

B. IMPROVE THE INDEPENDENCE, QUALITY OF LIFE, AND REHABILITATION (TO THE EXTENT POSSIBLE) OF INDIVIDUALS WITH ESRD THROUGH TRANSPLANTATION, USE OF SELF-CARE MODALITIES (E.G. PERITONEAL DIALYSIS, HOME HEMODIALYSIS), IN-CENTER SELF-CARE, AS MEDICALLY APPROPRIATE, THROUGH THE END OF LIFE

➤ **Withdrawal from Dialysis Trends**

End stage renal disease continues to impose a high mortality burden. Life on dialysis has improved, but complex medical and emotional challenges remain. As dialysis has become increasingly accepted as a routine medical intervention, the population receiving this difficult and intrusive treatment has become increasingly elderly, sick, fragile and vulnerable.

It is well known that every year, a substantial proportion of dialysis patient deaths are preceded by discontinuation of treatment. CMS Form 2746, the Death Notification Form, has data elements inquiring about discontinuation of dialysis. Questions about patient and family involvement in the decision to discontinue, whether the patient received hospice care and a cause of death item #104 related to discontinuation, “Withdrawal from dialysis/uremia”. If the response to renal replacement therapy was discontinued prior to death is “yes”, the reason for withdrawal are also recorded. Five choices are provided:

- A) Following HD and/or PD access failure
- B) Following transplant failure
- C) Following chronic failure to thrive
- D) Following acute medical complication
- E) Other

Network of New England’s data has been used to follow the trends in this important area of end of life care. Table I contains the number of deaths reported in Network #1 for ESRD patients in the six states of New England from year 1995 to 2008. The data are analyzed for the number of patients that discontinued from dialysis prior to death and also by diabetes, the primary cause of ESRD (Figure 19 & 20). Withdrawal in the diabetic population due to medical complications is higher than the non-diabetic population. This is likely due to the complex multi-system complications experienced by many long-term diabetic patients. Based on data from the 2746 form, the withdrawal from dialysis rate for this Network Organization is one of the highest in the country.

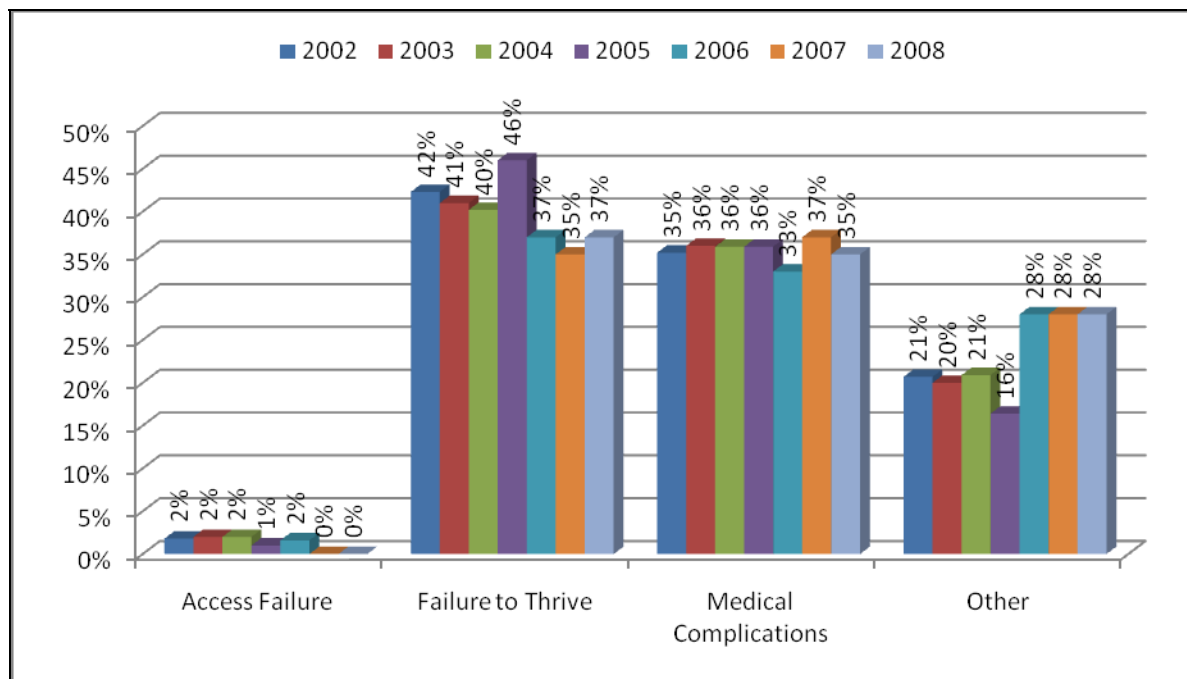
Table I: Network #1 Annual Number of Deaths, Discontinuations by Diabetic Status

