Vocational Rehabilitation for the ESRD Patient: Fulfilling the Promise Transcript

Joan Wickizer: Good afternoon, everyone. This is Joan here from Network 3 and I'd like to welcome everyone to the first Learning and Action Network conference call and webinar presentation for the increasing employment, for the gainful employment for the ESRD patient quality improvement activity. We have attendees here from Networks 3, 4, 5, 8 and 11. So I welcome you all. During today's presentation, if you would like to ask a question, please go to the chat box and enter your question and that will be addressed throughout the presentation.

Joan Wickizer: Today, we have Beth Witten who is here to present to us on Vocational Rehabilitation for the ESRD Patient: Fulfilling the Promise. So I'd like to introduce Beth and then turn it over to Beth to begin the presentation. So Beth provided clinical social work services to dialysis patients and transplant recipients for 18 years, starting in 1978. As a volunteer, she helped write patient and professional education materials for NKF on multiple topics including rehabilitation.

Joan Wickizer: And as a member of a prime study group, she helped write a national training manual for vocational rehabilitation counselors for the rehabilitation services administration. For over 20 years, she has consulted with the nonprofit medical education institute and contributed content to life options, kidney school and home dialysis central as well as home and the national dialysis... I'm sorry, as well as Home and Dialysis Central Facebook group and message boards.

Joan Wickizer: More recently, she began serving on the National Dialysis Accreditation Commissions advisory board. Since early in her nephrology social work career, Beth has been a keen interest in improving rehabilitation outcomes for people with kidney disease. So it's a real pleasure for me to introduce Beth and to ask for your attention as I turn the presentation over to her. Beth, it's all yours.

Beth Witten: Thank you, Joan and thanks everybody for inviting me to present on vocational rehabilitation. This is a topic that I'm really passionate about. As you heard, I've worked in dialysis transplant programs as a social worker for 18 years before I started a consulting business. In my last clinic, we had about 42% of our patients who were either at home or in center. They were working or in school. So I know that it is possible to get dialysis patients to work. It's not always easy and I appreciate what you're doing to try to improve the vocational rehab outcomes for your patients and hopefully that will then lead them to get jobs and keep their jobs that they have.

Beth Witten: There will be some questions for you in the chat box and Mitzi is going to read those questions to you. We hope you respond to them. At the end of the presentation, there's also going to be time I believe to ask questions in the chat

box then Mitzi or Joan will read those to me and I'll try to answer those and then if I don't get to all your questions, they're going to send me what questions are not answered that are in the chat box and I will answer them and send them back to be shared with you.

Beth Witten: I also wanted to let you know that I am going to be doing a pre-conference at the National Kidney Foundation with a woman from the Missouri kidney program who is a state health insurance assistance program counselor. We're going to be talking about a lot of stuff related to insurance and she's going to be helping people with knowing how to search for part D plans. And then I'm going to talk about vocational rehab and it's going to be a different presentation from the one that I'm doing today. In fact, it's going to go more into the work incentive programs. So hopefully those of you that are coming to the National Kidney Foundation meeting consider coming to the pre-conference.

Beth Witten: So today, we're going to be looking at dialysis employment data, how the dialysis clinics can develop policies that promote rather than discourage work, what the team can do to help patients feel well enough to work. And we're going to talk about some of the laws and work incentives and rehab providers that can help. Finally, I'm going to share some resources with you, and if you get a copy of this presentation that is an electronic copy, the text that's hyperlinked, if you just click on that, then you'll be able to go to the link that I cited.

Beth Witten: So in the early days of dialysis, there was no government payment for dialysis and access was limited. People with kidney failure were selected for dialysis. There's a really interesting life magazine article from 1962 entitled... Well, it's not entitled this, but talks about the God committee and that's what they referred to those committees that chose people for dialysis. And if you go on YouTube, you can find a 1965 documentary called Who Can Live, and that is really eye opening for people that have not been in dialysis very long and don't realize what the history is.

