Disabilities Act) information
  - Maximizing life activities (for retired/disabled patients)
  - Stress and coping mechanisms for chronic illness. *Renal organizations, Networks, Advisory Council*

- Target referring physicians for educational intervention.
- Develop educational materials for referring physicians.

3. **Educate the renal community about employment opportunities, support programs, and the advantages of staying/becoming employed.**

Please refer to recommendations under Employment.

4. **Educate patients and their families about ESRD treatment options.**
   - Distribute information about ESRD treatments. *Facility staff, renal organizations, NKUDIC*

5. **Educate renal community on value of exercise for renal patients.**

Please refer to recommendations under Exercise.

6. **Educate renal community on results and importance of research and evaluation.**

Please refer to recommendations under Evaluation.

7. **Educate patients, family members, and the dialysis community to foster successful adaptation to ESRD.**
   - Distribute Renal Rehabilitation Report to a wide audience. *Advisory Council*
   - Distribute People Like Us series and other educational materials to a wide audience. *NKF*
   - Establish a nationwide renal rehabilitation patient information clearinghouse which would: *Cooperative effort of renal community*
   - Develop a library of source materials and bibliographies for lay and professional audiences, updated annually.
   - Maintain a list of available programs and services for ESRD patients.
   - Distribute educational materials to facilities, certification bodies, NKF.
affiliates, and Networks (check on available materials in facilities for staff and patients annually—information from AAKP, AKF, NKF, NRAA, ANNA, NANT, RPA, ASN, CSAVR/RSA.)

- Establish a toll-free “hotline” to answer patient questions and provide referrals.
- Offer physician phone consultation on rehabilitation.
- Begin a job bank and matching service.
- Offer legal advice regarding insurance, disability issues, and the ADA.
- Develop awards/visibility for patients who have successfully adapted. Renal organizations

8. Educate physicians about rehabilitation issues (target primary care physicians, endocrinologists, urologists, nephrologists). The renal and medical communities

- Develop a medical education curriculum for physicians regarding the importance of and strategies for rehabilitation. This curriculum should include such topics as:
  - What is chronic illness
  - The importance of maintaining employment
  - The importance of early referral to other services such as physical or occupational therapy
  - Information about insurance, disability programs, the benefits of physical activity, etc. (eg., renal fellowship curriculum)
- Develop educational module/materials to be used in the medical education curriculum, with emphasis on:
  - Scientific/medical framework for rehabilitation
  - Psychosocial factors, i.e. motivation, role of depression, etc.
  - Available resources
  - Patient’s role in treatment team
  - MD role in dynamic treatment team with rehabilitation as integral part of the treatment plan
- Educate physicians about the importance of exercise in rehabilitation, including methods for incorporating exercise that have been used in other patient groups. (i.e. cardiac and stroke rehabilitation)

9. Educate professional staff and administrators about rehabilitation issues. The renal and rehabilitation communities

- Submit articles on rehabilitation to professional publications.
- Hold informational seminars/workshops on rehabilitation at association meetings.
- Expand rehabilitation components of core curricula.
- Add rehabilitation components to certification exams.

10. Educate VR counselors about specific rehabilitation issues of ESRD.

- Arrange for VR counselors to provide services at facilities to help them better understand the process of dialysis, and for patient convenience. Facility staff, State VR agencies
- Teach VR counselors about the effects of renal failure on patients, including:
• Physical functioning
• Realistic expectations and limitations for the work life of renal patients
• Necessary employer accommodations required by renal patients
• Functional rehabilitation needs of non-working ESRD patients
• Assist VR counselors to identify and address employer concerns about hiring renal patients, including:
  • Absenteeism statistics
  • Productivity statistics
  • Cost of insurance benefits and accommodations
  • Available tax credits

**Bridges to Rehabilitation:**

**Exercise**

“Patients need to be able to walk and climb stairs in order to work. They experience a gradual decline in muscle strength and endurance, and end up with severe deconditioning. Part of their limited exercise capacity is simply a result of not doing anything. ...We need to use physical therapy as a preventive measure.”
Patricia Painter, PhD, Exercise Physiologist

“I had to quit my job because I was no longer physically able to walk around the plant. My doctor said I’d need a transplant in a year. I asked to try exercise—I now I can walk seven miles, no problem.”
Bruce Lublin, Patient

The low tolerances for exercise typically found in renal patients can adversely affect their ability to walk independently, perform self-care activities, do housework, or pursue paid employment. To some extent, these tolerances may be limited by the pervasive effects of kidney failure on the body (Painter & Zimmerman, 1986) or by changes in the muscles themselves (Diesel, et al, 1990).

Hemodialysis patients, in particular, are also prone to many of the factors that accelerate development of coronary artery disease, including hypertension, reduced levels of HDL (“good” cholesterol), high triglyceride levels, elevated insulin levels, and a sedentary lifestyle (Goldberg et al, 1986).

However, numerous studies have found that the work capacity of renal patients can be significantly improved, and the risk of cardiac complications reduced, when they follow a program of regular aerobic exercise—and these effects are independent of erythropoietin (EPO). The ability to exercise is further improved as EPO raises the hematocrit above 30 percent. Physical rehabilitation is an important bridge to renal rehabilitation because it can enhance the patient’s ability to carry on normal daily activities such as walking, climbing stairs, pursuing gardening or other hobbies—and holding employment.

In 1983, Goldberg et al reported a 19 percent increase in treadmill time, a 27 percent increase in hematocrit, and significantly improved scores on the Beck Depression
Inventory among hemodialysis patients on a regular program of stretching, walking, and bicycling; compared to sedentary controls (Goldberg et al, 1983). In addition, the exercising patients demonstrated significant decreases in blood pressure (enough to reduce or stop hypertension medications) and fasting plasma triglyceride levels. Other investigations have reported increased exercise tolerance and peak oxygen consumption (Painter, 1986; Zabetakis et al, 1982; Shalom et al, 1984; Painter, 1988); reduced blood pressure, and increased hematocrit (Hagberg et al, 1983).

Renal transplant patients can also benefit from a well-designed exercise program. Their exercise capacity is essentially similar to that of sedentary normal individuals (Painter et al, 1986). Miller et al (1987) found that transplant patients who had participated in supervised treadmill walking and bicycling for several weeks achieved normal exercise capacities by eight weeks after transplantation.

Some of the most safe, effective, and promising interventions invite patients to use exercise bicycles in the dialysis facility while they are dialyzing. Patients who exercised on a stationary bike during dialysis have increased exercise capacity, and, in some cases, improved blood pressure control (Painter et al, 1986) as well as reduced hypotension during dialysis, better sleep, less leg cramping, and improved personal control (Boettcher, 1989). Treadmill walking and exercise bicycle use immediately after dialysis has also been found to be safe for patients, and to improve exercise capacity (Ross et al, 1989).

**Advisory Council Recommendations**

Develop programs that encourage exercise and physical rehabilitation. (Suggested participants are in italics. A list of renal organizations can be found in Addendum J.)

1. **Educate the renal community on the value of exercise.** Renal organizations, *American Physical Therapists Association (APTA), American Council of Sports Medicine (ACSM), American Association of Cardiovascular and Pulmonary Rehabilitation (AACPR)*
   - Develop presentations and informational packets for national organizational meetings.
   - Encourage organizations to sponsor local events to promote renal fitness.
   - Incorporate the need for exercise into training programs for renal professionals.
   - Add a segment on renal exercise to certification programs.
   - Develop an educational packet to teach patients about the need to be physically active. *Renal organizations, publications, Advisory Council*
   - Educate exercise professionals on appropriate exercise for renal patients. *APTA, ACSM, AACPR*

2. **Incorporate exercise into the standard plan of care.**
   - Establish practice guidelines. *Renal organizations, exercise specialists*

3. **Collect renal fitness data and incorporate with other outcomes data.**
   - Develop specific assessment items related to practice guidelines. *USRDS*
Establish a multi-center exercise intervention. Researchers in exercise physiology

4. Contain costs through innovative programming.
   - Educate the renal community about availability of funding for physical therapy services. Renal organizations, HCFA, publications
   - Develop liaisons with established community-based exercise programs (YMCA, cardiac rehabilitation, etc.). Facility staff, renal organizations
   - Share services of a renal exercise professional among several facilities. Facility staff

5. Establish guidelines and resources for facilities for ongoing renal exercise programs. ACSM, AACPR, APTA
   - Compile examples of successful programs.
   - Draw from guidelines for other established programs ie. cardiac rehabilitation.

Bridges to Rehabilitation: Employment

“Vocational rehabilitation statistics for ESRD patients are the worst among all types of disabled populations, according to the RSA. The numbers referred to VR programs are dismal. We need to make sure that the rehabilitation system is educated about these patients.”
Beth Witten, ACSW, LSCSW, Social Worker

Just as ESRD patients must be educated about their own illness, vocational rehabilitation (VR) counselors must be educated about the unique needs of ESRD patients. As stated earlier, dialysis patients experience periods of relative well-being, alternating with periods of relative disability, and their work weeks are disrupted by the need for treatment. Despite this reality, many patients report a desire to work, but would require various levels of VR assistance to do so.

Due to the complex nature of renal failure and its treatment, designating specialty VR counselors who develop a “practice” in vocational counseling for ESRD patients has proven useful in larger metropolitan areas (Witten, 1993).

An important goal of VR counseling for ESRD patients must be to help patients continue their current jobs, perhaps with accommodations in scheduling. If this is not possible, the local VR agency should attempt to work with the employer to determine whether another position within the company would be more appropriate. Apparently such efforts are not being made, at least not on any consistent, nationwide basis. Kutner, Brogan & Fielding (1991) found that only 15 percent of the unemployed patients in their study reported that someone had talked to them about getting a job—although one third of the same group stated that they would be able to work, and their physicians agreed.

VR efforts, including evaluation, job training, placement, and supervision can be costly.
In light of limited resources, VR counseling for ESRD patients should be targeted at the substantial minority of patients who have been identified as most likely to succeed in employment.

**Advisory Council Recommendations**

Improve employment opportunities and vocational rehabilitation.

(Suggested participants are in italics. A list of renal organizations can be found in Addendum J.)

1. **Promote job retention.**
   - Educate facility staff and physicians on the importance of retaining employment.
     *Renal organizations, facility staff, physicians, Advisory Council*
   - Refer patients to State VR agencies for supported employment; have VR counselors come to the unit to meet with patients. *Facility staff, patients*
   - Allow flexible dialysis scheduling to maximize employment possibilities.
     *Facility staff*
   - Educate family to encourage patient to retain employment. *Facility staff, family, renal organizations*
   - Encourage social workers to intervene early, and refer patient for VR services or assist with a patient/employer problem (These services could be reimbursed by Medicare and insurance). * Physicians, social workers*
   - Educate employers about medical status, productivity and needs of patients.
     *Facility staff, renal organizations, Advisory Council*
   - Seek legal advice for job discrimination (ADA, Rehabilitation Act). *Social workers, EEOC, Legal Aid center, Networks*

2. **Improve employment opportunities to increase positive VR outcomes.**
   - Advocate for policy changes that remove disincentives to return to work.
   - Extend Medigap provisions to ESRD patients under age 65 to give these individuals six months after eligibility for Medicare to apply and receive Medigap coverage. *Social Security Administration*
   - Allow ESRD patients to serve as a Research and Demonstration Project by extending SSDI work incentives without requiring patients to meet the SSI resource limits. *Social Security Administration*
   - Extend the SGA earnings level for the blind (currently $800) to ESRD patients. *Social Security Administration*
   - Streamline reapplication process for disability if needed after a work period due to complications or illness. *Social Security Administration, renal coalition of organizations*
   - Encourage flexible dialysis scheduling and/or increase utilization of home dialysis options. *HCFA (reimbursement), facility staff, Networks, renal organizations*
   - Educate patients about how to present self for employment. *VR Job Club, renal organizations, Advisory Council*
   - Educate employers to dispel myths about ESRD patients. *Labor Department, President’s Commission on Employment of Disabled, Networks, renal organizations*
• Establish demonstration project testing strategies to examine/remove barriers to employment. *HCFA, SSA, RSA, Advisory Council, renal organizations*
• Assess a sample population of working patients who are nearing the need for dialysis, to determine the assistance needed to maintain their current jobs.