	Patient Deaths			Patient discontinued		Total Discontinued	
	Diabetic	Non-Diabetic	Total	Diabetic	Non-Diabetic	N	%
1995	760	1,298	2,049	167	317	484	23%
1996	865	1,341	2,203	201	355	556	25%
1997	852	1,406	2,218	231	350	581	26%
1998	983	1,426	2,395	240	434	674	28%
1999	1,104	1,510	2,593	297	452	749	28%
2000	1,081	1,583	2,665	261	552	813	31%
2001*	1,118	1,630	2,748	349	534	883	32%
2002**	1,139	1,638	2,777	338	558	896	32%
2003***	1,234	1,615	2,853	387	574	961	33%
2004	1,217	1,668	2,885	398	620	1,018	35%
2005	1,102	1,848	2,956	378	656	1,034	35%
2006	1067	1790	2857	362	687	1103	39%
2007	1090	1614	2804	391	633	1024	36%
2008	1103	1620	2723	393	666	1059	39%

Note: * Primary diagnosis was missing for 26 patients. ** Primary diagnosis was missing for 10 patients. ***Primary diagnosis is missing for 4 patients. These patients were grouped in the non-diabetic column for all years.

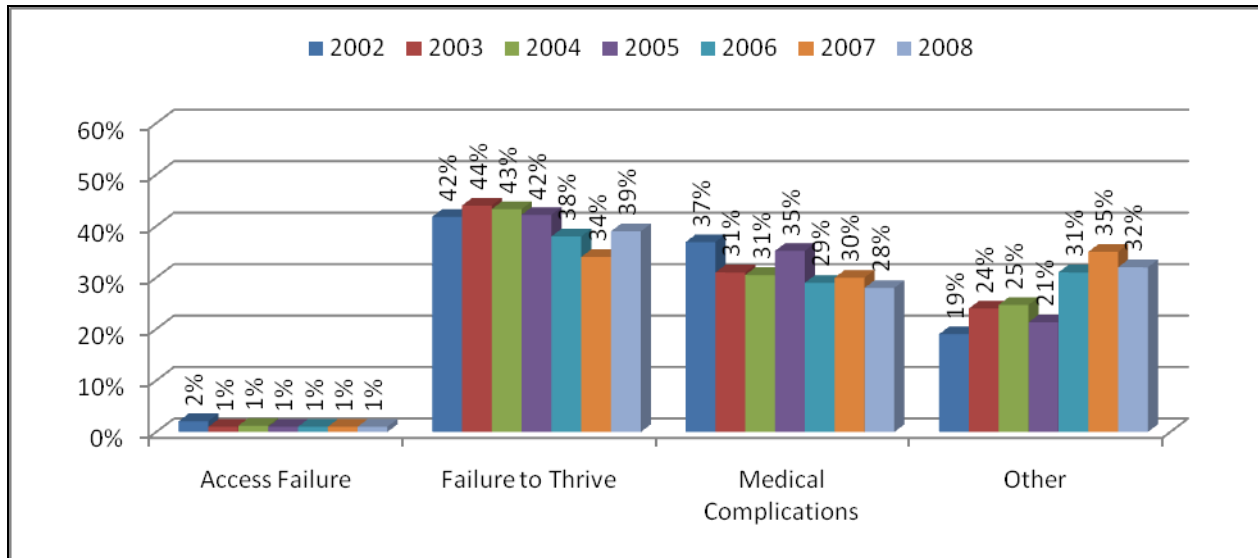
Source: CMS Form 2746

Figure 19: Reason for Withdrawal from Dialysis: Trend for Diabetic Patients



Source: CMS Form 2746

Figure 20: Reason for Withdrawal from Dialysis: Trend for Non-Diabetic Patients



Source: CMS Form 2746

➤ **Withdrawal Special Project**

The introduction of the new 2746 form in 2004 captures more information on withdrawal of dialysis before death. However, no definitions or instructions exist as to when to use withdrawal or discontinue dialysis. Based on these observed trends, this Network along with ESRD professionals submitted and was awarded special project funding by CMS. The project was conducted from July 2005 to June 2006. Network #5 and #12 were partners in this activity.