Beth Witten: In 1971, a dialysis patient called Chip Glazier dialyzed briefly on the floor of the House Ways and Means Committee, and in 1972 Senator Vance Hartke testified before Congress with this statement that 60% of those on dialysis can return to work but require retraining, and most of the remaining 40% require no retraining whatsoever. These are people who can be active and productive, but only if they have the life saving treatment they need so badly.

Beth Witten: Now, I will tell you that the demographics were a lot different then because there were more people since everybody had to pay out of pocket before Medicare started paying. There were more people that were younger that didn't have the comorbidities that we have today. They were generally insured so that they could pay for the dialysis. So that is part of the reason why this was kind of a rosy picture of the patients who could continue working or go back to work.

Beth Witten: In 1972, Nixon signed the social security amendment that extended Medicare to people with chronic kidney disease who require dialysis or transplant and Medicare started paying for dialysis in July of 1973, and interestingly Nixon saw the Medicare ESRD program as a stepping stone to universal healthcare and we've never quite gotten there yet.

Beth Witten: So let me change slides. So how many dialysis transplant patients in the United States work? Well, we really don't know. Employment data is collected on the CMS 2728 dialysis initiation and it asks about their employment status six months prior and current. We don't know how accurate the information is or whether the patient is asked about their work status or whether all dialysis clinics collect it in the same way.

Beth Witten: The form doesn't ask data that might help us in studying employment like what is the patient's education level and whether or not the patient had preexisting depression. It's true in small studies that there are patients on different modalities that work and we can look at those studies and say which modality seems to be the better, but we don't know it on a national level. They do in the United States renal data system, annual report, report how many people are working, and I'm going to talk about that in a minute, and they talk about how many people are on different modalities, but they don't put those together.

Beth Witten: And if a transplant is really supposed to return people to a fuller life I don't understand why there isn't more employment data in the UNOS Annual Report. We know that patients do fear, lots of benefits and some who work off the books may not be honest with you about whether they're working or not because they don't want to lose those benefits and they may not understand that there are work incentive programs that could help them keep their benefits when they're working.

Beth Witten: Okay. So this is from the CMS 2728. It's for the period of time from 2014 to 2016. The United States renal data system reports employment data on all new patients of all ages initiating treatment for ESRD. The reason why it's 2014 to 2016 is that the most recent data report has not been published as it was in years past. There's just like a summary of some of the data. But if you look in the red box, it shows the patients from ages 18 through 54, and if you look at the prior to current for both full time, part-time employment, you will see that there's a pretty precipitous drop in employment and too many patients who were working prior to dialysis leaves their job by the time ESRD treatment is initiated.

Beth Witten: So some of you may be entering data and CROWNWeb. I'm kind of hoping you're not. CROWNWeb has the directions in it for how to enter data on patients that are 18 through 54 and what data to enter. It's really important that whoever is entering the data understands how to do it, understands what the definitions are. The hyperlink text at the bottom of this slide will take you to the

instructions on one network's website and to the CROWNWeb glossary that helps define what they're wanting.

Beth Witten: So it's very important that when you talk with your staff there and you are dealing with the person who is entering the data in CROWNWeb, make sure they know that's the information so the data is as accurate as it can be. Now, I stupidly did not include Networks 8 and 11 on here when I put the red bar, but you can look down and you can see what the statistics are for the network for all of you that are on the call today.

Beth Witten: These data are from the 2016 network organization programs summary annual report, and it shows that 18% of the patients were working full or part time. 1% were receiving VR services, 1% were in school, and 24% of clinics offered evening shifts starting after 5:00 PM. Interestingly in 2015, I looked back to see what the data they were for number of clinics offering evening shifts and it's dropped from 30% in 2015 to 24% now.

Beth Witten: I really do believe that having evening shifts and offering home dialysis are two ways to increase your patient population that's working. I'm thrilled to know that you're working on improving these statistics. So this was data from the comprehensive dialysis study. It was done a few years ago, and if you look at this, you can see that dialysis patients can work in all kinds of jobs. You can see that there were fewer dialysis patients working in manual labor jobs and as executives or major professionals.

