Welcome to our program about Survivorship and Employment. I’m Lex Frieden.

I am Professor at The University of Texas Health Science Center at Houston. And I direct the Independent Living Research Utilization and the ADA Technical Assistance programs at TIRR Memorial Hermann.

Today we want to look at issues that survivors face related to employment. We want to look at the rehabilitation and other kinds of issues about the Americans with Disabilities Act and the Family Medical Leave Act that may help employers and survivors to address cancer-related employment issues. We’ll talk about how healthcare providers can assist in the process of recovery. And we'll give you some references and resources for survivors and providers that will help them address these problems.

In our society a person is defined by his or her work. When you introduce yourself to someone else you most often give your name, maybe where you live. You seldom say much about your family but you often say where you work. People identify in our society with their employment.

There are two primary findings that we have from our research that motivate us going forward. First of all, we know that cancer survivors face discrimination in employment. And we know that employment-related concerns constitute the second greatest informational need of survivors. We’ll take a look at that.

Our research has two goals. The short-term goal is to design and implement resources for cancer survivors that will improve their levels of understanding and the use of legislative protections and vocational support services available to help them maintain or transition back into employment.

Our long-term goal is to validate selected interventions and evaluate how they assist cancer survivors in maintaining employment or in attaining their desired vocational outcomes.

We have conducted two surveys, one of cancer survivors and the other of providers. Our survivor survey included 166 individuals from a national sample. And our staff or provider survey included 86 individuals from the UT MD Anderson Cancer Center in Houston and the Memorial Hermann Cancer Clinics. We have also designed an online training module for cancer clinic staff. And we have done several publications including one in the journal WORK: A Journal of Prevention, Assessment, and Rehabilitation dated September, 2013.

The research questions that we’ve tried to address during our work the past three years: First, what are the effects of cancer on the employment status of cancer survivors?

Second, do cancer survivors know about the different legal and programmatic supports that may help to address their employment-related needs?
And third, what are cancer survivors preferred modes of receiving information about resources to address their employment-related concerns?

In our survey, we found that 14.5% of the population surveyed had a disability in addition or coincident with that of cancer. Most of the survivors who we surveyed had really had cancer for some time. The mean number of months were 41. The type of cancer that we found most often among our survey participants was breast cancer, although there was a range of other cancers among the survivors who we surveyed.

Since their last employment most of the survivors had worked at least two years, actually closer to three, and the days missed because of cancer ranged greatly. But the mean was 111 days missed or a little more than three months. The estimated out-of-pocket cost for the survivors was an average of $12,400.

Let’s look at the survey results. You can see that in every case along each dynamic that we looked at, the providers had a little better sense of the secondary effects of cancer that affect work. And some might say the providers actually exaggerated the degree to which work was affected by cancer. You can see that the individuals themselves, the survivors, ranked among the primary issues they had concerns about. Fatigue was number one, loss of concentration, number two, and treatment related to illness that they had was number three. Among the providers, I think they probably underestimated the amount of problems caused by loss of concentration. But we’ll look more [at it] now. (Next slide please.)

We asked the survivors and the providers if they knew what kinds of legislative and program supports were available to survivors. And we found that again providers were more aware than survivors of some of the kinds of supports available. But what really surprised us was that neither providers nor survivors had a good sense of some of the kinds of supports available. Most everybody has heard of HIPAA and they understood there were protections for survivors as well as anybody else involved in the healthcare business. But FMLA was another one people heard about. And they've heard about ADA although we’ll get to what their understanding was in a minute. You’d be surprised though, the Genetic Protection Act (GINA) was little known relatively speaking by both survivors and providers. And ERISA, people didn’t understand the implications of ERISA for cancer survivorship. Also the Rehabilitation Act of 1973 was little known particularly for survivors; and DARS, the Rehabilitation Services Administration, again providers had heard of it, they didn’t know much about it and survivors, less likely.

So what can we do with the information we have? What kinds of infor --- interventions can be helpful in assisting people who've had cancer to return-to-work?

The systematic review that is most significant here shows that only multidisciplinary interventions of physical exercise with or without vocational counseling plus either patient education, counseling, or behavioral feedback were proven to be effective in improving return-to-work.
So physical exercise, always include that in the regimen information, it’s vital. And when we come to information, vocational rehabilitation is probably that service that is most underused and understudied.

Cancer survivors represent only 0.4% of vocational rehabilitation agency services that represented closed cases or completed placements in 2005.

Following the receipt of services, more than half of the cancer survivors who participated in the vocational rehabilitation program were employed. And that’s a remarkable rate of achievement by these vocational rehabilitation programs. So we need to know more about them.

The Americans with Disabilities Act is also an important piece of legislation that protects the rights of people with disabilities. When he signed the law in 1990, President Bush said, “We will not accept, we will excuse, we will not tolerate discrimination in America.” And yet cancer survivors face discrimination when they try to return to work.

So in 2008, the ADA was amended to change the definition of disability so that it was clear cancer survivors were protected by the ADA. Also, in the 2008 amendments, reasonable accommodation and non-discrimination were more or less personalized for people who’d had cancer. And so we can look at the 2008 ADA Amendments Act as being an important piece of information that survivors and providers need to have.

Now in terms of protections by the ADA, there are several provisions in place to protect workers who have disabilities from discrimination and technical assistance is readily available. Make a note of that. We’ll give you some numbers to call later on. Individuals are not required to reveal a disability at any time in the pre-employment process. So a person who has had cancer, and it’s not evident to employers to whom they make a job application, need not reveal that they have had cancer when they make an application for a job. That’s a very important issue. We’ll talk about that again in a second. Employers may not inquire about disability or potential accommodations prior to making an offer for employment. So if an individual who is a survivor or another person with a disability has an evident impairment and they’re applying for a job, the employer may not ask them about that impairment or how it would affect their job in the process of employment. They can explain what the job is and ask if the person can do that job. And the person obviously if they have a disability, they’ve applied for a certain job, they must know that they can do the job. And they would explain to the employer that they are perfectly qualified and able to do so. Once the individual is hired, however, they do have a right to request a reasonable accommodation. And it’s up to the employee to request that reasonable accommodation. The employer then must negotiate with them what is the appropriate solution. And then must provide that accommodation to them in order to help them do their job effectively.