This project used a structured questionnaire for telephone interviews with the professionals at the provider that had the most knowledge about the patient death event. The patient sample was drawn from the death events reported in the three Network Organizations that participated in the study between 9/1/2005 to 2/28/2006. Provider sample from the deceased patient population was developed to assure sufficient representation for facilities that reported African American patient deaths and experience in small dialysis providers. Interviews were conducted with facility personnel related to 578 patient deaths in the three participating Networks. A final report was submitted to CMS with recommendations. The study shed light on racial and regional disparities in discontinuation of dialysis with African American’s discontinuing dialysis at half the rate as Non African Americans.

The study identified a need to increase the level of understanding of ESRD professionals on hospice benefits and how they can be used with ESRD Medicare benefits. A need to educate patients and professionals by promoting the End of Life Coalition, its activities and use of its website was also identified. It was recommended that CMS should clarify its policy on hospice services availability to dialysis patients and inform the hospice and ESRD community of the acceptable protocols. Furthermore, definitions were recommended for discontinuation of dialysis and withdrawal from dialysis. The new Conditions for Coverage for End Stage Renal Disease facilities require addressing

end of life choices under patient rights. The results of this study related to hospice issues were published in ANNA in 2008 and another paper is being developed.

References:

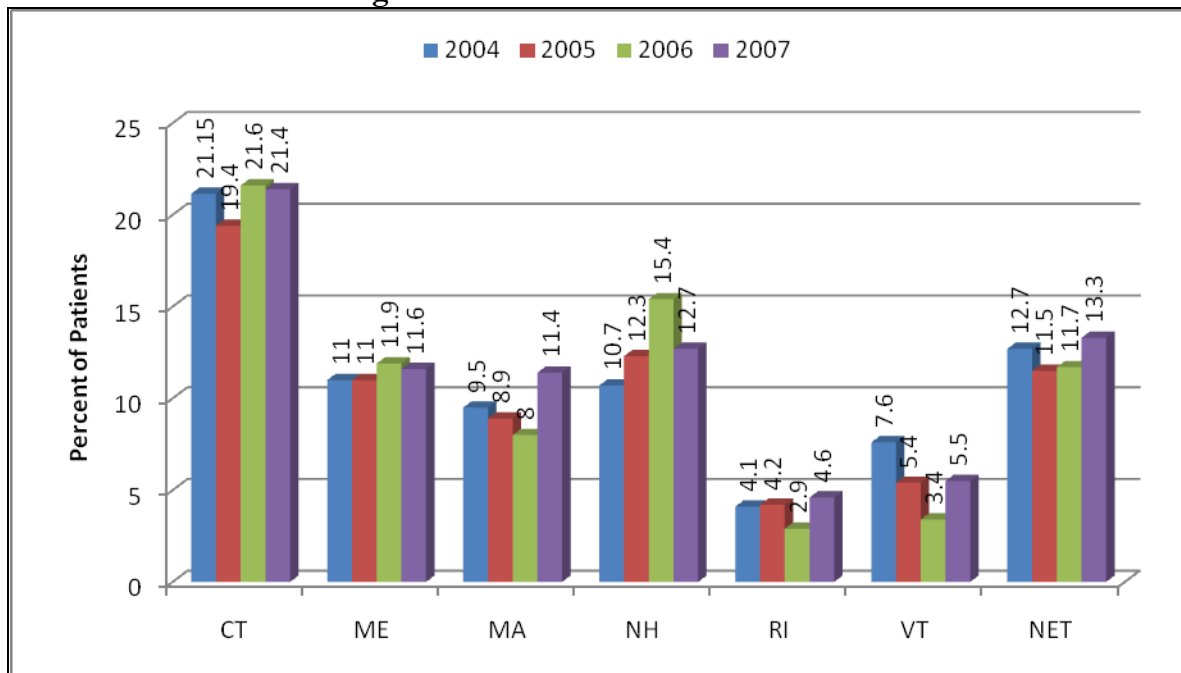
Thompson K, Bhargava J, Bachelder R, Bova-Collis R, Moss AH. Hospice and ESRD: Knowledge deficits and underutilization of program benefits. Journal of the American Nephrology Nurses Association 2008; 35:461-467.