3. **Increase number of state VR referrals.**
• Educate patients regarding importance of VR. *Facility staff, renal organizations, Advisory Council*
• Establish program to change VR attitude about ESRD patients. *VR, renal organizations, facility staff*
• Establish baseline data on ESRD patient-specific VR statistics including demographic data, work, insurance, and income source status; number desiring employment; and results of patient efforts to improve VR status. *Networks, RSA, USRDS*
  
  Establish written agreement of understanding between state VR agencies and Networks. *Networks, RSA*
• Establish Network task force with VR involvement, including VR membership on Network medical review boards. *Networks, RSA*
• Establish ESRD patient-specific VR tracking system by facility, monitor annually, and share data with renal community. *Networks, RSA, facility staff, USRDS*
• Develop ESRD patient-specific VR referral criteria which addresses patient motivation and use of an ESRD patient-specific measurement tool to determine potential for vocational rehabilitation. *Networks, RSA, renal organizations*
• Establish cross-training and ongoing communications between social workers and VR counselors. *VR, renal organizations, CNSW, facility staff*
• Place renal rehabilitation on the agenda for the CSAVR (Council of State Administrators of Vocational Rehabilitation) biennial meetings. *RSA, CSAVR, Renal community*
• Establish ESRD “expert” in State VR offices in metropolitan areas, and encourage visits to facilities. *RSA, Networks, HCFA, facility staff*
• Establish patient advisory committees to ESRD Networks to increase patient involvement from each facility in Network decision-making. *Facility staff, Networks, patients*
• Provide incentives (awards, recognition) to VR counselors, renal professionals who refer patients to VR. *RSA, renal organizations, Networks, facility staff, Advisory Council*
• Identify disincentives to ESRD patient referrals within State VR agencies. *RSA, HCFA, Networks*

4. **Establish national renal service corps.**
• Provide personnel to perform needed community services and fill competitive employment positions. *RSA, renal professional team, patients, employers, renal organizations*
• Create a training system that would educate patients, employers, and renal
professionals about ESRD rehabilitation, and promote advancement to full-time work. *RSA, renal professional team, patients, employers, renal organizations*

- Match potential ESRD employees with employment opportunities (internships, temporary or seasonal, full- or part-time permanent positions). *RSA, renal professional team, patients, employers, renal organizations*

**Bridges to Rehabilitation: Evaluation**

*“We need practical instruments and measures to show what interventions would actually be helpful to the majority of patients. We need to identify best practices. Data, collected appropriately and applied strategically, will enable the clinician to focus rehabilitation resources on the patients most likely to respond.”*

Richard Rettig, PhD, Health Policy Analyst

The need for systematic data collection on rehabilitation outcomes of ESRD patients—such as morbidity, functional status, health status, and quality of life—has been recognized for more than a decade. As early as 1981, John Newmann suggested that in order to obtain accreditation, dialysis units should be required to report salient outcome measures including morbidity, mortality, employment status, rehabilitation, and quality of life (Newmann, 1981). In that same year, Robert Gutman suggested surveying existing rehabilitation efforts for evaluation against a standardized framework, and establishing a clinical medical information system to collect outcome data (Gutman, Stead, and Robinson, 1981). Creation of the United States Renal Data System (USRDS) in 1988 was an important step in this direction.

Ten years later, the call for research has been echoed, with a suggestion to begin a focus on a specific vocational rehabilitation outcome by having ESRD Networks routinely and consistently collect rehabilitation data (Kutner, Brogan & Fielding, 1991).

The potential value of systematic data collection resides in two distinct areas. First, government policy decisions cannot be made in a vacuum—information detailing the present status of ESRD rehabilitation interventions and their outcomes is necessary to guide policy making.

The second area where systematic research is needed is at the dialysis facility level. Health care professionals interested in maximizing ESRD patients’ level of functioning, improving their care, and enhancing their quality of life currently have few benchmarks by which to measure or evaluate their progress. Clinicians need reliable indicators to identify which interventions work, which patients can be more fully rehabilitated, which areas of patients’ functioning are adequate, which aspects of quality of life are satisfactory, and which components of dialysis care are of sufficient quality (cf. Kutner, Brogan & Fielding, 1991; Evans et al., 1985; Evans, 1991; Quevedo, 1991; Simmons & Abress, 1990; Harris et al, 1993). These data are also needed to provide adequate and appropriate information to help patients make decisions about treatment modalities.
Instruments devised to evaluate patient outcomes must be reliable, valid, and designed to be easily implemented/administered in the treatment center. (Please refer to the Appendix, Addendum D on Health Outcomes Assessment for more in-depth information).

Advisory Council Recommendations
Develop systematic assessment of outcomes relevant for rehabilitation goal-setting. (Suggested participants are in italics. A list of renal organizations can be found in Addendum J.)

1. Test, validate and achieve consensus on adequacy measures.
   - Hold NIH consensus conference on mortality/morbidity. *Renal community*
   - Develop and validate a standardized assessment tool. *USRDS, Networks, researchers*
   - Perform an Adequacy of Dialysis clinical trial. *Renal community*
   - Assure ongoing HCFA/USRDS database studies. *Renal community*

2. Develop research-based practice guidelines on adequacy.
   - Develop an RPA Practice Guidelines process. *Nephrologists*
   - Ensure that existing federal regulations related to patient rights and care plans are enforced. *State survey agencies*
   - Recommend revision of federal regulations to include documentation of rehabilitation status in the long- and short-term patient care plans, under section 405.2137. *State survey agencies*

3. Develop and use ESRD-specific instruments for rehabilitation outcomes and predictors.
   - Develop an assessment tool to quantify patient rehabilitation potential, current status, goals, and evaluation of progress. *Renal community, Networks, researchers*
   - Continue development of measures and instruments. *Renal community, researchers from other fields.*
   - Continue development of functional status measures. *HCFA, renal community, researchers*
   - Publish USRDS Severity II study results. *USRDS, publications*
   - Encourage AHCPR PORT II study. *Renal community*
   - Develop educational programming and materials for interpreting and applying outcomes measures. *Renal community*

4. Develop and implement research and evaluation framework specific to rehabilitation.
   - Review and summarize related, current studies. *Rehabilitation medicine consultants, publications*
   - Design pre-dialysis intervention study. *Rehabilitation medicine consultants, Advisory Council, investigators*
• Design dialysis intervention study (demonstration project). *Advisory Council with other groups, investigators*
• Develop intervention studies specific to medicine, nursing, social work, exercise physiology, and other groups. *Renal community, investigators*
• Develop practice guidelines for all disciplines. *Renal organizations, investigators*

5. **Publish all study results and guidelines.**
Renal community, publications
VI. Case Report

CENTRAL FLORIDA KIDNEY CENTER

The renal rehabilitation goal “To provide patients the resources and opportunities to participate in desired and beneficial life activities” is a conceptual framework upon which to build an ideal rehabilitation program. As discussed in the preceding pages, five “core principles” for the rehabilitation of patients with ESRD have been identified:

- Encouragement (patient and staff commitment)
- Education of patients and staff
- Exercise to improve physical function
- Employment for patients capable of it
- Evaluation based on systematic data collection

These broad, comprehensive principles are valuable in building a model program. To demonstrate how these concepts can be useful in the clinical setting, it is helpful to examine them in light of actual practice. The Central Florida Kidney Center in Orlando was identified by the Advisory Council as being unique in its rehabilitation focus.

Relying on community resources and a strong patient education philosophy, the Central Florida Kidney Center was able to engage patients in scholastic, technical, and leisure pursuits brought directly into the units by educators. Both administration and staff were committed towards patient self-direction and goal attainment, professional education, community involvement, vocational rehabilitation activity, and an awareness of financial realities impacting rehabilitation efforts.

Unfortunately in 1992, the program ceased to be funded and special dialysis center classes ended. And although the formal education program cannot resume without an infusion of outside funding, the philosophical commitment to rehabilitation at the Central Florida Kidney Center continues.

Background/History

This unique program was created by Maureen Michael, BSN, MBA, chief executive officer of the two Central Florida hemodialysis units. Within four miles of one another, each free-standing, not-for-profit unit offers hemodialysis as the primary treatment option.

One unit, with 28 stations for in-center dialysis, has three home-training stations, as well as two isolation stations. Three shifts of dialysis are offered on Mondays, Wednesdays and Fridays, and two shifts on Tuesdays, Thursdays and Saturdays. The second center has 12 stations with two shifts of dialysis offered on Mondays, Wednesdays and Fridays, and primarily serves vacationing patients.

According to Michael, patients dialyzing at the two centers exhibit no unusual social, medical, financial, or educational needs. The ethnicity of the group reflects that of the United States, with the exception of a slightly higher Hispanic patient population.
Nephrologists, registered nurses, licensed practical nurses, and technicians provide care to patients. An in-service educator orients new nursing staff, conducts in-service training, and assists the home training nurse in educating patients and family members in home dialysis. A social worker and a nutritionist complete the multidisciplinary team.

A combination of events led to the creation of the program concept. After attending a meeting where community outreach programs were discussed, Michael heard of a local nursing home holding adult education classes for residents. “I thought,” she says, “If in a nursing home, why not in a dialysis center?”

Working in dialysis since 1976, Michael had observed the advancement of dialysis technology as well as the lack of growth in the facilitation of patient independence and productivity. Believing patients were capable of accomplishing more personal and dialysis-related self-care goals and in life pursuits, but were inhibited by poor reading skills, identification with the sick role, or malaise, Michael established program goals to address these issues.

The practical goals set forth for the project were: teach reading, help use treatment time productively, allow the opportunity to learn something new, encourage wellness and independence, and assist with the attainment of GED.

**Development and Funding**

To initiate the program, Michael secured funds from a school administrator in the district where the dialysis unit was located. The district was anxious to become affiliated with and fund a new approach to adult education. Under the auspices of the Boone Community School’s “Life-Long Learning” program, the dialysis education venture was launched. After patients completed a written survey about classes of interest, teacher Gloria Gonzalez interviewed patients about specific skills and hobbies, and discussed classes to be offered.

**Patient Participation and Class Content**

The program was offered to all patients. According to Michael, “At first, patients seemed reluctant, but they usually signed up after seeing how much fun everyone else was having.” Eighty percent of the dialysis patients participated in the nine-week sessions. Class offerings ranged from computer skills (with a lap-top computer used during dialysis) to sewing and wood burning. “We started out with ‘books and paper’ classes,” she said. “Later there wasn’t anything we wouldn’t try, with the teacher there.”

She credits the teaching staff and their flexibility with much of the program’s success. Over a period of six years, approximately 10 teachers taught in the dialysis unit, working individually with their students three times a week. Patients’ involvement became so great that some didn’t want to be transferred to the smaller unit, where teacher contact was less frequent. Eventually, teachers began to travel to the smaller unit, having become deeply committed to the program themselves.

Encouraging Patient and Staff Commitment and Education
Fostering patient commitment to rehabilitation may not always occur in an obvious, direct fashion. As stated in the core principles, one method of fostering commitment is through peer counseling. While Central Florida provided support groups, no formal peer counseling program existed. Yet peer counseling did occur.

Michael reports that when she first introduced the educational program, many patients were resistant to take part. “Some patients were reluctant because they felt they had no control over when they were going to be hospitalized, or sick. The whole ‘loss of control’ issue is a very important one,” she explains.

The program began with only those patients who wanted to enroll. Non-participants observed the learning, enjoyment, and accomplishments of the others. Over time, patients talked about the advantages of the program, and in effect “peer counseled” one another. As a result, patient participation in the program soared to 80 percent of the centers’ dialysis patients. Michael also credits the tenets of the center’s philosophy: meeting individual needs of patients; and offering, but not mandating, involvement in the program.

The unit’s philosophy of increasing patient commitment through education extends to teaching patients about rehabilitation resources in the community. A social worker or nurse describes vocational rehabilitation services.

The core principles also outline numerous strategies for increasing staff interest in and commitment to rehabilitation. Although the strategies vary between each discipline, the common goal of establishing clinical practical guidelines for rehabilitation runs throughout.

Central Florida has instituted multidisciplinary clinical guidelines for rehabilitation. An initial assessment of the patient’s abilities and life goals is done within one month of beginning dialysis. This assessment is incorporated into a long-term care plan, with goals contributed by all team members and the patient. Staff commitment is enhanced by reviewing goal attainment every six months and reformulating goals as needed.

Michael states that staff interest in rehabilitation must also be fueled by professional continuing education. “To understand what information patients need and what they risk losing by becoming rehabilitated (especially in obtaining a job) is important,” Michael maintains. “This type of education needs to take place during the orientation of new staff. And our physicians, I think, appreciate journal articles as a means of becoming aware of rehabilitation issues.”

**Increasing Community Awareness of ESRD Rehabilitation Issues**
In addition to educating patients and staff, the core principles also emphasize the importance of increasing service organizations’ awareness of rehabilitation of persons with ESRD. Through public speaking, Michael has informed philanthropic organizations about the problems facing persons with ESRD and the means by which such problems can be ameliorated. She also encourages patients to learn about and become involved
with agencies. “Two of our patients are regular volunteers in the Kidney Foundation office. The office is pleased that they are regular volunteers who can be counted on to be there,” she reports. Patients are also helping to make arrangements for transient dialysis for persons attending the American Association of Kidney Patients in Orlando this year.

**Employment Through Vocational Rehabilitation**

At the heart of improving patient access to rehabilitative resources is the state vocational rehabilitation (VR) agency.

Some of the initiatives for improving vocational rehabilitation of persons with ESRD suggested within the core principles will require political action. Others can be accomplished in the clinical setting. Central Florida has begun working towards improving patient access to vocational rehabilitation services in the clinical setting.

“We make an effort to get everyone to a VR evaluation. I believe that every person between 18 and 55 who is not working should be evaluated,” Michael asserts. VR evaluations performed by on-site VR counselors, as well as adequate funding for the VR agency are vital elements in assuring patient exposure to valuable resources.

**Evaluating Outcomes**

As stated earlier, the need for systematic data collection, research, and development of methods of measuring rehabilitation outcomes is critical. Without such guideposts, national policy decisions are hindered by limited information. On the facility level, clinicians lack consistent criteria by which to measure patient progress, and improve their care and quality of life.