We should address the issue of disclosure. People with cancer have many, many different types of stigma associated with their survivorship. Not everyone will have the same feeling about cancer as the survivor. And it is even possible that a survivor may
have negative attitudes about their history with cancer. Nonetheless, it’s not incumbent upon the individual to reveal that they have had cancer. And many people deal with this in talking with family members, with friends, and certainly with employers. In fact, if people do disclose that they’ve had cancer, some people may not want to associate with them. They feel like there is something about the cancer that could be affecting them as well. Obviously we know that’s not the case, but in fact it happens and we’ve demonstrated that in our research.

It’s important to talk about accommodations that can be made for cancer survivors in the workplace. Now we know that the two most interesting or most important issues that are faced by survivors are fatigue and loss of concentration. How do we deal with that in the workplace? One way to deal with it is shorten the number of work hours or maybe place them over breaks during the day. Employers can accommodate that and they are required to do so if it is a reasonable accommodation. So think about working part-time to begin with. Think about doing a split shift, a little bit in the morning and a little bit in the afternoon. Think about work at home. More and more employers are providing that opportunity for people. And survivors and also other people with disabilities find it helpful to be able to work from their own environment where they can deal with personal issues without having to excuse themselves from the workplace.

And then talk about the issue of driving. This is an interesting one. It did not reveal itself in the process of our surveys. But the physicians whom we’ve spoke to tell us that survivors come back to them. They are concerned about going to work because they are not sure if they can drive safely. And that’s a real concern for everybody, for family members, and employers as well. So talk about the issue of driving. Consult the physician if necessary to determine whether the effects of loss of concentration or fatigue may have an impact. But the issue of driving is one that we know survivors are concerned about.

What can providers do to assist people who’ve had cancer, survivors, in the process of recovery?

First of all, get training on post-discharge employment-related issues. Many, many social workers, navigators, other helpers in the hospital and clinic environment really haven’t thought too far ahead about employment-related issues of their patients. They’re dealing strictly with the issues of cancer that are before them, the acute issues that arise during the treatment of cancer. But think down the road a little bit and begin from the beginning, well before discharge, to work with survivors and their families about employment-related issues.

Be aware that patients may focus on medical problems in their conversation. And you may need to prompt them about the loss of concentration, anxiety, and depression they will feel. People obviously in a clinic set --- situation, in a medical center first think about their medical issues and they may not get around to talking about some of the issues related to employment unless you prompt them.
If you’re documenting medical need for accommodation, ask the patient whether or not to use institutional letterhead. If a patient has not told their employer that they have had cancer and they are coming back to work as a result of that particular illness, you certainly don’t want to send a letter to the employer saying they are ready to return to work and do so from stationary that would indicate what kind of treatment they’ve been having. Again, that can affect the attitude of the employer and have an implication for the employee later on.

Administrators should consider fostering inner institutional networks that include legal service providers, vocational rehabilitation agencies, and others. Again, we know that vocational rehabilitation is really important to recovery. We know that vocational rehabilitation providers can assist in this process and be significant. We also know that legal aid may be necessary for people who’ve faced discrimination. And they certainly want to know what their rights are and what they can do if they have had --- been the victims of discrimination. So these types of providers should be included in the team that’s actually dealing with the outpatient issues, I think.

Free training is available for providers and folks should take a look at these opportunities. Cancer and Careers is an organization, [www.cancerandcareers.org](http://www.cancerandcareers.org) is the URL that provides free training. The Cancer Legal Resource Center has a lot of online information and you may call them and get information from them. It’s [www.disabilityrightslegalcenter.org](http://www.disabilityrightslegalcenter.org). And then finally in the southwest region of the United States, we have the Southwest ADA Center which is currently developing a Partners in Learning program for staff at Memorial Hermann Hospital and will provide additional institution --- additional assistance to other clinicians who may need training assistance. The number for the Southwest ADA Center is (800) 949-4232 and that number is good all over the United States. In other parts of the United States outside the southwest, you may reach the Northeast Center, the Northwest Center, the Central US Center or whatever, but (800) 949-4232 will get assistance for you.

In summary, cancer survivors are discriminated against in employment. We don’t know when it happens. We don’t know whether it’s going to happen, but it does happen. Providers are more aware of the legislative and program supports available to survivors than the survivors are themselves. Both survivors and providers rank fatigue as the biggest issue impacting work. Providers consistently report side effects as being a bigger obstacle than do survivors. We’re not really sure why that’s true. But obviously providers can be preoccupied with these kinds of side effects when, in fact, the survivor may have already dealt with them. And we know that vocational rehabilitation is underused and understudied as it relates to cancer survivors.

If you need technical assistance, again, the number to call is (800) 949-4232. We have a number of collaborators that I want to acknowledge. First of all, The University of Texas Health Science Center at Houston, MD Anderson Cancer Center, and the Memorial Hermann Cancer Centers have been working with us for the past three years on this research and will also be able to provide assistance.
This program has been a part of research funded by the National Institute on Disability and Rehabilitation Research and also with the assistance of CPRIT.

And I’d like to acknowledge in closing my colleagues Vinh Nguyen, Kathleen Murphy, Ki Shin, Amy Deutsch, and Roxy Funchess.

Thank you all very much for watching our program today.