INside the OUTcomes: A Rehabilitation Research Podcast

Episode 8: An online decision aid for people considering asking for an accommodation at work

SHARON PARMET, HOST:

Today I'm speaking with Mark Harniss and Heather Evans of the University of Washington, Seattle. They're part of the Rehabilitation Research and Training Center on Employment in the Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab. They're working on developing a unique decision aid to help people think through disclosing a disability at work. I'll let Mark and Heather introduce themselves.

HEATHER EVANS:

Thank you so much, Sharon. My name is Heather Evans, I identify as a white woman, I also identify as disabled. So I have a chronic illness that causes a variety of physical and cognitive impairments. And they flare and fluctuate depending on different circumstances. So in addition to the lived experience that I bring to this work, I have a PhD in sociology, and I'm currently an Acting Assistant Professor in the Department of Rehabilitation Medicine at UW. I'm also faculty in the UW Disability Studies program and director of research for the Northwest ADA Center.

SHARON:

Thanks, Heather. Mark, how about you?

MARK HARNISS:

Hi, everyone, my name is Mark Harniss. I'm an associate professor in the Department of Rehabilitation Medicine at the University of Washington and I direct the University Center for Excellence in Developmental Disabilities. I do not identify as disabled, but have worked in the field of disability for 25 years, I guess, and I have family members with disabilities and I strive to connect and engage with the disability community as an ally.

SHARON:

Thanks, for those intros. I'm gonna get right into the meat of the podcast here. Deciding to disclose a disability at work can bring up a lot of emotions and questions and disclosing?

HEATHER:

Sure, you know, making a decision about disclosing any kind of identity that is stigmatized in our society involves weighing potential benefits against the risks. There were made a lot of misunderstanding or simple lack of knowledge about people with disabilities, and certainly a lot of lack of information about specific conditions or impairments in general, you know, so there's, there's always potential for well intentioned confusion when disclosing but we also know from current research, that there's a lot of stigma, a lot of prejudice, harmful assumptions and stereotypes about disability, and about disabled people that, you know, we call ableism.

And ableism simply being the belief that, you know, one way of being is not only normal, but is ideal, that one way of moving or processing information, one way of communicating is superior to all others. And we know that disability bias, you know, a bias against disabled individuals. It operates at a conscious level at which we're aware, but it can also be unconscious. And so that means that, you know, most of us carry negative assumptions about disability that we aren't even fully aware of. And all of that means that there really are risks to disclosing a disability on the job, even for folks for whom a disability might be, you know, readily apparent, say someone who uses a wheelchair, well, it might be obvious that that person has a mobility impairment, you know, that alone can lead folks to question that person's cognitive abilities or make assumptions about their capacity or even aspirations.

So when disclosing, you know, on the job, there are all these questions swirling, you know, circling or swirling around in someone's mind about will my colleagues, you know, think of me as a competent worker, will my bosses be confident that I can do the job that they hired me to do. And that there's also risks, a personal risk of really stepping into a space where you're, you're making yourself vulnerable to disclose information that can be sometimes used against you.

But you know, that's got to be balanced with the ability to do a more efficient job or to do a job easier with accommodations. And so it, it is not a simple matter. It's not a simple matter for those who request accommodations, and it's not necessarily a simple matter, for those who are in the position to, you know, supply or grant accommodations.

SHARON:

Before we go into the decision tool. Heather, can you tell me what an accommodation might be that someone might ask for?

HEATHER:

Oh, absolutely. And you know, I'll use my experience. So again, I have a chronic illness, it impacts my mobility at times. It also really impacts my energy levels and fatigue. So you know, an accommodation a frequently ask for is, when I teach in classrooms they need to be accessible by an elevator, or accessible if I'm using a wheelchair, but also smaller things that have to do with fatigue.

For example, when I'm teaching, I need to be able to sit, I can't always stand at a tall, you know, tall podium, for example. So I'll ask for a stool or a higher chair or something to sit. But there's lots of accommodations. And what's amazing is that the research shows that the vast majority of accommodations are not expensive. They're not necessarily high-tech things. Sometimes it's just, you know, rearranging the environment a little bit. And oftentimes, there are technological accommodations that make things easier. But I would point out that, you know, all of us are using technological accommodations that make our jobs easier. And I'm happy to provide more examples of accommodations, maybe as we talk through the tool as well.