Beth Witten: We all know that manual labor jobs may be hard for workers on dialysis, especially if they don't know to ask for workplace accommodations, and if they have fatigue and their endurance is poor. Employers could provide labor saving equipment that could help patients keep their jobs if the patients knew to ask for that, and a lot of patients don't know about asking for accommodation, so that may be something you can help them with, and I'll talk a little bit about that later on.

Beth Witten: The low employment of executives and professionals maybe explained if they have what some people Cadillac disability plans that pay much more than social security and other people don't have access to those types of plans. And in case you're not aware, social security disability benefits only replace about 40% of work earnings and even less for higher wage earners.

Beth Witten: So this particular study looked at 528 eligible patients. I think I skipped a slide. Let me go back. Nope, I didn't. Okay. Maybe I moved a slide. So anyway, this one is 528 eligible patients and they were 18 to 64. They'd been on dialysis at least three months. And the study found that 35.8% of them said they were able to work and obviously fewer patients were working than that. Demographic and quality incentive program metrics were not significantly different between those thing. They were able to work and unable to work. The significant findings were that those who were younger, better educated and healthier were more

likely to work and those who were unable to work were more likely to have a hemodialysis catheter and be clinically depressed.

Beth Witten: Working benefits patients, and if you think about your working patients, do you find that this is true that they seem more independent? They may be have higher self-esteem. They talk about getting out and socializing more. They seem to be less depressed, less anxious. Do they have higher income and better health plans. If you have a better health plan, then it may be easier for a patient to follow their treatment plan. Do your patients know that research has shown that those who work are more likely to get transplants and those kidneys are likely to last longer? It might help patients to know that because that may motivate them more to seek voc rehab help or other employment services to work.

Beth Witten: And working benefits, the facilities and the staff. Studies have shown that working patients have fewer emergencies requiring staff time and supplies and they have fewer and shorter hospitalizations and live longer. Being unemployed and trying to live on a disability check is very stressful and having that level of anxiety can lead to challenging behavior at dialysis and dealing with upset patients can lead to worst job satisfaction and costly turnover of staff. So well-informed, new and established working patients may choose home options that allow them to keep working and keep their employer health plan.

Beth Witten: I am a real strong enthusiast for home dialysis PD or a home hemo. Home options may be less costly to provide and commercial insurance pays much more than Medicare during the Medicare secondary payer period making dialysis clinics with higher numbers of working in job based insured patients more profitable. With higher profits, it should be possible to provide more dialysis facility level supports for employment and that to me includes being able to have lower patient to staff ratios for nurses and especially for social workers to have the time to help patients keep or find new jobs.

Beth Witten: And employers benefit from hiring and retaining dialysis patients. Hiring and retaining new workers is costly, especially when you have a worker who knows the job and can do it well with or without accommodation. There are government tax credits that are available to help employers hire and accommodate people in targeted groups including those who are getting help from private or public vocational rehab services or veterans vocational rehab.

Beth Witten: Terminating somebody who has a disability may violate laws and be costly to employers financially and to the reputation that the equal employment opportunity commission findings are publicly reported and I'm going to talk later on when we talk about laws about a specific law or a specific case, legal case that provided the precedent for dialysis patients to be protected under the Americans with Disabilities Act. So you can help your patients work. As I said, when I started this presentation, my clinic had good employment outcomes by doing things I'm going to suggest next. Mitzi?

Mitzi Vince: Yes. So just a question to everyone on the webinar. How have you or would you involve your team in promoting vocational rehabilitation with your patients? Feel free to type your answer into the chat box.

Beth Witten: So what's important is to provide high quality care and that is not just the social worker, that's everybody. It's a team effort and hopefully you'll get your dialysis staff to understand that everybody can work together on this. Patients who have symptoms during the three or four hours of dialysis may not stay for their full treatment and they may think you are totally not suggesting they do longer and more frequent dialysis. But research has shown that for the average three to four-hour dialysis session, it takes about seven hours for a patient to recover.

Beth Witten: It's shorter time for short, daily and only a few minutes for nocturnal hemodialysis, whether it's done in center at home. And there's been a lot more attention placed now on fluid removal and what they've found is that removing too much fluid too fast during a dialysis session makes the patient feel nauseated, have cramps and even worse it can send their heart and other organs increasing their risk of death.