Until a standardized means of outcome measurement is implemented, clinicians have opted to monitor rehabilitation progress and outcomes based on patient-specific guidelines. As a case in point, Central Florida staff and patients have worked together to assess individual patient needs and formulate goals. The outcome measure of a goal is its accomplishment. Goals are reviewed twice yearly by the multidisciplinary team and patient. While this individualized method of outcomes measurement cannot be generalized beyond a single patient, it is useful in following intra-patient progress and change.

**Conclusion**

With the help of community resources, the center has been able to build on some core principles of rehabilitation. Through education and by focusing on patients’ areas of interest, the center was able to foster patient commitment to the concept of rehabilitation. There are many programs throughout the country engaged in rehabilitative efforts. By examining one case example, people interested in renal rehabilitation may be able to analyze their own local programs and perhaps adapt ideas to fit their needs.
VII. Appendix

Addendum A

ESRD Treatment Modalities

Choosing the appropriate treatment option for an individual with chronic renal failure is of utmost importance. Every effort must be made to select the modality that will maximize well-being, promote adherence, blend with lifestyle, and mesh with the life stage of the person with renal failure.

The following section briefly describes the types of treatments available today and offers a short historical view of hemodialysis and renal transplants.

**Hemodialysis**

Hemodialysis (literally, “blood cleansing”) is a process of removing blood from the body through tubing, cleaning it by passing it through an artificial kidney, and returning it to the body. During dialysis, waste products in the blood are filtered out by a semipermeable membrane and passed into special fluid called dialysate. Both the membrane and the dialysate allow only toxins to be removed from the blood; other molecules needed by the body are not removed. A mechanical pump is used to force the blood through the machine.

In order to clean the blood, it is necessary to gain access to the bloodstream. Via surgical intervention, a vascular access is created usually by connecting an artery and a vein in the arm. Once healed, the access vessel can permit the high blood flow rates required for hemodialysis. Needles inserted into the access connect the patient’s bloodstream to the machine. Care must be taken to prevent infection or damage to the access.

Hemodialysis treatments are commonly required three times a week, for 2.5 to 4 hours per treatment, plus travel time to a facility, time needed to connect to and disconnect from the machine, and any waiting time that occurs before the patient is connected. Several hours of fatigue often follow each treatment as well, making it difficult for many patients to accomplish heavy physical or high level intellectual tasks during or after dialysis.

**History of Hemodialysis**

The first artificial kidney machine was invented by Dr. Willem Kolff in 1942 (Rettig, 1990). Dialysis was so difficult that it was only used to treat cases of acute renal failure, in which recovery of kidney function was expected. In 1960, Dr. Belding Scribner developed a permanent method of vascular access, allowing dialysis to be offered to sustain the lives of persons with chronic renal failure (Rettig, 1990).

Shortly after this milestone, dialysis centers slowly began to be established throughout the country, with 30 centers initiated by the Veterans Administration by 1963. Due to shortages of the costly equipment, there were not enough facilities to treat every patient
who needed dialysis. Committees were established to choose which patients would receive the life-saving treatment, usually based on the patient’s continued ability to support him or herself and family members. Patients who were not selected for treatment died.

In acknowledgment of the critical need for dialysis, the federal government extended Medicare benefits to all ESRD patients by passing Public Law 92-603 of Section 2991, in 1972. The availability of federal funds for dialysis treatment enabled enough facilities to be opened to care for all the patients who required dialysis.

**Types of Hemodialysis**

In-center hemodialysis is performed in hospital-based and free-standing dialysis centers.

Staff-assisted hemodialysis is performed entirely by nurses and technicians.

Self-care hemodialysis entails assistance from staff members, but enables the patient to control many elements of dialysis, including preparation of the machine, recording of vital signs, needle insertion, and monitoring of the treatment.

Home hemodialysis allows the partner (often the spouse) of a patient to perform the treatment independently at home, following a training program with a home dialysis center. Telephone back-up is available 24-hours a day in case of emergency. Staff-assisted home hemodialysis is available in some areas for patients who do not have a partner who is able or willing to help with the dialysis. Home hemodialysis allows patients and their families to schedule dialysis when it is most convenient and least disruptive to work life and family activities. This flexibility has enabled some home hemodialysis patients to hold demanding jobs as physicians and consultants.

**Peritoneal Dialysis**

Peritoneal dialysis utilizes the peritoneal membrane, the tissue that covers the outside of the abdominal organs and the inside of the abdominal wall, to filter out wastes. A catheter is surgically implanted in the abdomen through which dialysate is infused and dwells in the peritoneal cavity for a period of time. During the dwell time, toxins are attracted into the dialysate from the capillaries in the peritoneal membrane. The dialysate is drained out of the abdomen and replaced with fresh in a procedure called an exchange.

**Types of Peritoneal Dialysis**

Continuous ambulatory peritoneal dialysis (CAPD): With CAPD, exchanges are commonly performed four times a day, so dialysis is constant, but patients can freely move about doing work or other activities between exchanges. Each exchange may take 15 to 20 minutes or more, and must be done using sterile techniques to avoid introducing bacteria from the skin into the peritoneum. Infection (peritonitis) is an important risk of peritoneal dialysis, and the main reason for CAPD patients to switch to other forms of dialysis. On the other hand, CAPD allows the flexibility to schedule the exchanges for less- hectical periods of the day, and the renal diet and fluid restrictions can be less stringent because dialysis is occurring continuously.
Continuous cycling peritoneal dialysis (CCPD) uses an automated dialysis machine to infuse a measured amount of dialysate into the abdomen and drain it at prescribed times. The exchanges are repeated 8-10 hours per day, usually at night while the patient sleeps. The last exchange usually stays in the abdomen during the day, thus prolonging dialysis time. New cycling machines are lighter in weight and less complicated than earlier versions, promising greater ease of use and perhaps allowing CCPD patients greater freedom to travel.

It is interesting to note that substantially larger percentages of continuous ambulatory peritoneal dialysis patients were able to perform physical activity or employment than home hemodialysis patients (Diaz-Buxo and Holt, 1989).

**Renal Transplant**

Renal transplantation is the surgical implantation of a donor kidney into the body of a person with renal failure. Kidney donors may be close relatives or persons unrelated to the recipient (such as spouses or friends). Kidneys may also be procured from cadaveric donors.

Candidacy for transplantation is determined by the evaluation of medical condition, desire for transplant and, in some centers, age.

**The Transplant Process**

Historically, physicians and others in the field of transplant waited for persons with renal failure to develop specific symptoms and to become significantly uremic before transplant was considered timely. Because of advanced technology in immunosuppression, patients are now eligible for surgery earlier (sometimes before dialysis becomes essential), thus minimizing the uncomfortable and debilitating symptoms of advanced renal failure. In general, nephrology and surgical staff take into account not only the physical needs of the patient, but also the patient’s psychological readiness in scheduling transplant. As a consequence, some persons may wish to “stabilize” on dialysis before considering transplantation.

**Cadaver donors**

Most kidney transplant patients enroll on the “waiting list” for a cadaver kidney, donated by an individual who suffered a fatal injury or illness and who indicated the desire to donate his or her kidneys. Through the United Network for Organ Sharing (UNOS), transplant centers nationwide are made aware of available organs. Organ procurement teams recover organs via surgery. When a suitable recipient is identified, he or she is contacted and the transplant is performed as soon as possible. Histocompatibility, an analysis of tissue and blood typing to obtain a good “match” is an important consideration in the pairing of kidney and recipient.

**Living Donors**

Some patients with kidney failure obtain a kidney transplant from a living donor, usually a close relative. When a living donor is available and willing to donate his or her kidney, an initial series of medical tests must be performed to determine suitability of the kidney
for transplantation. Tissue- and blood-typing, chest x-rays, blood testing, and other tests are done, with different transplant centers requiring different tests. Close histocompatibility (blood and tissue matching) is essential to minimize the chance for rejection. The recipient receives similar tests as well as procedures to measure heart and kidney function. If the test results are acceptable, a date for surgery is made.

Transplant surgery generally takes about three hours. The new kidney is inserted into the lower abdomen and may begin working during the operation. Hospitalization following transplant typically lasts from 10-14 days. During this time, immunosuppressive medications are begun and carefully monitored. After discharge, patients must maintain regular, life-long lab and clinic appointments to measure both the new kidney’s function and the impact of the anti-rejection medications. Adherence with the medication regime is essential in preventing rejection.

Complications and Side Effects of Transplantation
Technology of immunosuppression has grown dramatically since the first transplants were performed. However, infection, side effects of the medications, rejection episodes, and other problems can occur. While not always requiring hospitalization, these can significantly disrupt life and work.

The long-term use of immunosuppressants can lead to Cushings Syndrome (re-distribution of body fat), emotional lability, cataracts, peptic ulcers, pancreatitis, diabetes, arthritis, and, rarely, cancers of the cervix, skin, or lymph glands.

After Transplant
Most transplant recipients can resume a normal lifestyle following transplant. In the absence of chronic illness, such as diabetes or hypertension, a routine diet may be resumed. Exercise is not only permitted, but is encouraged, and high levels of fitness are again possible for recipients. Many recipients are able to resume work.

Complications and side effects from medications do occur post-transplant (see below). In the absence of these, persons with a well-functioning transplant report high levels of well-being that surpass those of persons on dialysis. Recipients often express deep gratitude for their “Gift of Life” and donors (and families, in the case of cadaveric donors) frequently derive significant fulfillment from their donation.

Addendum B

Demonstration Projects and Model Programs

Current Major Initiatives in Rehabilitation
There is no doubt that health care professionals at all levels and all over the nation are actively involved in promoting the rehabilitation of ESRD patients. Unfortunately, a search of the indexed literature for published information regarding rehabilitation programs or protocols does not yield a large volume of information.
In part, this is due to the fact that most of the programs which have been initiated represent isolated, individual, and unreported efforts at rehabilitation. In many cases, creative and relatively successful rehabilitation programs are implemented by clinical practitioners, who may or may not have the time or financial resources required to document their protocol and its outcomes in published form.

In order to get some sense of current renal rehabilitation program design, the Medical Education Institute has conducted interviews with key sources associated with nine rehabilitation programs around the country. The programs chosen became known to us through publication or by reputation. The key source from each program provided information about the programs’ philosophy, inception or basis, funding, goals, outcomes and current status. The purpose of this section is to describe these programs, particularly their similarities and differences.

Because of the selection process, the “sample” of ESRD rehabilitation projects or programs cannot be considered representative of all renal rehabilitation programs. It is difficult to generalize from these programs to all programs. Nonetheless, there are valuable insights to be derived from the descriptions of these rehabilitative efforts, especially in light of the fact that there appear to be some underlying concepts in renal rehabilitation which are common to most of the programs studied.

A prominent theme which emerged from the descriptions of the programs is that rehabilitation involves more than just employment issues. Each of the nine programs addressed psychosocial concerns as well as adjustment, motivation, relationships, self-esteem, and vocational topics. Another striking characteristic is the discontinuity caused by inconsistent funding.

Another obvious conclusion which might be drawn from this exercise is that the current programs tend to be conducted on an ad hoc basis. Clearly, the time has come for a macro level plan for structured, organized, and well-coordinated rehabilitation programs, applicable “across the board” for ESRD patients.

**Program 1: Florida Network 7**  
**Information Resource: Spero Moutsatsos, Network 7**

In the Florida Network (Network 7), several studies conducted suggested that a large number of patients of working age were strongly motivated to return to work and that a higher rate of successful rehabilitation and employment might be attainable if resources were devoted to encouraging rehabilitation efforts. Based on these findings, the Florida ESRD Network, through its Statewide ESRD Patient Services Committee, in cooperation with the Florida Department of Health and Rehabilitative Services (HRS) and the Office of Vocational Rehabilitation (OVR) mounted a cooperative VR effort in the state.

The initial objectives of the project were: (1) to conduct a statewide program to educate ESRD patients and professionals about Florida’s VR program utilizing specially prepared
brochures; (2) to develop and provide informational materials to VR counselors about the nature and employment implications of persons with end-stage renal disease, for patients and staff of ESRD facilities about the VR program, and to employers about the benefits of hiring ESRD patients; and (3) to conduct workshops involving VR counselors and ESRD patients and professionals.

The following is a summary of the project’s achievements: 1) more than 20,000 brochures were prepared and distributed to VR counselors, patients, professionals and employers; (2) a training guide for conducting VR workshops was developed (16 have been conducted over the past three years involving more than 100 VR counselors); (3) information about the project was disseminated in a variety of statewide publications; and (4) VR was included as a subject for discussion on the agendas of the annual educational meetings of the ESRD Network, and at patient and professional meetings.

With the successful completion of the first phase, the Network is now well into the goals of the second phase, which are to: (1) conduct additional VR workshops; (2) develop more effective procedures for referring patients and documenting their status; (3) focus increased attention on employers; and (4) implement an ESRD patient job referral system.

Network Seven has implemented a procedure under which each dialysis facility in the Network is required to review the VR potential of each patient semi-annually, report the results of this assessment to the Network, refer each suitable candidate to OVR, and remain informed about the patient’s progress. The facility must report information about the number of patients reviewed, referred, not referred and the reasons for those decisions, and the number currently in VR programs or engaged in full- or part-time employment.

Since this review process has been made a continuing element of the Network’s review activities, it is expected that many patients who might have been overlooked in previous years will now be carefully reviewed and referred whenever it is found appropriate to do so.