SHARON:

Mark, do you want to add something to what Heather just said?

MARK:

Yeah, I just wanted to highlight something, in addition to what Heather said, and that is, you know, she talked about risks of disclosure, stigma associated with disability, all of that's really relevant and true. I think another thing that folks don't often think about is that the employment settings are very social spaces, and people's identities, not just about disability, but about themselves, and about their competencies as a worker, are tied to their employment setting. And so you know, asking for an accommodation can be hard for somebody who maybe has not really come to terms with the idea of disability or, or maybe not created an identity, that includes disability. So some people have to disclose if it's not obvious. And so that means telling somebody about something that they might not, might not know otherwise. And so, so there's, there's that risk, certainly, but somebody also has to kind of, to, to wrestle with their own self-concept, if you will.

And then the other piece of it is, this is an accommodation that will happen within the context of your boss and other employees that you work with. So a lot of people, when they think about asking for an accommodation, even though this is a right that they have, as a person with a disability in the United States, many people think of it as asking for a favor or asking for help. And we are trained not to ask for help. If we ask for help, that's a sign of weakness. And so I think that those things add to the complexity, there's risk, but there's also this sort of psychosocial element that's involved in making the ask.

SHARON:

Can we talk a little bit about the tool that you have created to help people walk through that process?

MARK:

Sure. So we decided to try to create a decision support tool or a decision aid. And, and we did this, acknowledging that making a request for accommodation isn't simple, as we've talked about. And so the structure that we're using is similar to the structure that's used in patient decision aids. These are aids that are used in medical settings. And when somebody's making a decision about whether to have a surgery, or whether to take certain kinds of medicine, these are aids that that kind of balance risk, with potential positive outcomes. And so people are thinking about those risks within their own context.

And for some people, depending on the resources they have, and how they're feeling at that time, they may choose to take certain risks that they might not, and other times in their life. So this decision aid fits that structure. And it's organized around three large phases. So before of the request, everything that you need to think about before you actually make the request, how to actually make the request itself, and then after the request. And the decision that people are trying to reach is whether and how to make a reasonable accommodation request and employment. Each of the phases have a number of steps to them. And those steps all kind of are organized around a certain model.

They start with a section called Learn where somebody learns new information. And there's a section called Reflects where they reflect on what they learned and how it applies to their own context. And then there's a section where they actually apply it to their own context and begin to make some decisions.

SHARON:

Heather, can you talk a little bit about your part in creating the decision tool?

HEATHER:

Yeah, you know, Mark and I work really closely together through all of these different stages or phases of the decision making process. And you know, this is one benefit of having not only different kind of lived experiences and perspectives but also having you know, different research and different expertise background so we were able to go through each of the steps and really talk to each other and think about what are the kinds of questions that would arise? What kind of information would a person want, or what kind of anecdotes and that is one thing that was really important to both of us throughout this tool.

Of course, we talked to employers, we talked to human resources personnel, we talked to vocational rehabilitation counselors, and we talked to a lot of disabled folks about their experiences around accommodations.

And so we tried to build in examples, real life examples, little vignettes of things that worked for folks or things that didn't work for folks. And so I feel like it was very much a joint effort in putting together not just the factual information, the legal information, the procedural information, but as Mark said earlier, really playing into and thinking about a lot of the psycho social dynamics that folks go through in in making an accommodation request.

SHARON:

So before you even started drafting the tool, you reached out to several different populations to get their input. Can you talk a little bit more about that process?

MARK:

Sure. Yes, I absolutely can talk about that. So we did, we did, again, focus groups, with some employers, employers who represented both very large corporations and businesses, as well as some small business employers talking about the kinds of concerns or questions that they had their experiences, the types of information, they needed, to really understand what their responsibilities were, under the law. And, you know, also to kind of identify gaps, clear gaps in knowledge from our perspective with these individuals.

And then I would say it was just really powerful talking to individuals with disabilities with a variety of disabilities, folks who have mental disorders, individuals who had mobility impairments, or, or, you know, low vision, for example, and the kinds of both the technology but also the workarounds that they have used in their careers in an attempt to avoid formal accommodations. And so there was a lot of information gathering about that.