Beth Witten: Patients may not think to report all their work limiting systems symptoms, so it's important that they know what symptoms to report and who to report them to and that they report all those symptoms to their nurse, their technician, to whoever happens to be talking with them that day. It's important also to teach patients the skills to help them be active participants in their treatment. Doing more self-care may help them feel confident enough to choose a work friendly home dialysis option.

Beth Witten: Patricia Painter is an exercise physiologist and she did a lot of research with dialysis and transplant patients and she would talk about the cycle of deconditioning that occurs when patients on dialysis stop being active and this leads them to being unable to do the activities that they want to do. So it's very important that patients stay active and it's important that their doctor and their team helps them understand what activities are safe for them to do and how to do them.

Beth Witten: Social workers are all doing the KDQOL-36 and that again is not just a social work activity because social workers cannot fix everything that may appear as a problem on that tool. So that tool can help you, your patients and your team identify work limiting problems and develop interventions that can help.

Beth Witten: I always say that people live up or down to your expectations. It's important for staff to have high expectations for patients, expect and support workers to work and students to stay in school. One of the reasons why we had such good vocational rehab outcomes was the physician that I worked with at my last dialysis clinic was very, very much involved in encouraging patients to keep their jobs or find new ones and he would do whatever he could to try to help them do that.

Beth Witten: So if you can get your physicians to do that, that will really help you. It's important to look at clinic policies that may discourage work and change them. Use working age employed patients as mentors. Alert working patients that they may qualify for leave under the Family and Medical Leave Act rather than taking a social security disability. Help employers understand that your dialysis patients can be productive workers with or without job accommodations and that you and your staff are available to help them as needed.

Beth Witten: The link that I provided here is to a document produced by the Life Options program that's called practical guides for renal rehabilitation and it has a checklist of things that you can do in the employment chapter is online and that's in chapter three. Mitzi. Question?

Mitzi Vince: Yes. A question to all attendees. What strategies have you developed for promoting work or school with your patients? Again, feel free to answer in the chat box.

Beth Witten: Okay. So when you look at your patients, you can look at who's not working, who's willing to work and who's able to work. Know about and help your patients understand work incentives or encourage them to talk with the work benefits counselor, social security with voc rehab or with an employment network. Talk with them about their work history, their goals, what transferable skills they might have and let them know about that there is a vocational rehab agency and there are private employment networks.

Beth Witten: Help patients regain their confidence to be able to self-promote. Having a gap in employment can be hard on the self-esteem and self-confidence. Encourage small steps towards work and school goals. Talk to patients about job accommodations they may need and how to ask employers for them. I'll talk later in the resources about the job accommodation that work. They have a list of accommodations that patients may need by the particular disability group. Some of your patients may have what it takes to be an entrepreneur and we're going to talk about that later of them.

Beth Witten: So it's important, like I said before, to review your facility policies. Do you offer home options? Do you have shifts that start after 5:00 PM. Do you have early morning shifts? Do you prioritize shift assignments for patients who are working or in school? Does social workers have time to learn as much as they can about work incentives to collaborate with folk rehab counselors to maybe bring counselors into the clinic to see what dialysis is all about and to counsel with patients teach them what they need to know to keep their jobs or to find new ones.

Beth Witten: Do your staff know what symptoms to ask about that could be limiting a patient's ability to work? do they encourage patients to participate in their care? Do your doctors routinely sign disability pay burrs or do they know how much disability replaces from work income and that patients may be eligible for

the Family and Medical Leave Act? Do you let in-center patients use cellphones, computers, laptops, iPads or tablets, so they can keep up with work while on dialysis? Those are all things that may help people be able to keep their job.

Beth Witten: A lot more jobs are having flex time and work at home. So allowing people to use technology to be able to do their job can really help them keep working. We know that CMS is requiring clinics to screen eligible patients for depression unless they refuse. Not only does depression increase the risk of hospitalization and death, but it also contributes to job loss. And this slide discusses some of the ways to reduce the pressure and I'm sure social workers on the call, I'll know all these ways to help patients. And we know that social workers have the education and skills to do brief counseling with patients to identify contributors to depression and motivators that can help overcome it.