➤ **Profile Analysis of ESRD Incidence Population**

Network #1 annually profiles the utilization of treatment options available to new patients with ESRD. Network #1 is interested in analyzing facility activities as it relates to selection of modality options by new patients during the first twelve months of their individual ESRD experience with the emphasis being on self care dialysis or transplantation. In order to accomplish a twelve-month retrospective analysis of “new patient” experiences, a full year must lapse for all members of the study cohort. Therefore, the most recent data analyzed is representative of the 2007 incidence patient census by provider of service.

Network of New England promotes new patients select home dialysis within first one year of ESRD. This rate is 13.7 for the Network in 2007. In recent years home hemodialysis is on the rise. However, the individual state experience ranged from a high of 21.4% in Connecticut to a low of 4.6% in Rhode Island (Figure 21).

Figure 21: 2004, 2005, 2006 and 2007 Incidence Patients by First Provider of Service Selecting Home Self-Care Within First 12 Months

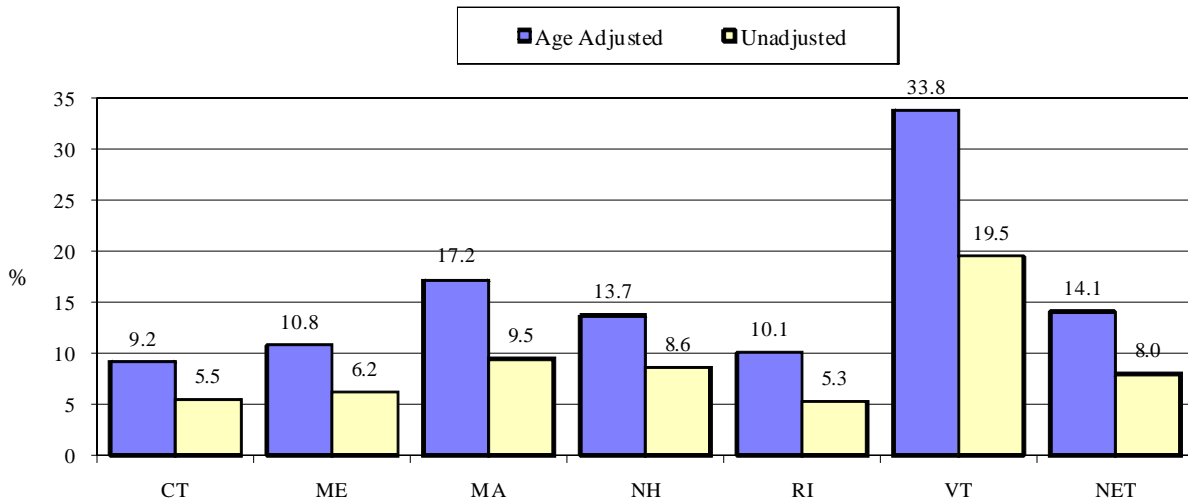


Note: Home patients for each state or Network are divided by the incident population for that state or Network. Source : SIMS data files

There continues to be high utilization of in-center treatment and steady slow growth in the total number of ESRD providers in New England. New England providers continue to expand the number of treatment stations at existing facilities or open treatment centers at new locations. This improved availability of treatment resources may be one factor contributing to a low percent of patients selecting home/self care. Incident patients selecting home/self care is; 1994 - 27.8%; 1995 - 24%; 1996 - 19.9%; 1997 - 17.7%, 1998 - 16.8%, 1999 - 19.7%, 2000 - 15.7%, 2001 - 14.9%, 2002 - 13.7%, 2003 - 13.1%, 12.7% - 2004, 11.5% in 2005, 11.7% in 2006 and 13.3% in 2007.

The percent of new patients in 2007 who were transplanted in their first twelve-month experience was 8.0%. Adjusted for age by excluding patients over age 70 of the 2007 incidence population reveals a higher transplant activity rate of 14.1% (Figure 22). Network of New England promotes new patients select transplantation within the first year of ESRD based on age-adjusted population (Table J).