Inquiries and referrals alone, (no matter how much the rate improves) are not a final measure of rehabilitation success. As a result, the Network has arranged with VR to track the rate of success experienced by ESRD patients in completing their VR programs and returning to employment. Thus, the Network is now able to measure both the referral rate and the rate at which patients return to employment.

The impact of the project on patient and professional interest in VR is evident. The office of vocational rehabilitation reports, for example, that during the 30 months that the project has been in full swing, they experienced an increase of approximately 30 percent in the number of referrals received from and on behalf of kidney patients. While all of this increase may not be directly attributable to the project, it is clear that it is a major contributory factor in the increase.
As of December 31, 1992, Florida had a dialysis patient population of 9,278 with 3,187 between the ages of 18 and 55 (considered eligible for VR services). Of the eligible patients, 646 were working either full or part time or were attending school, an increase of 35 percent over the 1990 figure of 480. Additionally, 353 patients had been referred to the Florida State Department of Vocational Rehabilitation during 1992, an increase of 77 percent over 1990 during which 199 patients were referred.

It is clear that both processes—the referral of ESRD patients by facilities for VR and the effective delivery by OVR of vocational rehabilitation services—are working moderately well (but obviously far better than they have ever worked in the past).

Two important conclusions can now be expressed. First, the effort to stimulate ESRD facilities to periodically review the VR status of their patients and to refer patients who appear to be suitable candidates has borne fruit. While it is impossible to quantify the increase, as no data were kept on referrals prior to the Network’s interventions, it is generally agreed that the great majority of the patients referred to OVR during this period under study would not have previously found their way into the state VR program.

Second, despite widespread doubts on the part of both VR and ESRD professionals about the interest and willingness of patients and VR counselors to work effectively together, the data shows that both counselors and patients have responded to the opportunities provided. Certainly the figures are not overwhelming. Continued effort is needed to encourage more patients to attempt VR and more information is needed about those referrals who do not become “active cases”. But the fact remains that a fair number of referred patients do actively complete their programs. In short, many patients have worked hard to successfully complete their VR programs with the objective of returning to the work force; and OVR counselors have effectively provided the guidance and assistance essential to the design and completion of these programs.

Program 2: Development of a Comprehensive Job Retention/ Return Service Delivery System for People with Kidney Failure, New York, New York

Information Resource: Herbert Krauss, PhD, Principal Investigator, International Center for the Disabled

A collaborative pilot rehabilitation project is being undertaken by the International Center for the Disabled (ICD) and the ESRD Network of New York. This project is designed to develop and test a model program that uses a case-management approach to help patients with chronic renal failure retain their jobs for at least six months after the start of dialysis, and to provide emotional support while fostering independence. The study is funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services, Rehabilitation Services Administration.

The justification for this project is based upon two important concepts. First, chronic renal failure frequently progresses to end-stage renal disease (ESRD). Second, helping
patients keep their current jobs (even with vocational interventions) is easier than helping patients to find new jobs.

Objectives of the three-year project are: 1) to develop patient, physician and employer education modules; 2) to help at least 50 patients maintain employment; 3) to determine the effectiveness of the model, and; 4) to offer information necessary to allow this approach to be used for other patients with chronic renal failure.

Participants are divided into control and experimental groups. The experimental group receives direct and indirect services including education; an individualized disability management plan; case management and vocational rehabilitation services; peer support counseling; assessment of employer involvement; collaboration between physician and employer; employer and physician education; and an Industrial Rehabilitation Program, using simulated job tasks to help patients regain their maximum work capability.

Program effectiveness will be measured after three years, including evaluations of successful maintenance of employment, quality of work performance, cost effectiveness, value of the educational modules, and overall patient well-being. Successful aspects of the program will be incorporated into ICD’s Industrial Rehabilitation Program and published in professional journals, and educational modules will be disseminated.

Program 3: Renal Rehabilitation Assessment Center (RRAC) Pilot Project, Madison, Wisconsin

Information Resource: Annette Ellstrom Calder, MSSW, University of Wisconsin Hospital and Clinics, Madison, WI

The Renal Rehabilitation Assessment Center Pilot Project was launched by Annette Ellstrom Calder in the fall of 1985. Defining rehabilitation as “both a physical and mental effort in which the patient uses residual capabilities to compensate for losses,” Ellstrom Calder envisioned an intensive 2.5- to 3-day patient assessment by an interdisciplinary team including an occupational and physical therapist, a social worker, a dietitian, and, in certain cases an endocrinologist and ophthalmologist. The emphasis of the RRAC assessment was to develop an individualized set of goals for each patient. These goals were to be realistic, feasible, attainable within one year or less, and were designed to encourage independence. Patient participation in the goal-setting was essential.

The RRAC pilot design called for four groups of four patients and their families to pass through the program each month. New patients, hemodialysis patients, peritoneal dialysis patients, and renal transplant patients were eligible for the program. Each participant met individually with a team member from each of the professional disciplines, who completed a written assessment and summary on the patient. For example, the occupational therapist evaluated upper extremity motor status and strength, range of motion, coordination, and need for adaptive equipment; with different specific attention given to the different needs of CAPD and hemodialysis patients. The dietitian
evaluated the patient’s nutritional intake and recommended changes.

Additional funding was scheduled to expand the RRAC pilot to a regional program. Unfortunately, due to a technicality, funding fell through and the program did not survive. However, a considerable amount was learned during its brief tenure. The feasibility of a short-term interdisciplinary assessment with a goal attainment model was demonstrated. The various professionals who participated were excited about the program and quite able to cooperate in the brief time period to provide solid assessments.

Patient participants also enjoyed the program and benefited from it. Four dialysis and four transplant patients received RRAC assessments, and informal follow up during regular rounds demonstrated that these patients were more compliant with their diet, had increased their physical exercise, and in some cases were able to perform self-care activities that were not possible for them prior to the program.

The practical and interdisciplinary nature of the RRAC program makes it a concept worth considering further for renal rehabilitation.

**Program 4: Satellite Dialysis Centers Exercise Program, Northern California**

**Information Resource: Patricia Painter, PhD**

In 1981, Satellite Dialysis Centers made a decision to initiate an exercise program for patients in their 10 free-standing dialysis clinics in Northern California. The program was directed by an exercise physiologist trained in cardiac rehabilitation who was committed to transferring principles of cardiac rehabilitation to dialysis patients. The program, which had dialysis patients using exercise bicycles during the dialysis treatment, was set up as follows:

1. **Staff Inservice**: The exercise physiologist first educated the dialysis staff about the program. Inservices included a one-hour presentation on the importance of exercise training in dialysis patients, which included improvements in functional capacity and possible improvement in cardiovascular risk profile. The second hour trained the patient care staff how to set up the exercise bicycles and developed strategies to motivate patients and encourage participation.

2. **Patient Participation**: Patients were recruited by both patient care staff and by the exercise physiologist. Physician approval was obtained for any interested patients and they were evaluated for exercise using a symptom-limited exercise test during which blood pressure and electrocardiogram (single-lead), symptoms and perceived exertion were monitored. Patients were then started on the program during their next dialysis session. They were monitored by the exercise physiologist during their first and second sessions, during which they were instructed on how hard to work (warm-up, conditioning and cool-down intensities), how to progress in duration, and what to be aware of (ie. symptoms of chest discomfort, excessive shortness of breath, etc.).
3. **Maintenance of program**: Patient care staff was responsible for assuring their patients exercised. The exercise bicycle was given to the patient as soon as they were set up on dialysis, and the patient was then responsible for carrying out their program independently. Staff was encouraged to give positive feedback to the participants and refer any concerns to the exercise physiologist. One staff member was given the responsibility for the exercise program in the unit, kept track of participation, and referred any new patients to the program. The exercise physiologist would visit the unit on a regular basis (usually monthly) to assess the progress of those involved in the program, and to start new patients with the bicycles.

Participation in the program varied between the 10 dialysis units. However, on average, 30 percent of patients in the units participated. The highest participation was in a dialysis unit with a population of mostly non-Caucasian patients. In fact, only 17 percent of patients in this unit had English as their primary language. The main reasons for not participating were medical concerns (orthopedic problems and cardiovascular considerations). The main reasons for discontinuing the program were transplantation and beginning an independent home exercise program.

This program was discontinued because of financial difficulties. The program itself was an important experience for the following reasons: 1) It demonstrated that there could be significant participation in a program during the dialysis treatment; 2) It demonstrated that such a program could be easily incorporated into the routine dialysis treatments, and was well accepted by the dialysis staff; 3) It was designed for efficient use of the exercise physiologist - shared between 10 dialysis units. 4) It was designed to give patients responsibility for their program, and only required dialysis staff for motivation and setting up the bicycles; 5) The only cost involved was the exercise bicycles, and the exercise physiologist’s salary, travel and expenses when visiting each clinic (approximately $150 per patient). The program definitely changed the atmosphere in the dialysis units - from patients who were passively receiving treatment to a group of patients actively participating in a program to improve their functioning and well-being.

**Program 5: Rehabilitation Project, Cleveland, Ohio**

**Information Resource:** Martin Schreiber, MD, Director of CAPD Unit, Cleveland Clinic Foundation Department of Hypertension and Nephrology

As a nephrologist, Dr. Martin Schreiber is acutely aware of issues surrounding rehabilitation of ESRD patients, and believes that it is important to emphasize independence with activities of daily living as well as vocational skills. During 1988-1990, Dr. Schreiber conducted a demonstration project funded by the Social Security Administration.

The study goals were: “to develop and document an early intervention vocational adjustment program to enhance the treatment protocols, patient skills, motivation and employer-SSA policies that promote or impede the successful employment of individuals
Participants included were 133 medically stable patients ages 18-60, with late stage chronic renal failure or ESRD, who were on or soon to be on dialysis or who received a kidney transplant during the study period. All were randomly assigned to an experimental or control group.

All participants underwent physical/occupational therapy and vocational rehabilitation evaluations; and the 69 experimental patients also participated in a four-week readiness group program that included information on adjustment counseling, the impact of renal disease on employment, vocational issues, transfer of skills, exercise, and worker attitudes toward their jobs.

Follow-ups of vocational status were done at ten weeks and six months. At ten weeks, both groups experienced a significant improvement in their vocational status. By the six-month follow-up, only the experimental group had maintained the significant improvement.

Study funding was not renewed, nor was a permanent program established based on its findings.

**Program 6: Springboard, Atlanta, Georgia**

Information Resource: Chuck Brown, Patient and Community Services Manager, National Kidney Foundation of Georgia, Inc.

Springboard is sponsored and funded by the National Kidney Foundation of Georgia and the Georgia Department of Human Resources, Division of Rehabilitation Services.

Tess Bowles, CNSW, recognized special needs in young kidney patients who had to make life choices. The program is designed to remedy these patients’ depression, and lack of self worth and motivation, and replace these with increased self esteem and independence. The program is directed by Dr. Dean Erguson, a psychologist, assisted by Vocational Rehabilitation counselors and other “experts and role models.”

The program is offered annually to Georgia ESRD patients ages 19 to 30. Every Georgia dialysis center is notified, and patients are nominated by renal social workers. The first 25 applicants with complete applications are accepted; the rest are placed on a waiting list.

Springboard consists of four weekend retreats on topics including assertiveness training, dealing with anger, team building, government benefits, dating and sexuality, independence, goal setting, job skills and opportunities, values clarification, money management and long-term planning.

Follow-up includes a patient survey conducted shortly after program completion,
evaluation of progress by renal social workers, and monitoring of work progress by vocational rehabilitation counselors.

Though at the moment, funding for Springboard is not completely secured, it continues to address problems of approximately 25 enrollees each year.

**Program 7: Forward Bound, Jackson, Mississippi**

*Information Resource: Harriet Williamson; Vice-President of NKF of Mississippi*

Forward Bound is sponsored by the NKF of Mississippi. Inspired by Georgia’s Springboard, Forward Bound initially received start-up funding from Network 8 and has subsequently received grant money from private corporations (i.e., Amgen, DCI). The program is managed/directed by Harriet Williamson, Vice-President of the National Kidney Foundation of Mississippi and Dr. Robert Hosford, psychologist.

Mississippi transplant and/or dialysis patients between the ages of 18 and 37 are eligible to apply; only applicants who are literate, possess a sufficient degree of self expression for group discussion, are highly motivated to attend, and have no serious dysfunction or additional psychological difficulties are accepted.

The program addresses low self-esteem, inadequate job readiness and dependence on public assistance. The goals of Forward Bound are to offer patients a therapeutic encounter with peers and professional staff and to “motivate and equip them to strive for a more productive and meaningful life.”

Forward Bound sponsors three weekend retreats. Patients participate in group discussions, group therapy and individual counseling sessions. The first retreat focuses on life planning, acceptance and developing a healthy self-concept. The second session introduces vocational preference and aptitude testing, career assessment and goal planning, explanation of Social Security and Disability status, and job search skills. The last session deals with relationship building, independent living and conflict management.

Follow-up consists of a questionnaire sent to participants several weeks after the program, and phone contact with each patient’s renal social worker asking about patient compliance, attitudes and work status. To date, about thirty patients have successfully completed the program. Of these, 18 have initiated positive steps toward their own rehabilitation, i.e., are now in school or working as a result of their participation.