Beth Witten: But as I've kind of alluded to before, they need time to do this. If the social worker is doing tasks that can be done by somebody else who does not have the master's in social work degree, find somebody else to do those tasks that's really expensive to pay a social worker to make copies and fax document. Giving patients hope is the first step toward improving their willingness to set short term goals and take steps towards them. Using well adjusted mentors and encouraging families to foster independence, not dependency will be good for patients, families and staff.

Beth Witten: So what are your patient's expectations about dialysis and work? I had patients who thought being on dialysis meant death was near at hand and the media doesn't do a real good job of changing that perception. They always pay transplant as saving somebody from the dread dialysis. And if patients believe they're going to die soon, why would they take the time to learn about kidney disease and much less work? So patients need to know that people have lived on dialysis for decades and that learning and doing what they can to stay healthy and keep their lives as close to what they were pre-dialysis can help them be one of those longterm survivors.

Beth Witten: I knew a patient who had been on dialysis, never had a transplant for over 35 years. And I know a patient now who started on dialysis in 1966 and has had four transplant, had a full time job working as a rehab nurse and now is retired and enjoying her grandchildren. So use your plan of care meetings to invite patients to discuss their goals and challenges, document the plan of care, the actions the patient and team are taking to work towards those goals including the year referrals and services provided, so you can go back and collect that data for this project. Use the quality assessment and performance meetings to look at facility wide employment outcomes regularly, not just once a year. And I've provided a link to an article by Lisa Hall who is the patient services director at Network 16 about ways to improve employment outcomes.

Beth Witten: So here's some of the criteria for voc rehab acceptance. It's really important to know what the eligibility criteria are. So they need to have a physical or mental

disability that interferes with becoming employed. They want to be employed and they need help finding a job. So make sure your patients that you refer to voc rehab, express that they want to have a job, that they need help to get a job because sometimes voc rehab, people look at the diagnosis of end stage renal disease and they say, "Why should we help this person? They're dying." And they need to understand the end stage renal disease means in stage of the kidney, not in stage of the person.

Beth Witten: Now, without dialysis or transplant, obviously the person would die, but with dialysis or transplant they may be able to live many years. So it's important that the patient express motivation and express what limits they have to finding or keeping a job. Did you know that dialysis in the first year post-transplant are listed by social security as conditions that may prevent gainful activity? That's the medical evidence needed for disability payments and that's also the medical evidence that would be needed for voc rehab. States with limited funds choose who they're going to serve under order of selection.

Beth Witten: My state has been in order of selection as long as I can remember, and they're supposed to serve people with the most severe disabilities under priority one and then social securities listing makes our patients who want to work priority two. If they're on a wait list for services, they need to ask how long it might be because vocational rehab is supposed to evaluate them and refer them. There are other entities that can help.

Beth Witten: The choose work site on social security describes each of these resources. Now when you're looking at functional capabilities or capacities, some of the things that voc rehab looks at when they're counting the number of functional limitations somebody has, our mobility, communication, self-care, self-direction, interpersonal skills, work tolerance and work skills, and under mobility they look at how far you can walk and how many stairs you can climb. So a lot of our patients are limited in that way, so they could maybe be for sure a priority two but if they've got other functional limitations that could move them up into priority one.

Beth Witten: Now, they're employment networks. Those are private contractors with those security. They're client directed and some of them provide online versus face to face help. If people use them and go off disabilities, they may even be able to reimburse the person for work related expenses to keep a job. There are two that I've talked to. I did not put them on this slide, so you may want to note them. One of them is called AAA TakeCharge. And so it's www.aaatakecharge.com. And another one is NTI Central, which is www.nticentral.org.

Beth Witten: That particular site has landed a job and worked at home. So a lot of our patients may be able to work at home but may not be able to go and work a normal eight-hour a day sitting at a desk. Mitzi, you want to throw out a question?

Mitzi Vince: Yes. A question for attendees. Which approaches have you had success with as far as getting patients through the vetting process for vocational rehabilitation services?