Figure 22: Transplantation 2007: Incidence Patients Receiving Transplant Within First 12 Months



Note: Adjusted = Denominator Removes Pts. >= Age 70

Note: Transplantations for each state or Network are divided by the incident population for state by residence or Network. Age adjusted category removes patients of age >=70 from the denominator.

Source: SIMS data files

Table J: 2005 - 2007 Incidence Patients By State of Residence Selecting Home Dialysis By 1st ESRD Provider: First 12 Months ESRD Experience

State	New Patients			Transplanted			Home		
	2005	2006	2007	2005	2006	2007	2005	2006	2007
CT	1002	990	991	50	29	55	194	214	212
ME	341	344	268	21	23	17	36	41	31
MA	1734	1794	1723	137	156	164	158	144	196
NH	280	259	268	27	17	23	40	40	34
RI	326	311	326	25	26	17	15	9	15
VT	150	146	128	14	17	25	5	5	7
Total	3867	3870	3732	274	268	301	446	452	495
Total %	100	100	100	7.1	6.9	8.1	11.5	11.7	13.3

Note: 34 patients with state unknown or residing in NY are not in state totals for YR 2005

27 patients residing in NY or other states are not in state totals for New England for YR 2006

28 patients residing in NY or other states are not in state totals for New England for YR 2007

➤ Prevalence Population and Employment Status

One of the functions of Network Organizations, consistent with sound medical practice, is to encourage participation of the patients and providers of the services in vocational rehabilitation programs. As part of the new 2744 (annual facility survey) form, Network Organizations collect information on vocational rehabilitation referrals, employment and student status among patients between the ages of 18 to 54. This age-range cohort is often referred to as “working age”.

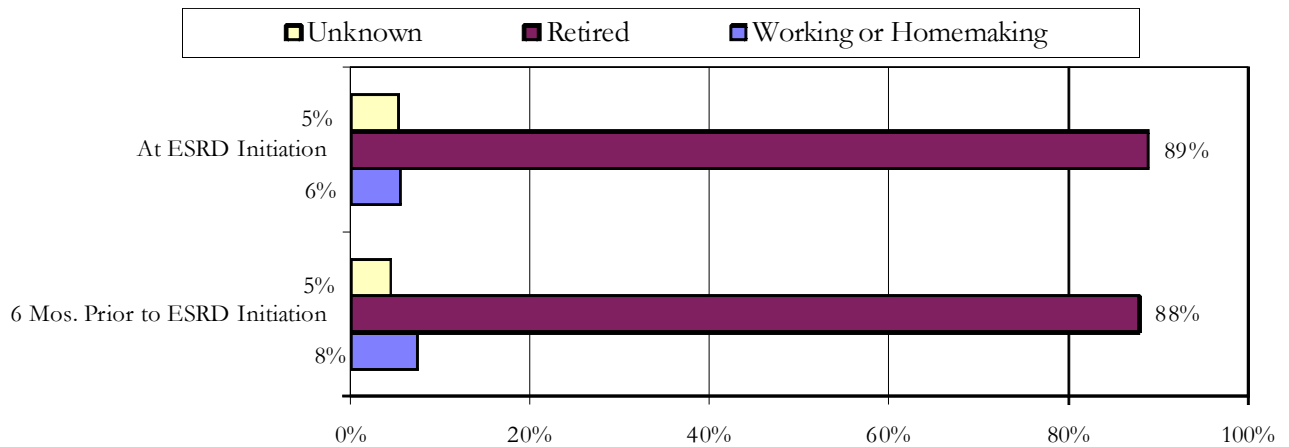
Based on the prevalent population as of December 31st 2008, there were 3,205 dialysis patients in New England within the working-age range (See Table 8 in data tables sections). One hundred and twelve patients, or 3.5% were referred to or receiving VR services during the reporting year. Twenty six percent (26%) of the patient group was reported as either workers or students. Combined, 30% of New England dialysis patients are actively involved in traditional life pursuits (employment or education).