Forward Bound is an on-going program. A weekend retreat for health care professionals who care for ESRD patients has been planned to focus on issues surrounding staff burnout and effective patient management/ rehabilitation.

**Program 8: Career Workshop, Lansing, Michigan**

*Information Resource: Paul Wright, Michigan Rehabilitation Services, Department*
of Education.

The Michigan rehabilitation program is carried out with the sponsorship of the Kidney Foundation of Michigan and the Michigan State Rehabilitation Services. It is designed to address kidney patients’ perceived loss of power, control, and identity; and to improve their largely negative attitudes toward employment.

All Michigan dialysis patients are eligible. Nephrologists and/or social workers in every dialysis center are contacted and patients who wish to participate are enrolled.

Michigan’s career workshop consists of a three-day, two-night intensive career “exploration” experience. The goals for the workshops are: 1) to remove the patients from their ordinary environment to help them gain perspective on their lives; 2) to allow patients to identify barriers to rehabilitation in their lives; 3) to debunk myths about employability and career options, and; 4) to empower patients.

Topics covered in the workshop include internal and external barriers to work, SSA and Medicare policies, leisure assessment, problem solving and analysis, vocational exploration, and job preparedness. The workshop is staffed by rehabilitation counselors and accommodates about 15-20 patients per session.

Each participant is required to develop and sign a “contract” outlining what he/she intends to accomplish in career development over the next six months. Surveys of participants are conducted three months and six months after completion of the program.

Some patient participants actually exceed their contracted goals. Because of its success, career planning workshops for patients with ESRD/CRF have become a part of the ongoing rehabilitation program in Michigan.

Program 9: Vocational Rehabilitation for ESRD Patients, Austin, Texas
Information Resource: Ilene Gray, Former Director, Interagency Liaison and Gov. Relations, Texas Rehabilitation Commission

For nearly 10 years, the Texas Rehabilitation Commission, which had been mandated to increase services for the severely disabled, sponsored a program intended to maximize the employment potential of patients with ESRD. The Vocational Rehabilitation staff perceived that patients’ lives seemed entirely tied to dialysis and that patients tended to be inordinately dependent upon the dialysis staff.

The specific goals of the program were: 1) to discourage patients from abandoning their life goals because of renal disease; 2) to improve motivation for employment through job readiness training; 3) to combat the pervasive attitude of victimization among dialysis patients; 4) to involve dialysis center staff in the rehabilitation effort, and; 5) to encourage local employers to modify job requirements so that ESRD patients would be able to return to at least part-time employment.
All dialysis patients in the Austin metropolitan area were informed about the program and those who expressed an interest were included. If six or more interested patients were concentrated in a single center, a trainer would be assigned to that unit to work intensely with the clients; otherwise patients attended the classes at a different location.

The trainer conducted classes over a 12-week period. Topics covered included interpersonal relationships, defining vocational goals, identifying interests, career opportunities, job-seeking skills, appropriate attire for interviewing, self presentation, etc.

During the 12-week period, the regular rehabilitation counselor was also working closely with both clients and trainers, counseling individually as necessary, and making sure that patient participants were continuing to pursue independent, vocationally-related activities.

Because of the close contact between patients and counselors in this program, patient follow-up occurred on a regular and individual basis. Records show that the majority of the ESRD patients who participated in the program demonstrated improved vocational status.

However, despite the success of this program, when the directorship of the Texas Rehabilitation Commission changed, the program was discontinued presumably due to lack of sufficient interest in the program on the part of the new leadership.

**Program 10: Promise for Living, Hartford, Connecticut**

**Information Resource: Molly Sherman; Executive Director, NKF of Connecticut**

Promise for Living is sponsored by the National Kidney Foundation of Connecticut Patient Services Committee. The program has received grants from Amgen and from a local ambulance company, but is primarily and currently funded by the National Kidney Foundation.

The idea for the program came in 1991 from several key women working in rehabilitation or renal services. They were concerned about attitudes of defeatism, despair, depression, and dejection that they saw in dialysis patients, and felt that patient “empowerment” would be a solution. The team sought to provide an opportunity for ESRD patients to explore new possibilities in their lives, seek new interests, develop new skills, and consider that their lives are not over—just different.

Promise for Living offers day-long conferences to Connecticut patients. Each conference presents the history of dialysis, its current status and impact on patients’ quality of life, plus several workshops on topics including physical and emotional fitness and well-being, medications and side-effects, dialysis families, advance directives, employment choices and benefits/concerns, and hobbies and recreation. Vocational rehabilitation counselors, renal social workers, community businessmen, dietitians, educators and most importantly, patients themselves have been among the presenters.
A survey administered at the end of each conference obtains patients’ impressions of program mechanics such as food, accommodations, location, organization, scheduling, etc., for future planning. A second questionnaire one month later queries respondents about workshop subject matter, quality of the material, value of the information, topics to address in the future, and their intention to attend more conferences. To measure outcomes, respondents are asked if there are any changes in their lives which might have been inspired by Promise of Living attendance.

Promise of Living is an ongoing, active rehabilitation program. One hundred and fifty patients have participated to date and a fourth session is in the planning stage at this time. The fourth session will be expanded, and is slated to contain workshops/group discussions dealing with sexuality/intimacy and renal disease as well as the previously included topics.

Addendum C

Recommendations for Renal Rehabilitation Made In Past 15 Years

Introduction
Although there has been a resurgence of interest in renal rehabilitation during the past several years, the issues involved in the implementation and management of efforts to further the rehabilitation of ESRD patients have never been totally ignored.

At the very outset of the ESRD Program one of the key legislators responsible for its enactment suggested that rehabilitation and return to work was a principle motivation for creating the program. Unfortunately, the initial legislation itself made no reference to rehabilitation. Subsequent amendments provided only passing, vague references to the need to encourage rehabilitation. These amendments failed to provide the institutional resources and coordination essential to the achievement of that goal.

When eventually a more specific mandate was provided in law, HCFA, the federal agency responsible for the ESRD program, recognized it lacked the experience and knowledge to effectively carry out the mandate. As a result, in the early 1980s HCFA sponsored a Rehabilitation Task Force to the ESRD program to provide guidance on how best to proceed. The task force, which included about 30 persons representing a broad spectrum of interests in the renal community (professionals, researchers, patients and government staff), set up three subcommittees on data, reimbursement policies, and the evaluation of rehabilitation programs.

The report submitted by the task force to HCFA proposed a number of broad policy initiatives relating to the needs for a data collective system and expanded research activities, changes in reimbursement and disability program policies, and the development and evaluation of rehabilitation programs focused on ESRD patients. In addition, the Task Force recommended a number of more specific administrative and
procedural changes to emphasize and enhance efforts to improve the effectiveness of renal rehabilitation programs.

Regrettably most of these recommendations were not followed. While renal rehabilitation continued to receive sporadic attention in Congress and HCFA, little was done to embody these task force recommendations in regulations or practice. Additional suggestions continued to surface in the years following the Task Force but renal rehabilitation proved to be an inspiring, but somewhat elusive sentiment, which captured the imagination of the renal community but eluded its grasp. Nonetheless, the ideas (listed below) for reforming the approach to renal rehabilitation, which have been expounded during the past 15 years, retain their appeal and are as relevant today as when they were first presented.

A. For Patients
   • Reprint the HCFA booklet “Living with ESRD” (HCFA, 1981)
   • Begin rehabilitation counseling and education before dialysis (Gutman, 1981)
   • Encourage expansion of home dialysis/exercise programs (Newmann, 1981)
   • Improve efforts to obtain donor kidneys for transplant (Rettig and Levinsky, 1991)

B. For Dialysis Facilities
   • Make an ESRD rehabilitation guidebook available to all providers (Gutman, 1981)
   • Make VR information and skills available to ESRD facilities (Gutman, 1981)
   • Mandate evening dialysis (after 5 PM) in all areas, or have centers face loss of HCFA reimbursement (Newmann, 1981)
   • Identify incentives for units to do evening dialysis (Gutman, 1981)

C. For the Business Community

D. For National Service Organizations
   • Add “Rehabilitation” to the NKUDAB charter (Vachon, 1991)
   • Involve the National Council on Disabilities in the development of rehabilitation policies and goals (Vachon, 1991)
   • Establish coalitions between kidney and disability groups (Vachon, 1991)
   • Involve kidney advocates in reauthorization of the Rehabilitation Act of ’73 (Vachon, 1991)

E. For Government
1. Data Collection
   • Establish a “JCAHO” for dialysis unit accreditation, and include outcome measures of morbidity/mortality/employment/rehabilitation/quality of life (Newmann, 1981)
   • Survey existing rehabilitation efforts to evaluate cost and outcomes against a standardized framework (Gutman, 1981)
• Develop a clinical medical information system to collect outcome data, including data on physical rehabilitation (Gutman, 1981)
• Study problem of reemployment to determine definitive answers (Vachon, 1991)
• Have ESRD Networks collect rehabilitation data (Vachon, 1991)
• Authorize the USRDS to conduct research linking epidemiological and economic data on the ESRD population, and extend the USRDS contract for an additional five years (Rettig and Levinsky, 1991)
• Expand NIDDK support for basic research into prevention and/or treatment of pre-dialysis chronic renal failure and ESRD (Rettig and Levinsky, 1991)
• Support health services research to determine which components of medical care lead to better outcomes, and to identify and validate research measures in this area (Rettig and Levinsky, 1991)

2. Social Security Administration
• Do not require employer health insurance to cover the first year of dialysis (Gutman, 1981)
• Extend Medicare entitlement for ESRD treatment to all Americans (Rettig and Levinsky, 1991)
• Remove the three-year limit on Medicare eligibility after transplant (Rettig and Levinsky, 1991)
• Continue payment for immunosuppressive drugs for renal transplant patients for the period of entitlement (Rettig and Levinsky, 1991)
• Do not reduce the composite rate or recalculate it using recent cost report data (Rettig and Levinsky, 1991)
• Update the composite rate for ESRD services annually (Rettig and Levinsky, 1991)
• Disability: SSDI and SSI
  • Reduce disability payments on a sliding scale with income, and permit more than one Trial Work Period (Gutman, 1981)
  • Increase SSA staffing to increase SSI efficiency (SSI, 1992)
  • Increase federal benefit rates to raise the income floor (SSI, 1992)
  • Increase resource limits and streamline exclusions (SSI, 1992)
  • Eliminate consideration of in-kind support/maintenance as dollar income (SSI, 1992)
  • Allow SSDI clients who earn at SGA to qualify for section 1619 (SSI) work incentives if they meet the resource limits for SSI (Majority of experts favor an SSA national demonstration) (SSI, 1992)
  • Increase earned income exclusions to $200, and two dollars maintained for each three dollars earned (and eliminate impairment-related expenses) (SSI, 1992)
  • Establish a 30-day time limit for SSA approval of a Plan to Achieve Self Support (PASS) (SSI, 1992)

3. Rehabilitation Services Administration
• Do not limit ESRD VR referrals (Gutman, 1981)
• Make other rehabilitation service options available (besides DVR), such as private
agency support (Vachon, 1991)
• Conduct a SSA demonstration project of ESRD clients, choices of public vs. private VR agencies, reimbursement of private VR activities, and revitalization of public VR (Vachon, 1991)

4. Health Care Financing Administration
• Conduct a HCFA evaluation of Network VR activities (Vachon, 1991)
• Establish a HCFA ruling to make Network annual reports open to the public (Vachon, 1991)
• Have ESRD services coordinated by a designated lead agency (Vachon, 1991)
• Increase funding for renal research (Vachon, 1991)

Addendum D

HEALTH OUTCOMES ASSESSMENT:

Relevance for Renal Rehabilitation Research

Evaluating and Improving Medical Practice
Promoting effective health care and developing better information for patients, physicians, and health care organizations about the effectiveness of particular health services are goals that should benefit all participants in health care (Roper et al., 1988).

To promote these goals, a science of health care evaluation is developing, patterned after industrial quality management science (IQMS). IQMS is also known as continuous quality improvement (CQI), or total quality management. Three activities are considered central to a quality management approach:
(1) Efforts to better understand the “customer” (in this case, the patient)
(2) Efforts to mold the culture of the organization through effective leadership to foster joy, pride, collaboration, and scientific thinking
(3) Efforts to continuously improve the quality of a service or product by modifying it based on systematic data collection and analysis (Blumenthal, 1993). While IQMS is not equally applicable to all clinical situations, physicians in daily practice may find it to be the tool they need to turn data into information as quickly and efficiently as possible.

Collection of outcomes data using well-validated measures is a prominent component of the quality management approach. Appropriate outcomes data for assessment include patients’ functional status, well-being, satisfaction, morbidity, and mortality (e.g. Health Outcomes Institute, 1993). In particular, data on ESRD patients’ functional status would provide an important marker of rehabilitation status and potential. Unfortunately the initiative to improve health care quality in the ESRD program—part of HCFA’s Health Care Quality Improvement Initiative (HCQII)—has not yet formally established a mechanism for comprehensive outcomes assessment.

HCQII of HCFA is a broad-based effort to provide information and feedback to health
care providers to use in improving care for Medicare beneficiaries. The HCQII is implemented through peer review organizations’ (PROs) use of explicit, nationally uniform criteria to examine patterns of care and outcomes, to identify “Persistent differences between the observed and the achievable in both care and outcomes...” (Jencks and Wilensky, 1992).