Beth Witten: So here are our list of services that vocational rehab agencies can provide. They can obviously do counseling and guidance. Obviously before that, even the evaluation, counseling and guidance, job placement, they can help people with college or vocational training. They can help people that are working who need additional help to keep their job, skills training, job coaching. They can pay for transportation for people to get back and forth to their job. They can provide interpreter services for youth who are transitioning from being used to adults.

Beth Witten: They can help with those kinds of services. They can help employers to provide the accommodations to know what accommodations a patient may need. They can provide things to help people that has hearing vision, computer access things. Some of those rehab tech services. They can also refer people and they can do support, advocacy and follow up after someone gets a job.

Beth Witten: So the idea is you don't want to just place somebody in a job and leave them unsupported. You want to give them a support they need to keep that job. So this is the manual that was talked about in the introduction. This manual was funded by the rehab services administration, which is the umbrella agency over the state VR agencies. Another renal social worker, Mary Beth Callahan and I helped develop this manual several years ago. They're on the prime study group. There were rehab counselors, directors of state VR agencies, patients, and we had a physician who reviewed the manual for medical accuracy.

Beth Witten: You can see what's in it. Here's the table of contents. The goal in developing this manual was to help voc rehab counselor see that although people with kidney disease and kidney failure have worked challenges, they can have success with help from voc rehab. Back in the day, copies were sent to state VR agencies, but I suspect most counselors know nothing about it. So if you're working with a vocational rehab counselor with a voc rehab agency, you might want to share this with them.

Beth Witten: Some of the information in it may be somewhat outdated, but the medical stuff is mostly the same. And it might dispel some of the misconceptions they have about the workability of people on dialysis and with transplants. It really helps to know your local VR counselors. Invite them to your clinic if that's something that your clinic will approve. At my last clinic, the administrator and I did a tour for several VR counselors when patients weren't there and we explain dialysis to them. You can invite the area work incentive coordinators to your CNSW meetings. They're supposed to be going out and doing public education about vocational rehab.

Beth Witten: With the patient's permission, you can refer patients to the VR staff at any of these opportunities. Something that some clinics have done is to hold VR Lobby

Days that encourage vocational rehab counselors to meet with patients during that time. You could make your staff and your doctors know about VR services and recognize how important it is for patients to complete their evaluation. Even if that means changing their shifts briefly. I'm going to say, please make sure your doctors know that forms for voc rehab need to promote the patient's ability to work as opposed to disability forms that do just the opposite.

Beth Witten: I know that back in the day, Lindsay Shrug who works for Fresenius, she had posted pictures and vignettes about working patients with their permission and their waiting room, and she found that the doctor's staff and other patients learned a lot from those inspiring vignettes. So you might ask your patients if that's something that they'd be willing to do or put it in a newsletter, something to help inspire other patients to consider working. Finally, advocate for federal, state and local policies that promote work.

Beth Witten: Now this slide is kind of a busy slide. It's important to know about all the different social security work incentives. You can read about them in the social security red book. I just type into Google self-security red book and it pops up and you can look at the most recent one that's published and the article I wrote for Home Dialysis Central, which is also linked here, I kind of described those work incentive programs. There are benefit counselors that you can find on the Social Security's Choose Work site. Those people can help you and your patients understand work incentives and what going back to work could do so far as affecting their other benefits that they get.

Beth Witten: The figures on here are 2020 figures. They change every year, so I've talked to people that still had in their head years ago figures. There's a nine-month trial work period and that allows someone to attempt work. If they don't earn $910 or more, they will not use a month of trial work. So somebody who's working at $900 a month keeps their social security disability check and their income from their job and they don't use any trial work month. If they work the nine trial work months during any 60 months period, then social security would look at whether or not their job is providing substantial gainful activity.

Beth Witten: And blind people get a lot more money because they had a really good lobby and so they get 2,110 before they could possibly lose their benefit. Whereas people who are, who don't are not legally blind can earn 1,260 a month. From that, social security can deduct impairment related work expenses. so if somebody has receipts for expenses they paid out of pocket, not paid by insurance or anyone else, but paid out of pocket for drugs or doctor appointments or anything that helps to keep them healthy enough to work, they can show those in the same month that they had income from work. And social security can deduct those.