➤ Incident Population and Employment Status

Analysis of the Network of New England’s incident data gives insights into patients’ employment status 6-months prior and at the initiation of the ESRD. CMS’s Medical Evidence Report and Registration (2728) form contains data elements, which allow for comparison between patient employment status, six months prior to initiation of ESRD treatment, and at the initiation of ESRD treatment. This form also captures data on the type of employment, such as whether a patient is a student, homemaker, retired due to disability, or retired due to age/preference. In 2008 a total of 3,852 individuals were registered as new patients for the New England states. Of those patients,

56% were over the age of 65 when first becoming ESRD patients. Analysis of the employment status of the incident population over the age of 65, 6-months prior to initiation of ESRD, indicates that 88% were retired due to disability, age or by preference, while 8% were working or homemaking. However, analysis of the employment status of the same population at the initiation of ESRD indicates that the number of retired increased to 89 % (Figure 23).

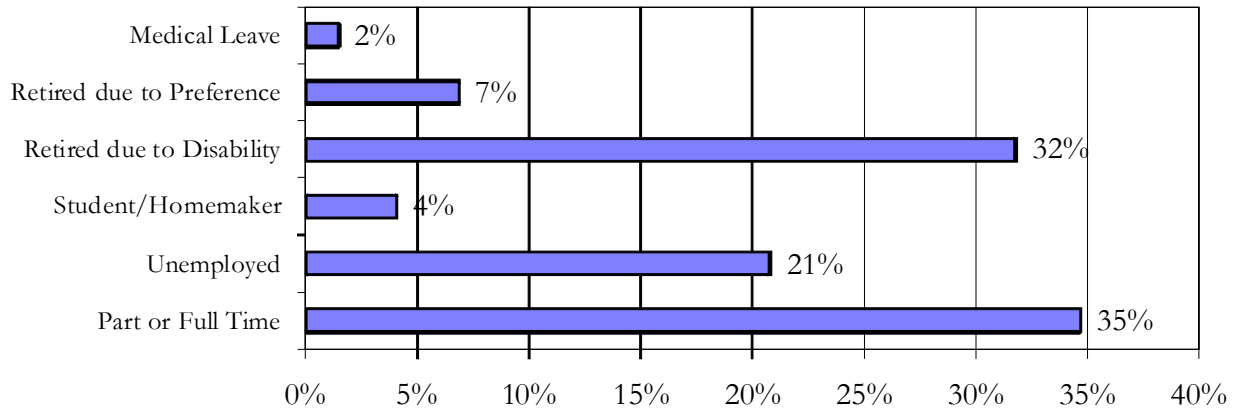
**Figure 23: 2008 Incidence Patients ≥ 65 *
Role Functioning Status (N = 2,163)**



* Percent will not equal 100, due to other functional status categories not included in this figure.
Source: CMS Form 2728

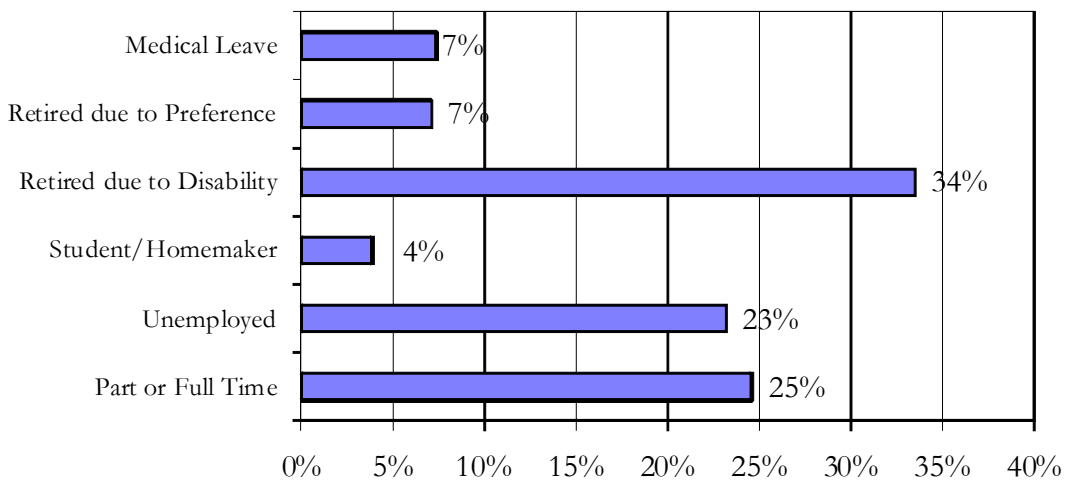
In 2008 there were 1,689 (44%) incident ESRD patients who were under age 65. Six months prior to initiation of ESRD treatment, 35% of this cohort group was working, 4% were students or homemakers and 32% reported retired due to disability or age preference. Looking at the same group at the initiation of ESRD, 25% were working, 4% were students or homemaker, and 34% were reported retired due to disability or age preference (Figures 24 and 25).