This “Effectiveness Initiative” was proposed in 1988 by HCFA “to bring the resources of Medicare to bear on the question of what works in the practice of medicine” (Heithoff, Lohr and Rettig, 1990). A closely related effort is the Outcomes Research Program authorized by Congress in 1987 and administered by the National Center for Health Services Research (renamed the Agency for Health Care Policy and Research, or AHCPR, in 1989).

Outcomes and effectiveness research are conceptually very similar. In 1989, the DHHS announced that it was including the HCFA Effectiveness Initiative in a comprehensive outcomes and effectiveness research program. The evolution of this DHHS program “has made it clear that improving patient outcomes is a unifying, primary objective and that identifying additional issues for further research is also important” (Heithoff, Lohr and Rettig, 1990). In addition to its responsibility for health services research, including outcomes research, and technology assessment, the AHCPR has the responsibility of developing medical practice guidelines. The congressional view is that such guidelines represent the practical application of outcomes and effectiveness research to the practice of medicine.

A major goal of HCQII is “to use practice guidelines to define a set of objectives around which HCFA, PROs, hospitals, and physicians can work together” (Jencks and Wilensky, 1992). HCFA believes that physicians become more willing to change medical practice when concepts are backed up with specific information on how individual clinicians’ practices and outcomes conform to those in the community.

**Specification and Measurement of Health Outcomes**

Strategies for health outcomes assessment are beginning to be applied to other groups of patients with chronic health conditions. These strategies can provide a useful framework to define and collect outcomes data related to rehabilitation of ESRD patients. As determined by studies of other chronic illness patients, major dimensions of health outcomes include:

- Mortality
- Morbidity and impairment (long-term clinical status)
- Health status/functional outcome/health-related quality of life

Mortality (death) may be treated as all-cause mortality, or the cause of death may itself be an outcome for analysis.

Morbidity and impairment (according to the World Health Organization, “any loss or abnormality of function or structure”) are outcomes of chronic diseases and conditions, for which many standardized clinical measures exist (blood pressure, hematocrit, tumor
Health status/functional outcome/health-related quality of life represents what the individual is able to do and how he perceives his overall health and well-being. Useful discussions of these health outcome concepts can be found in Ware (1990) and Patrick (1990). Functional outcome and functional status include disability assessment, and refer to behavioral dysfunctions due to health. Functional status measures use a standard external to the individual, such as usual role activity, walking at a certain rate, or customary self-care behaviors. These outcomes in themselves can serve as indicators of rehabilitation status—or may be predictive of other rehabilitation outcomes such as employment.

Selection of specific assessment tools to measure health status/functional outcome-health-related quality of life outcomes requires consideration of several measurement issues:

Is information most usefully collected with:

- Performance-based measures (e.g. timed walk test or chair stand, functional reach),
- Patient-reported assessments (e.g. Medical Outcomes Study Short-Form 36, or MOS SF-36),
- Health provider-reported assessments (e.g. Spitzer Quality-of-Life Index), or
- Some combination of these?

Is information desired in a:

- Generic format, allowing comparison to patients with other diseases or conditions for whom the same assessment tools are used,
- Disease- or condition-specific format uniquely relevant to the condition being assessed (e.g. hemodialysis or peritoneal access issues), or
- A combination format using both generic and disease-specific assessments?

Examples of widely used generic instruments are the MOS SF-36 (Ware and Sherbourne, 1992) and the Sickness Impact Profile (Bergner et al., 1981); disease-specific instruments relevant to ESRD are discussed in Ferrans & Powers (1985); Parfrey et al. (1989); and Laupacis et al (1992).

Utility of a Comprehensive Health Outcome Database for ESRD

Providers must place patients in a larger context to be able to compare and evaluate various forms of treatment over time and patients’ longitudinal experience. Health outcomes assessment provides a means for systematically assessing, tracking and analyzing health outcomes important to patients. When patient characteristics (age, race, gender, etc.) and treatment facility characteristics (e.g. size, profit status, urban/rural, etc.) are incorporated into the data system, the effects of care can be tracked for individual patients and for groups. Analysis of outcomes can be performed by patient demographics, diagnosis, treatment modality, provider group, cost, and many other variables.
 Appropriately analyzed, an epidemiologically sound database can furnish information to assist case management and therapy selection, including efforts to improve patients’ functional status. Such a database would be invaluable as an ongoing clinical information system, a resource for research investigations, and a basis for national health care policy related to ESRD.

HCFA’s Health Care Quality Improvement Initiative in the ESRD Program represents ongoing statistical surveillance of variations in the processes and patterns of care. These variations can be analyzed in relation to their outcomes to determine what type of care is effective, and to identify areas for improvement. HCFA has agreed to link existing databases to develop ESRD quality assurance and oversight systems. However, no proposal currently exists to include information about ESRD patients’ health status, functional outcome, and health-related quality of life in the combined database.

A comprehensive database must incorporate detailed information about morbidity and impairment in order to analyze sources of variation in patient outcomes. This information is essential to determine levels of functioning that characterize ESRD patients, relationships between functional outcome and patient characteristics, remediable sources related to poor functional outcomes, and interventions to be tested.

Addendum E

Philosophy of U.S. Programs for the Disabled

The United States spends large sums of money on the more than half of all the 30 million disabled adults in this nation who are not in the labor force. Unfortunately, no one is fully satisfied with the results of these expenditures. The disabled complain the expenditures are not enough and do not meet their needs for integration into the mainstream of society. Public officials express frustration at their inability to move a sizable portion of the disabled population into the work force despite massive expenditures on their behalf.

The patchwork of current programs aimed at the disabled expends a great deal of effort distinguishing the “disabled” from the “non-disabled,” yet gives relatively little attention to reemployment strategies for either group. Sophisticated medical rehabilitation techniques have been developed to aid certain disabled individuals, yet insufficient attention has been given to the problem of placing or retaining the individuals in the work force once their medical needs are met.

Current programs operate as work disincentives: Most disabled workers receive no benefits, yet those who do not work or who work for very low wages are offered cash benefits. The dilemma for policy makers, as in any social insurance on means-tested program, is how to balance this incentive issue with adequate benefits for those who cannot work.

A typical sequence now is for individuals to suffer an injury or illness, become
unemployed, exhaust all resources and then, facing an uncertain and threatening future, turn to disability compensation as the last remaining hope for a measure of economic security and personal dignity. It should not be surprising therefore, that the great majority who successfully run the gauntlet of the disability claims process are reluctant to seek out rehabilitation service and return to work.

Having achieved at least a modest degree of economic security, having made some adjustment to their new circumstances—and having proved that they are totally unable to work—it is no wonder many turn away the offer of rehabilitation.

A major source of the predicament in which policy makers find themselves stems from the lack of a useful and coherent definition of disability. It is widely recognized that neither the medical model of disease nor a sociological model of deviancy is entirely useful in describing disability. However, no adequate substitute model has been developed. Without a new and different conception of disability, there is not a rational model that holds constant over time.

**A Philosophical Conflict**

Much of the confusion in disability policy stems from conflicting attitudes toward the disabled.

Two opposing sets of attitudes—one contending the disabled are to be pitied and not expected to work and the other demanding full integration into society, including the opportunity to work—have coexisted uneasily for years. In fact, people subscribe to both viewpoints at the same time. As a result, our public policies are bifurcated: paying lip service to the goal of enhancing employment among the disabled while at the same time not really expecting the disabled to work.

The two major public compensation programs, Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) use “ability to work,” specifically, ability to engage in Substantial Gainful Activity, or SGA (work that pays $500 per month) as the test of who is and who is not disabled.

Once in the SSDI program, earning $500 per month over a period of nine trial work months is considered evidence of ability to engage in SGA, rendering an individual ineligible for cash benefits.

SSI cash benefits are reduced on a sliding scale as earned income increases. However, patients in both programs often refuse to try to work because they fear the loss of their cash safety net. Fear of the loss of disability cash benefits has been described as one of the most potent disincentives to a return to paid employment (HCFA, 1981; Kutner and Brogan, 1985). Uncountable numbers of patients work “under the table,” so their earnings will not jeopardize their benefits.

These disability programs have a limited goal: to provide income maintenance for those unable to work. Neither program was designed to provide a support system for working
disabled persons or to pay benefits for “partial” disabilities. Changing the programs to meet these kinds of objectives will require substantial revisions in the programs’ underlying administrative structures and philosophy.

Hope for Change
There is a hopeful aspect to the current situation. Congress (and indeed the public generally) has come to recognize three major concerns expressed about these programs:
1.) Requiring people with disabilities to emphasize their impairments in order to qualify for benefits
2.) Discouraging work efforts through the use of restrictive trial work provisions and the application of an “either/or” concept of disability
3.) Denying benefits to people with handicaps who do not find work.

During the past decade Congress has periodically debated these concerns. Although no comprehensive solution has yet been developed, the intensity of the debate has been elevated to a new level of awareness. Congress has shown a new receptivity to considering proposals for solutions to address the needs for continuity in health care, housing and related services; and for flexibility in cash and other supports to carry disabled persons through recurring spells of acute illness.

Rehabilitation Service Administration
The philosophy of vocational rehabilitation at the federal level, through the Rehabilitation Services Administration (RSA), has evolved from a purely market orientation (reintegration of physically disabled individuals into the work force to yield an economic return) to a broader viewpoint seeking to help all disabled—whether physically, mentally or economically handicapped, and regardless of the severity of the handicap or the return on that investment.

In short, the RSA broadened its focus from those with traditional physical and mental handicaps to those who are the “employment handicapped.” In response to this shift in philosophy, the rehabilitation program has increasingly provided services to handicapped persons when these services are of help in achieving a way of life which is economically and psychologically rewarding.

During these sixty years of rehabilitation efforts, program goals and priorities have greatly changed. At the start, the Vocational Rehabilitation program was limited to unemployed handicapped individuals who showed the greatest promise of returning to the work force. The philosophy was simple—returning these individuals to gainful employment meant more productivity to the nation as a whole.

Addendum F

Legislative History of the ESRD Program

The ESRD Program is a unique federal enterprise. Enacted in 1972, it is the only federal program that finances disease-specific services to a segment of the American population
on virtually a universal basis. The decision to enact this program was not a capricious one; it was done out of recognition that the medical knowledge and technology to successfully combat a formerly dreaded and fatal disease was now available, but at a cost only the federal government could finance. Members at the time thought that providing the financing to assure access to dialysis treatment would not only save untold lives but enable a large number of kidney patients to resume their careers as productive members of society.

From its beginnings, the ESRD program has been embroiled in a range of medical and political issues--the relative merits of dialysis and transplantation; center versus home dialysis; the function of Networks; the kinds of data that should be collected; and the nature of the reimbursement system. To some extent, debate over these subjects has been a healthy exercise leading to successive amendments that have improved and expanded the program over the years, largely to the benefit of patients.

The first and most significant amendments came in 1978 which filled in the details of the program. (The original enabling legislation in 1972 only authorized the program and did not provide any details on how it was to work.) The 1978 amendments sought to achieve several objectives: provide incentives to encourage the use of lower cost home dialysis; eliminate program disincentives to transplantation; create network organizations to collect data and help assure effective access to services; establish an incentive prospective reimbursement system to assure cost-effective delivery of services; and provide for continuing studies of ways to improve the program.

Over the years additional amendments based on the program’s experience (and new research) sought to make refinements without altering the program’s basic structure. In subsequent amendments, for example, the composite reimbursement method was created with the thought that it would encourage more use of home dialysis and help contain program costs; the secondary payer provision was enacted, under which Medicare would be the secondary payer for initially 12 months, later extended to 18 months, after onset of ESRD if the patient had private group insurance; the role of the Networks was expanded to include the management of a patient grievance system and encouraging patients and providers to participate in vocational rehabilitation programs; coverage for EPO was provided; and a national data system (USRDS) was created to assure the uniform collection of national data that could serve as the basis for ongoing basic and clinical research on ESRD in the U.S.

The amendments in 1986 which stipulated that Networks were to play a central role in carrying out federal policy to encourage vocational rehabilitation efforts reemphasized the congressional intent to promote rehabilitation. The committee report recognized that the promotion of vocational rehabilitation among renal patients had suffered because of a lack of “statutory clarity” about congressional intent. It asserted that while renal failure is life-threatening and chronic there is not inherent reason why it should always be considered a disability from an employment standpoint. The report suggested there is no reason why otherwise healthy dialysis (and transplant) patients whose treatments are properly synchronized to mesh with their work schedules cannot return to the work force.
Thus, it went on, the legislation explicitly states the congressional intent that the vocational rehabilitation of suitable ESRD patients be made a high priority and provides direction to the Networks to take all necessary and appropriate steps to encourage ESRD patients and facilities to participate actively in vocational rehabilitation programs.

Many of the issues which these amendments addressed are still with us and clearly the last words in the underlying policies that have not been spoken. But what is important is that these issues have not been submerged in partisan politics. They have been addressed seriously, if not always wisely, by Congress, balancing patients’ interests against program costs in such a way that the ESRD Program has successfully met the challenge of a growing renal population without suffering loss in coverage, access or public acceptance.

The legislative history of the ESRD program, in short, has been one of slow, steady progress and responsible engagement with the changing issues of cost, access, quality and rehabilitation. As the program continues to evolve it is apparent the attention of policy makers will be more sharply focused on the problems of assuring quality and promoting rehabilitation.