Beth Witten: In the red book, there are examples of countable and not countable impairment related work expenses. The continued payment under voc rehab, it's really more important for transplant patients and dialysis because people that are on

dialysis are going to be able to keep their Medicare. But with continued payment under voc rehab, if somebody is in a vocational rehab program and they are considered medically recovered, which when you're on dialysis, you're still on dialysis, but if you get a transplant a year after the transplant, you may not be still considered to be disabled.

Beth Witten: So if you're on a vocational program and you're not done with that program and that program is intended to provide you with the knowledge and the skills to be able to get a job that will take you off disability, then you can keep getting your social security disability check and you can keep Medicare. The continuation of Medicare work incentive that's under that one is for those who have worked and they've had their nine-month trial work period. After that nine-month trial work period, they can keep Medicare if they're still disabled from some other conditions, so it's not just the person with ESRD only, this would be somebody who's disabled due to something else.

Beth Witten: In addition to that, they can keep Medicare for seven and three quarters years after they lose their social security disability cash benefit. Expedited reinstatement is for those people that freak out while they are working become disabled again because of the condition that they had before that they could have a recurrence. This allows them to get back on disability right away, no waiting period. And while social security is re-determining their disability, they can continue to get that disability check.

Beth Witten: And if social security later finds that they're not disabled, they never have to pay the money back. So for people that have spent that five months, which really turns into seven months waiting for that first social security disability check, they're afraid they don't have the savings they had before that can really help them. There's an SSI earned income exclusion that allows patients or people to not have the first $65 of their income counted or $20 as a general income exclusion.

Beth Witten: That reduces their income by $85. When somebody is a student getting SSI, they can earn $1,900 a month or $7,670 a year. So maybe they don't work during the school year, but during the summer they get a good job and it pays them good money. If their income is less than that 7,670 per year or $1,900 a month, they can still get their SSI check.

Beth Witten: Section 1619a is a sliding scale reduction of their cash as their work income increases and it allows them to earn a considerable amount of money before they lose all their SSI cash. And even if they've lost all their SSI cash, they can still be eligible for Medicaid. If you go on the website for social security, the work site, you can look and see Section 1619b how much somebody in your state can make and keep Medicaid. And it's one heck of a lot more than someone can have and get Medicaid if they are not working.

Beth Witten: So that is a really, really big advantage. Unfortunately, not every state Medicaid agency is aware of the 1619a and b work incentive programs. Those are determined by social security. So somebody gets into the Medicaid system because of their 1619b classification. And you'll have sometimes the caseworkers at your Medicaid office telling patients you can't work or you'll lose your Medicaid, which is not necessarily true.

Beth Witten: The plan for achieving self-support patients can set aside money from their check to maybe go to school to buy equipment, to start a business, to buy a car, all kinds of different things, and interestingly enough, they set it aside in a different account from where the rest of their money is, and then social security replaces that money so they continue to get their full check while they're setting aside money for whatever they're trying to do that will help them to get off a disability.

Beth Witten: And then the reinstatement of SSI and Medicaid without a re-application is similar to the expedited reinstatement. As you can see, there are links at the bottom of this page and I encourage you to look at the information that's there. It's very helpful information and I always go back to that because it's not easy to remember it. It's pretty complex and so I'm sure if it's complex for us, it's really complex for patients. That's why talking with the representatives maybe really helpful to them with social security or the employment network people.

Beth Witten: So there are laws that protect workers with disabilities, the employment equal employment opportunity commission and forces, the three laws that are listed there. I told you I was going to tell you about the case that set the precedent for dialysis patients to be protected under the Americans with Disabilities Act. It's called Fiscus v. Walmart. Fiscus was a female dialysis patient who worked at a Walmart store and I think she had an injury initially and she went off the job because of that injury.

Beth Witten: They did not accommodate her and during her leave that she was off, she got a transplant which kept her out of going back to work longer than the one year Walmart had in its policies and they terminated her. She had a wonderful lawyer who was great at describing all the limitations that she had due to being on dialysis, and the third circuit court of appeals decided that the lower court had aired in going along with Walmart's arguments and they made the case go back to the court. And she ended up winning that case, and that proved that that dialysis is protected under the Americans with Disabilities Act.