Figure 24: 2008 Adult Incidence Patients Age <65 Functional Status 6 Mos. Prior to ESRD Initiation (N = 1,689)



Source: CMS Form 2728

Figure 25: 2007 Incidence Patients < 65 Functional Status At Initiation of ESRD Treatment (N = 1,597)



Source: CMS Form 2728

➤ **Vocational Rehabilitation**

Of the approximate 11,966 ESRD prevalence patients residing in the six New England states, only about 3,200 are of “working age” which is defined as between the ages of 18 to 55. That number represents 37% of the New England dialysis population.

Among working age New Englanders treated with dialysis 30% are working, going to school or are receiving vocational rehabilitative services. This is a decrease from 2007 reported for New England. Even with a slight decrease this percentage of patients who are engaged in life activities is a relatively good outcome. This outcome is considered good when taking into account the number of challenges associated with the demands of a thrice-weekly dialysis schedule, family, relationship, potential health complications and barriers to employment (Table K).

**Table K: Vocational Rehabilitation by State
Patients Aged 18 - 55 as of December 31, 2008**

PROVIDER STATE	NUMBER OF DIALYSIS PATIENTS AGED 18 -54 (NETWORK LIST)	NUMBER OF DIALYSIS PATIENTS RECEIVING SERVICES FROM VOC REHAB AND OTHER VOC REHAB RELATED SERVICE PROVIDERS (PUBLIC OR PRIVATE)	NUMBER OF DIALYSIS PATIENTS EMPLOYED FULL-TIME OR PART-TIME	NUMBER OF DIALYSIS PATIENTS ATTENDING SCHOOL FULL-TIME OR PART-TIME
CT	1,085	17	258	15
MA	1,398	41	340	42
ME	235	38	57	3
NH	187	4	48	3
RI	230	9	50	4
VT	70	3	15	2
Network	3,205	112	768	69

Source: CMS Form 2744

The Network of New England continues to encourage Renal Social Workers, individual patients and patient's family members to retain or pursue their careers upon initial diagnosis of ESRD and throughout their adjustment to treatment. Network #1 posts current contact information for the six New England State Vocational Rehabilitation programs on its website and distributes educational materials to patients and providers regarding the importance of employment retention for dialysis and transplant patients. Network #1 also serves as an advocate on behalf of patients when requested by Social Workers or patients themselves when a patient is threatened with job loss. In these cases advocacy takes the form of telephone conferencing, directing correspondence to existing or potential employers and referral to partner agencies such as Life Options, the Medical Education Institute, AAKP and the Americans with Disabilities Act administered by the US Justice Department.

➤ Network #1 Staff Provide Community Education

Pre-dialysis, dialysis or transplant patients and staff rely on the ESRD Networks as a resource for no cost educational material. Network #1 warehouses printed materials in large quantities for distribution to providers of renal healthcare upon request. Experience shows that the three most often requested educational products are: *Your New Life* (New England PAC), *Preparing For Emergencies – A Guide for People on Dialysis* (CMS) and the *ESRD Medicare Coverage for Dialysis and Transplantation* (CMS). These three multi-page booklets are the mainstay of patient education; is designed to orient and educate members of the renal community.

The following types of educational information or materials were given to patients and providers of CKD / ESRD healthcare throughout the year:

- QI Information
- Data Research Information
- Complaints and Grievances
- Treatment Options
- Transient Care
- Website Referral (DFC)
- Reimbursement Issues
- Other Requests

➤ **Achieving Network #1 Goals in Quality of Life for ESRD Patients**

The importance of patient quality of life has been a high priority for Network #1. The provision of educational materials on the website and distribution efforts to patients and professionals is an ongoing activity. Random feedback of utilization and effectiveness of these materials is conducted by Network staff. The conduct of the withdrawal study illustrates that commitment to quality of life. In addition, Network #1 leadership serves on the steering committee of the ESRD National End of Life Coalition. Analysis of access to services and employment status of dialysis population is reported annually to the Network Board to assure adequate regional availability of treatment.