Addendum G

Patient Education Resources

A major portion of this listing is courtesy of the National Kidney and Urologic Diseases Information Clearinghouse, an information and referral service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

Hemodialysis & other renal-related Audiovisual materials

- Regional Kidney Disease Program. Home Hemodialysis Training. (Available from DIALYRN. Regional Kidney Program, 107 Park Ave. South, Minneapolis, MN 55415. 612-347-5986. Price: $625.00 (Videotape Set); $25.00 (manual only), $20.00 each manual for ten or more manuals; Preview available.)
- Regional Kidney Disease Program. Vascular Access Surgery for Hemodialysis. (Available from DIALYRN. Regional Kidney Program, 107 Park Ave. South, Minneapolis, MN 55415. 612-347-5986. Price: $225.00 for videotape and 15 booklets; $3.00 (1 booklet only); $25.00 (10 booklets only.)


National Kidney Foundation, Inc.  (1987).  Meeting the Challenge of Kidney Disease and Treatment.  (Available from National Kidney Foundation, Inc.  30 East 33rd Street, New York, NY  10016.  800-622-9010. Price:  $425.00, includes six video programs and 50 accompanying booklets for each program. Also sold individually.  Payments must accompany order.)


Diabetes


Diabetes Services Division, National Medical Care, Inc.  (1989).  Living with Diabetes.  (Available from Patient Videotape, Diabetes Services Division, National Medical Care, Inc.  Reservoir Place, 1601 Trapelo Road, Waltham, MA 02154.  617-466-9850.  Price:  $19.95 includes postage and handling.)
Employment, Insurance, Rehabilitation

- Amgen Reimbursement Hotline 1-800-2-PAY-EPO. This toll-free hotline can answer questions related to Medicare and Medicaid reimbursement for Epogen®. The hotline may also be able to provide referrals for other information on insurance and reimbursement.


- U.S. Department of Justice, Civil Rights Division. (1990). The Americans with Disabilities Act. (Available from U.S. Department of Justice, Coordination and Review Section, Civil Rights Division, U.S. Department of Justice, P.O. Box 6618, Washington, DC 20035-6118. 212-514-0301 or 202-514-0381.)


Office of Programs, Office of Supplemental Security Income, Baltimore, MD 21235.

Living with Kidney Disease

- Renal Network of Illinois. What is a Grievance? (Available from Renal Network of Illinois, 800 S. Wells, Suite 550, Chicago, IL 60607. 312-431-3690.)
- American Association of Kidney Patients (formerly known as NAPHT). Kidney Patient (medical alert card). (Available from American Association of Kidney Patients. 111 South Parker Street, Suite 405, Tampa, FL 33606. 1-800-749-2257.)
• Campbell, A. Suggestions for Living More Comfortably with Kidney Disease. (Available from National Kidney Foundation of Eastern Missouri and Metro East, Inc. 225 South Meramec Ave., Suite 200, St. Louis, MO 63105. 314-863-5858.)
• Renal Network of Illinois. Kinds of Treatment. (Available from Renal Network of Illinois, 800 S. Wells, Suite 550, Chicago, IL 60607. 312-431-3690.)
• National Kidney Foundation, Inc. Family Focus. (Free subscription available from the National Kidney Foundation, Inc. 30 East 33rd St., New York, NY 10016. 800-622-9010. A quarterly publication for kidney patients and their families.)
• American Association of Kidney Patients. Renalife. (Subscription information for this magazine can be obtained by contacting American Association of Kidney Patients. 111 S. Parker Street, Suite 405, Tampa, FL 33606. 800-749-2257.)

Medication
• National Kidney Foundation, Inc. Erythropoietin Therapy for the Anemia of Chronic Renal Failure. (Available from National Kidney Foundation. 30 East 33rd Street, New York, NY 10016. 800-622-9010.)

Miscellaneous
• Pediatric Kidney Disease
• Children’s Hospital, Boston. (1989). Chronic Renal Failure: An Introduction for Parents. (Available from Children’s Hospital. Attn: Evelyn Corsini, LCSW, Social Service Department, 300 Longwood Avenue, Boston, MA 02115. 617-735-6129. Price: $0.75.)

Peritoneal Dialysis
1425 Lake Cook Rd., Deerfield, IL 60015.)


Spanish Materials

• National Kidney Foundation of Texas, Inc. Dieta Para Pacientes con Fallo Renal (Diet for Patients with Renal Failure). (order number: RD2). (Available from National Kidney Foundation of Texas, Inc. 3500 Midway Rd., Suite 101, Dallas, TX 75234. 214-934-8057. Price: $2.50 plus postage and handling: 1-10 pages, $0.75; 11-30 pages, $1.50; 31-70 pages, $2.75.)


Transplantation

Addendum H

State Kidney Disease Programs
This list is courtesy of Health Technology Associates, Inc., Washington, DC

ARKANSAS
AR Kidney Disease Commission
Program Administrator
Physical Restoration Services
Div. of Rehab. Services
PO Box 3781
Little Rock, AR 72203
(501) 682-6692

DELAWARE
DE Chronic Renal Disease Prog.
Div. of Public Health
PO Box 637
Dover, DE 19903
(302) 736-4651

FLORIDA
FL ESRD Patient Serv. Committee
1 Davis Blvd., Suite 303
Tampa, FL 33606
(813) 254-2558

GEORGIA
GA Kidney Disease Prog.
Dept. of Human Resources
878 Peachtree St. NE, Rm. 102
Atlanta, GA 30309
(404) 894-6640

HAWAII
HI Chronic Renal Disease Program
State Dept. of Health
PO Box 3378
Honolulu, HI 96801
(808) 548-5835

ILLINOIS
IL Chronic Renal Disease Prog.
Dept of Public Health
535 W. Jefferson St.
Springfield, IL 62761
(217) 782-3303

IOWA
IA Chronic Renal Disease Prog.
Dept. of Public Health
Lucas State Office Bldg.
321 E. 12th St.
Des Moines, IA 50319-0075
(515) 281-4258

MARYLAND
MD Kidney Disease Program
Dept. of Health & Mental Hygiene
201 W. Preston St.
Baltimore, MD 21201
(301) 225-5000

MISSOURI
MO Kidney Prog.
Univ. of Missouri - Columbia
114 Lewis Hall
Columbia, MO 65211
(314) 882-2506

MONTANA
MT ESRD Program
Dept. of Health & Environmental Sciences
Cogswell Bldg., 1400 Broadway
Helena, MT 59620
(406)444-2544

NEBRASKA
NE Chronic Renal Disease Prog.
Dept. of Health
PO Box 95007
Lincoln, NE 68509-5007
(402) 471-2647

NEW JERSEY
NJ Renal Prog.
State Dept. of Health
Div. of Epidemiology & Disease Control
University Office Plaza, CN 369
3635 Quackerbridge Rd.
Trenton, NJ 08625-0369
(609) 588-7474

NEW YORK
NY Home Dialysis Assist. Prog.
State Dept. of Health
ESP Tower Bldg., Room 523,
Albany, NY 12237
(518) 474-4444

NORTH CAROLINA
NC Kidney Prog.
Div. of Health Services
PO Box 2091
Raleigh, NC 27602-2091
(919) 733-7081

PENNSYLVANIA
PA Chronic Renal Disease Prog. Dept. of Health
Rm. 710 Health & Welfare Bldg.
Harrisburg, PA 17108
(717) 787-9772

TENNESSEE
TN Renal Disease Prog.
Dept. of Health & Environment
One Hundred 9th Ave. N
Nashville, TN 37219-5405
(615) 741-7366

TEXAS
TX Kidney Health Program
Dept. of Health
1100 W. 49th St.
Austin, TX 78756-3184
(512) 458-7796

WASHINGTON
WA Kidney Disease Prog.
Dept. of Social & Health Services
Health Div.
State Vocational Rehabilitation Agencies
This list is courtesy of the U.S. Department of Education Office of Special Education and Rehabilitation Services, Washington, D.C.

ALASKA
Division of Vocational Rehab.
801 W. 10th St., Suite 200
Juneau, AK 99801-1894
(907) 465-2814

ALABAMA
Div. of Rehab. Services
PO Box 11586
Montgomery, AL 36111-0586
(205) 281-8780

AMERICAN SAMOA
Div. of Vocational Rehab.
Dept. of Human Resources
American Samoa Government
Pago Pago, American Samoa 96799
10288011 684-633-2336

ARIZONA
Rehab. Services Admin.
Dept. of Economic Security
1789 W. Jefferson, 2nd Fl., NW
Phoenix, AZ 85007
(602) 542-3332

ARKANSAS
Div. of Rehab. Services
Dept. of Human Services
PO Box 3781
Little Rock, AR 72203
ARKANSAS
Div. of Services for the Blind
Dept. of Human Services
PO Box 3237, 411 Victory St.
Little Rock, AR 72203
(501) 324-9270

CALIFORNIA
Dept. of Rehab.
830 K St. Mall, PO Box 94422
Sacramento, CA 95814
(916) 445-3971

COLORADO
Rehab. Services
Dept. of Social Services
1575 Sherman St., 4th Floor
Denver, CO 80203-1714
(303) 866-2866

CONNECTICUT
Bureau of Rehab. Services
Dept. of Human Resources
10 Griffin Rd. N
Windsor, CT 06095
(203) 298-2003

CONNECTICUT
Board of Ed. & Serv. for the Blind
Dept. of Human Resources
170 Ridge Rd.
Wethersfield, CT 06109
(203) 566-5800

COMMONWEALTH OF NORTHERN MARIANA ISLANDS
Vocational Rehab. Div.
Commonwealth of the Northern Mariana Islands
PO Box 1521-CK, Saipan
Northern Mariana Islands 96950
10288-01 1 670-234-6538

DELAWARE
Div. for the Visually Impaired
Health & Social Serv. Campus
Biggs Bldg., 1901 N. Dupont Hwy.
New Castle, DE 19720
(302) 577-4731
DELAWARE
Div. of Vocational Rehab.
Dept. of Labor
Elwyn Bldg., 321 E. 11th St.
Wilmington, DE 19801
(302) 577-2850

DISTRICT OF COLUMBIA
DC Rehab. Services Admin.
Commission on Social Services Dept. of Human Services
Government of DC
605 G Street, NW, Rm. 1111
Washington, DC 20001
(202) 727-3227

FLORIDA
Div. of Vocational Rehab.
Dept. of Labor & Employment Security
1709-A Mahan Dr.
Tallahassee, FL 32399-0696
(904) 488-6210

FLORIDA
Div. of Blind Services
Dept. of Ed.
Douglas Bldg.
2540 Executive Ctr. Circle W
Tallahassee, FL 32301
(904) 488-1330

GEORGIA
Div. of Rehab. Services
Dept. of Human Resources
878 Peachtree St. NE, Rm. 706
Atlanta, GA 30309
(404) 894-6670

GUAM
Dept. of Vocational Rehab. Government of Guam
Harmon Industrial Park
122 Harmon Plaza, Rm. B201
Guam 96911
10288-01 1-671-646-9468
HAWAII
Div. of Vocational Rehab.
Dept. of Human Services
Bishop Trust Bldg.
1000 Bishop St., Rm. 615
Honolulu, HI 96813
(808) 586-5355

IDAHO
ID Commission for the Blind
341 W. Washington St.
Boise, ID 83702
(208) 334-3220

IDAHO
Div. of Vocational Rehab.
Len B. Jordon Bldg., Rm. 150
650 W. State
Boise, ID 83720
(208) 334-3390

ILLINOIS
IL Dept. of Rehab. Serv.
623 E. Adams St.
PO Box 19429
Springfield, IL 62794-9429
(217) 782-2093

INDIANA
Div. of Rehab. Services
IN Dept. of Human Serv.
IN Government Center
150 W. Market St.
PO Box 7083
Indianapolis, IN 46207-7083
(317) 232-1147

IOWA
Dept. for the Blind
524 4th St.
Des Moines, IA 50309-2364
(515) 281-1334

IOWA
IA Div. of Vocational Rehab. Serv. Dept. of Ed.
510 E. 12th St.
Des Moines, IA 50319
(515) 281-6731

KANSAS
Dept. of Social & Rehab. Services
Biddle Bldg., 1st Fl.
300 Southwest Oakley St.
Topeka, KS 66606
(913) 296-3911

KENTUCKY
KY Dept. for the Blind
427 Versailles Rd.
Frankfort, KY 40601
(502) 564-4754

KENTUCKY
Dept. of Vocational Rehab.
500 Mero St.
Frankfort, KY 40601
(502) 564-4566

LOUISIANA
Rehab. Services
Dept. of Social Services
PO Box 94371
Baton Rouge, LA 70804
(504) 342-2285

MAINE
Bureau of Rehab.
Dept. of Human Services
35 Anthony Ave.
Augusta, ME 04333-0011
(207) 624-5300

MARYLAND
Vocational Rehab. Div.
Vocational Rehab.
Administrative Offices
2301 Argonne Dr.
Baltimore, MD 21218
(301) 554-3000

MASSACHUSETTS
MA Rehab. Commission
Fort Point Place  
27-43 Wormwood St.  
Boston, MA 02210-1606  
(617) 727-2172

MASSACHUSETTS  
MA Commission for the Blind  
88 Kingston St.  
Boston, MA 02111-2227  
(617) 727-5550 Ext. 4503