Beth Witten: So if you ever run into problems with that, just know that case. The Department of Labor enforces wage and labor laws and Family Medical and Leave Act, which can allow people who have worked at least 1,250 hours in a year for an employer that has 50 or more employees to take up to 12 weeks of unpaid leave each year in increments as small as the employer tracks time. The FMLA protects the person's job, their health insurance, their right to promotions and

much more. So it's very important that if patients qualify for the FMLA, that they consider taking that instead of disability.

Beth Witten: You can advocate with employers, patients who want to work and responsible workers may not know what accommodations they need or how to ask for them. And employers may not know anything about kidney disease or dialysis, so they may need help to know how to accommodate patients' needs. In this employment booklet, that is really old and this is the life options booklet and life options is administered by medical education institute. We've talked about putting the employment book into kidney's school and hopefully it will end up there at some point so that you can see more updated information, but this does have at the back of this book and you can look for it at the link below, does have two sample letters.

Beth Witten: I used to talk with my patients and when they were concerned that they were possibly at risk of losing their job, I would sit down with them, find out what they needed to have in a letter. I would write the letter, I would have them look at it and then I would have the doctor sign it and we sent it in. And I think that they do jobs for some patients. So that's something else you might consider. Like I said before the website Askjan has a list of possible accommodations for people that are on dialysis or have transplants.

Beth Witten: There may be some people who have the entrepreneurial spirit and some of them, especially those that live in rural areas where they may not have as many opportunities to work for someone else, they may really want to start their own business. Here's some data on this slide about self-employment and characteristics of those who might be good candidates for self-employment. So if somebody is a self-starter and they're good planner and organizer and if they want or need work hours that are different from the typical 8:00 to 5:00, 9:00 to 5:00 job and especially if they have barriers to working for somebody else, like maybe they need to work certain hours of the day around how they're doing their dialysis or work at night.

Beth Witten: Some people like working overnight and that would be something that someone could do from home. And the self-employment rate, interestingly enough, is 50% higher among people with disabilities compared to those that are not disabled. And it's more common for people to be self-employed when they're in a rural area.

Beth Witten: So I put together some of the employment resources that I like to use. There's the Social Security work site, the Ticket to Work site and the list of service providers under this find help, part of the Choose Work site, the Office of Disability Policy, employment policy has some really good fact sheets. As I mentioned, the job accommodation network, which is Askjan that is supported by the Office of Disability Policy. It has great resources, and then there's a program called SCORE, which is a mentoring program that links people that

want to start a business with retired executives and that's supported by the Small Business Administration.

Beth Witten: Those are some of the resources that I've used in the past and they could really help your patients work. So I hope this presentation gave you some ideas of things you and your staff and doctors can do to help more of your patients choose to work. I really do appreciate you inviting me to present and I think we have a few minutes to take questions or you can also email me. I had my email address on the first slide, but it's Beth, like as in B-E-T-H, the nickname for Elizabeth @witten, W-I-T-T-E-N, llc.com. Thank you. Do we have any questions.

Joan Wickizer: Thanks, Beth. Thank you, Beth. This is Joan. I appreciate your presentation. I think it was full of a lot of useful information. We have many responses to the questions that came in through the chat box. Following the presentation...

Beth Witten: That is even better.

Joan Wickizer: Yeah. Following the presentation I'll be compiling all of the information and that will be forwarded to all attendees. And in there, there are a few questions for you, Beth and we'll ensure that you get those so that you'll be able to answer those and we can send them out with the participants' responses.

Beth Witten: Great.

Joan Wickizer: So I thank you very much for your time and I think that at this point the best way to approach this will be to send the information out directly to the attendees. It gets a little bit hectic when we open up the lines to take questions. So I think we'll avoid that and we will give everybody a few minutes of their time back. and thank you very much. I hope that the information everybody received will help them as they move forward with the work on this voc rehab project.

Beth Witten: Thank you.

Joan Wickizer: So everybody have a nice day. Thank you so much.