MICHIGAN  
MI Rehab. Services  
Dept. of Ed.  
PO Box 30010  
Lansing, MI 48909  
(517) 373-3391

MICHIGAN  
Commission for the Blind  
Dept. of Labor  
201 N. Washington Sq.  
Lansing, MI 48909  
(517) 373-2062

MINNESOTA  
Div. of Rehab. Services  
Dept. of Jobs & Training  
390 N. Robert St., 5th Fl.  
St. Paul, MN 55101  
(612) 296-1822

MINNESOTA  
State Services for the Blind  
1745 University Ave.  
St. Paul, MN 55104  
(612) 642-0508

MISSISSIPPI  
Dept. of Rehab. Services  
PO Box 22806  
Jackson, MS 39225-2806  
601-936-7790

MISSOURI  
State Dept. of Elementary & Secondary Ed.  
Div. of Vocational Rehab.
2401 E. McCarty St.  
Jefferson City, MO 65101  
(314) 751-3251

MISSOURI  
Rehab. Services for the Blind  
Div. of Family Services  
619 E. Capitol  
Jefferson City, MO 65101  
(314) 751-4249

MONTANA  
Dept. of Social & Rehab. Services  
Rehab./Visual Services Div.  
PO Box 4210, 111 Sanders  
Helena, MT 59604  
(406) 444-2590

NEBRASKA  
Div. of Rehab. Services  
State Dept. of Ed.  
301 Centennial Mall S, 6th Fl.  
Lincoln, NE 68509  
(402) 471-3645

NEBRASKA  
Services for the Visually Impaired  
Dept. of Public Institutions  
4600 Valley Rd.  
Lincoln, NE 68510-4844  
(402) 471-2891

NEW HAMPSHIRE  
Div. of Vocational Rehab.  
State Dept. of Ed.  
78 Regional Dr.  
Concord, NH 03301-9686  
603-271-3471

NEVADA  
Rehab. Div.  
Dept. of Human Resources  
5th Fl., 505 E. King St.  
Carson City, NV 90710  
(702) 687-4440

NEW JERSEY
NEW JERSEY
Commission for the Blind & Visually Impaired
NJ Dept. of Human Services
153 Halsey St., 6th Fl.
PO Box 47017
Newark, NJ 07101
(201) 648-2324

NEW MEXICO
Div. of Vocational Rehab.
State Dept. of Ed.
604 W. San Mateo St.
Santa Fe, NM 87503
(505) 827-3511

NEW MEXICO
Commission for the Blind
PERA Bldg., Rm. 205
Santa Fe, NM 87503
(505) 827-4479

NEW YORK
State Dept. of Social Serv.
Commission for the Blind & Visually Handicapped
10 Eyck Office Bldg.
40 North Pearl St.
Albany, NY 12243
(518) 473-1801

NEW YORK
Vocational Ed. Serv. for Individuals with Disabilities (VESID)
NY State Ed. Dept.
One Commerce Plaza, 16th Fl.
Albany, NY 12234
(518) 474-2714

NORTH CAROLINA
Div. of Services for the Blind
NC Dept. of Human Resources
309 Ashe Ave.
Raleigh, NC 27606  
(919) 733-9822  
NORTH CAROLINA  
Div. of Vocational Rehab. Services  
Dept. of Human Resources  
State Office  
PO Box 26053  
Raleigh, NC 27611  
(919) 733-3364

NORTH DAKOTA  
Office of Vocational Rehab.  
Dept. of Human Services Administrative Office  
400 E. Broadway Ave., Suite 303  
Bismarck, ND 58501-4038  
(701) 224-3999

OKLAHOMA  
Rehab. Services Div.  
Dept. of Human Services  
PO Box 25352  
Oklahoma City, OK 73125  
(405) 424-6006 Ext. 2840

OREGON  
Vocational Rehab. Div.  
Dept. of Human Resources  
2045 Silverton Rd. NE  
Salem, OR 97310  
(503) 378-3830

PENNSYLVANIA  
Bureau of Blindness & Visual Services  
Dept. of Public Welfare  
1301 North 7th St.  
PO Box 2675  
Harrisburg, PA 17105  
(717) 787-6176

PUERTO RICO  
Vocational Rehab.  
Dept. of Social Services  
PO Box 1118  
Hato Rey, Puerto Rico 00919  
(809) 725-1792
OHIO
OH Rehab. Services Commission
400 E. Campus View Blvd.
Columbus, OH 43235-4604
(614) 438-1210 Voice/TDD

OREGON
Commission for the Blind
535 SE 12th Ave.
Portland, OR 97214
(503) 731-3221

PENNSYLVANIA
Office of Vocational Rehab.
Dept. of Labor & Industry
1300 Labor & Industry Bldg.
7th & Forster St.
Harrisburg, PA 17120
(717) 787-5244

RHODE ISLAND
Vocational Rehab.
Dept. of Human Services
40 Fountain St.
Providence, RI 02903
(401) 421-7005

SOUTH CAROLINA
Commission for the Blind
1430 Confederate Ave.
Columbia, SC 29201
(803) 734-7520

SOUTH CAROLINA
SC Vocational Rehab. Dept.
PO Box 15, 1410 Boston Ave.
West Columbia, SC 29171-0015
(803) 734-4300

SOUTH DAKOTA
Div. of Rehab. Services
East Hwy. 34 c/o 500 E
Capitol Pierre, SD 57501-5070
(605) 773-3195

SOUTH DAKOTA
Div. of Services to the Blind & Visually Impaired
East Hwy. 34 c/o 500 E
Capitol Pierre, SD 57501-5070
(605) 773-4644

TENNESSEE
Div. of Vocational Rehab.
Dept. of Human Services
Citizen Plaza Bldg. 15th Fl.
400 Deaderick St.
Nashville, TN 37219
(615) 741-2521

TEXAS
TX Commission for the Blind
Administration Bldg.
4800 N. Lamar
Austin, TX 78711
(512) 459-2600

TEXAS
TX Rehab. Commission
4900 N. Lamar, Rm. 7102
Austin, TX 78751-2316
(512) 483-4001

REPUBLIC OF PALAU
Bureau of Ed.
PO Box 189, Koror, Palau
Western Caroline Islands 96940
102880011-680-488-2952

UTAH
UT State Office of Rehab.
250 E. 500 South
Salt Lake City, UT 84111
(801) 538-7530

VERMONT
Vocational Rehab. Div.
Agency of Human Services
Osgood Bldg.
Waterbury Complex
103 S. Main St.
Waterbury, VT 05676
(802) 241-2189

VERMONT
Div. for the Blind & Visually Impaired
Agency of Human Services
Osgood Bldg.
Waterbury Complex
103 S. Main St.
Waterbury, VT 05676
(802) 241-2211

VIRGIN ISLANDS
Div. of Disabilities & Rehab. Serv. Dept. of Human Services
Barbel Plaza S
St. Thomas, Virgin Island 00802
(809) 774-0930

VIRGINIA
Dept. for the Visually Handicapped
Commonwealth of VA
397 Azalea Ave.
Richmond, VA 23227-3697
(804) 371-3145

VIRGINIA
Dept. of Rehab. Services Commonwealth of VA
4901 Fitzhugh Ave.
PO Box 11045
Richmond, VA 23230-1045
(804) 367-0316

WASHINGTON
Div. of Vocational Rehab.
Dept. of Social & Health Services
PO Box 45340
Olympia, WA 98504-5340
(206) 753-5473

WEST VIRGINIA
Div. of Rehab. Services
State Board of Rehab.
State Capitol Complex
Charleston, WV 25305
(304) 766-4601

WASHINGTON D.C.
CSAVR
PO Box 3776
Washington, DC 20007
Addendum I

Glossary of Acronyms

AACPR - American Association of Cardiovascular and Pulmonary Rehabilitation
AAKP - American Association of Kidney Patients
AARP - American Association of Retired Persons
ACSM - American College of Sports Medicine
ADA - Americans with Disabilities Act
AIDS - Acquired Immune Deficiency Syndrome
AKF - American Kidney Fund
AHCPR - Agency for Health Care Policy Research
ANNA - American Nephrology Nurses’ Association
APTA - American Physical Therapy Association
ASN - American Society of Nephrology
BONENT - Board of Nephrology Examiners - Nursing and Technology
CAPD - Continuous Ambulatory Peritoneal Dialysis
CCPD - Continuous Cycling Peritoneal Dialysis
CNSW - Council of Nephrology Social Workers
CQI - Continuous Quality Improvement
CRF - Chronic Renal Failure
CNN - Certified Nephrology Nursing
CRN - Council on Renal Nutrition
CSAVR - Council of State Administrators of Vocational Rehabilitation
EPO - Erythropoietin (synthetic hormone to treat anemia)
ESRD - End Stage Renal Disease
FICA - Federal Insurance Contributions Act
GED - General Education Diploma
HCFA - Health Care Financing Agency
HCQII - Health Care Quality Improvement Initiative
HDL - High Density Lipoprotein ("good" cholesterol)
HHS - Health and Human Services
HRS - Health and Rehabilitative Sciences
ICD - International Center for the Disabled
IOM - Institute of Medicine
IQMS - Industrial Quality Management Science
JCAHO - Joint Commission on Accreditation of Healthcare Organizations
MOS - Medical Outcomes Study
NKF - National Kidney Foundation
NIDDK - National Institute of Diabetes and Digestive and Kidney Diseases
NKUDAB - National Kidney and Urologic Diseases Advisory Board
NKUDIC - National Kidney and Urologic Diseases Information Clearinghouse
NRAA - National Renal Administrator’s Association
OT - Occupational Therapy
OVR - Office of Vocational Rehabilitation
PASS - Plan to Achieve Self Support
PL - Public Law
PORT - Patient Outcomes Research Teams
PT - Physical Therapy
RN - Registered Nurse
RPA/REF - Renal Physicians Association/Research and Education Foundation
RRAP - Renal Rehabilitation Assessment Center
RRR - Renal Rehabilitation Report
RSA - Rehabilitation Services Administration
SGA - Substantial Gainful Activity
SIG - Special Interest Group
SSA - Social Security Administration
SSDI - Social Security Disability Insurance
SSI - Supplemental Security Income
UNOS - United Network for Organ Sharing
USRDS - United States Renal Data System
VR - Vocational Rehabilitation
Addendum J

Glossary of Organizations

AACVPR - American Association of Cardiovascular and Pulmonary Rehabilitation
AAKP - American Association of Kidney Patients
AARP - American Association of Retired Persons
ACSM - American College of Sports Medicine
AKF - American Kidney Fund
AHCPR - Agency for Health Care Policy Research
ANNA - American Nephrology Nurses’ Association
APTA - American Physical Therapy Association
ASN - American Society of Nephrology
BONENT - Board of Nephrology Examiners - Nursing and Technology
CCNDT - Council on Clinical Nephrology, Dialysis and Transplantation
CNSW - Council of Nephrology Social Workers
CNN - Certified Nephrology Nursing
CNNT - Council of Nephrology Nurses and Technicians
CRN - Council on Renal Nutrition
CSAVR - Council of State Administrators of Vocational Rehabilitation
HCFA - Health Care Financing Agency
ICD - International Center for the Disabled
ISN - International Society of Nephrology
ISPD - International Society of Peritoneal Dialysis
NANT - National Association of Nephrology Technologists
NKF - National Kidney Foundation
NIDDK - National Institute of Diabetes and Digestive and Kidney Diseases
NKUDAB - National Kidney and Urologic Diseases Advisory Board
NRAA - National Renal Administrators Association
OVR - Office of Vocational Rehabilitation
RPA/REF - Renal Physicians Association/Research and Education Foundation
RRAP - Renal Rehabilitation Assessment Center
RSA - Rehabilitation Services Administration
SSA - Social Security Administration
UNOS - United Network for Organ Sharing
VIII. References


HCFA, Division of Network Administration. (9/11/81). Rehabilitation and ESRD patients: A preliminary analysis of current barriers and disincentives to and options for enhancing rehabilitation of ESRD patients. Office of ESRD, Office of Special Programs.


Publishing. (Available from Amgen, Inc.)


Lublin, B. (1992, March). Vocational rehabilitation challenges in ESRD. Presentation at Emory University Workshop, Atlanta, Georgia.


Newmann, J. Letter to Edward Kelly. Personal correspondence, 7/22/81.

Newmann, J. (1982). Maximizing patients’ involvement in treatment and rehabilitation. Samuel B. Chyatte Memorial Lecture, presented to the Conference on Rehabilitation Involvement and Patient Options in Chronic Renal Disease, Center for Rehabilitation Medicine, Emory University School of Medicine, Atlanta, Georgia, May 13, 1982.


Newmann, J. (1993). Presentation recorded in minutes from the April 25-26, 1993 meeting of the Life Options Advisory Council, in Chicago, IL.


Vachon, A. (1991). Has the federal government failed people with disabilities? The promise of vocational rehabilitation to people with end-stage renal disease. The National Disability Policy Center. (Revised version of a paper presented at the 14th Annual Renal Rehabilitation Conference sponsored by the Department of Rehabilitative Medicine, Emory University, March 7, 1991)


Witten, B. (1993B). Presentation recorded in minutes from the April 25-26, 1993 meeting of the Life Options Advisory Council, in Chicago, IL.