And of course, our vocational rehabilitation counselors were a wealth of information, as they often have, you know, the experience of working with both parties in trying to get accommodations in place. And so we really, we wanted to make sure that as, as ingrained in, you know, legal understandings and procedural information as the decision aid is, we wanted it to feel very much like a lived experience very much gaining insight and input from those who've gone through this process in, in many cases, multiple times over their careers.

I'd like to get into the individual sections of the decision aid,

we decided to start way back at the very, very beginning, even before thinking about the law or thinking about accommodations. And so the very first part of the before section is really what is a disability, and how is disability defined in many different ways. And so the goal here was really, for people who maybe have not had an opportunity to

think about disability in this way for them to have an opportunity to start conceptualizing their experience and connecting it to this idea of disability. So in this section, it's really not about the legal definition of disability, but just more generally about disability and how it's conceptualized in and primarily Western society. And so out of that, people begin to think about how they identify. And some people will have very strong disability identities formed over many years, proud identities or disability, and others will have no identity really, you know, they might be aging into disability, they may have just had an event occur that resulted in disability and so they may be starting there. From there we move on to really talking about how his disability is defined within the Americans with Disabilities Act, to help them understand the definition that they need to meet in order to be considered a person with a disability under the ADA. And then as part of this definition, under Title One, the which is focused on employment of the ADA they also need to be able to identify or state how they are a qualified person with a disability. So not just a person with a disability but a person qualified for this job. And so the third section is really helping them understand whether they are qualified an individual with a disability. From there, we move on to talking about accommodations, what are reasonable accommodations, what kind of accommodations might be appropriate for me, and they identify what those are. And then we have a couple of sections that identify risks of disability disclosure, helping them think about what the risks might be personally for them, and then thinking about their own personal risk tolerance.

So we know there will be risks for disclosure, how confident Am I that I can tolerate those risks, and make this request. And just the same way that some people may choose not to take a certain kind of medical treatment or take decide to have a certain kind of surgery. In this case, there will be situations where people may decide not to ask for reasonable accommodation, because they, for example, look at their job or employments setting, and they just feel that it's too risky to make that disclosure. Hopefully, you know, hopefully, that's not the case. But there are still situations where people may make that decision, and it will be completely rational for them to do so.

And then at the end of this section, there's a section where they actually make a decision. So what do they want to do? Do they want to move forward? Or not? How confident do they feel in that decision? And after they've made that decision, they can choose to move on to the next large phase of the tool, which is how to make the best request?

SHARON:

Heather, before we move on, do you want to talk about that section, the request making?

HEATHER:

Yeah, you know, in the section of how to make a request, we start to really ground things in kind of the efficiency. So we lay out guidelines for what types of information are going to help make a good strong request, and also laying out the boundaries of what information you do not have to apply.

And again, this is not a clean-cut area for employers or for employees. And so it's really a decision aid that is designed not just for the individuals who are requesting accommodations, you know, we see this decision aid is also being very useful to human resource personnel, in reminding them what kind of medical documentation they can ask for, and what types of information is absolutely none of their business, for example. And so it kind of walks through what information you need to provide, what kind of context is helpful.

And, you know, we actually have it set up so that during these different kind of, you know, you learn, you reflect and you apply at each decision aid, it helps you produce somewhat of a form of a bit of a report or a letter that you can use to actually submit your request that shows how you're a qualified individual. That explains why an accommodation would help. That gives some suggestions of the kinds of accommodations, you know, recognizing that our big emphasis is this is intended to be an interactive process between employer and employee, you know, neither one just sets down what's gonna happen. It's interactive, you know, suggestions for what kinds of accommodations are common for specific types of impairments.

And then, you know, we really emphasize the transparency, the documentation, and again, that interactive part of the process. So that information helps really guide someone through making key decisions, deciding what documentation or information to compile, to submit as part of the request. And then at the end of it, the idea is, is that you actually have a written form that you can use to guide that conversation or even provide directly to an employer.

SHARON:

So it sounds like after you finish the second phase, you're armed with some documents to take your employer. What's next?

MARK:

Well, the next section, or the next phase, I guess, really has sections that address all the potential outcomes. And so there is a section that kind of talks through challenges that might occur after the request. And then there are three sections that deal with different potential outcomes.

One is, what do I do if my request is approved? Now, it might seem like well, if your request is approved, you're fine. But what we found in our interviews, and we've read in the literature is that, unfortunately, people tend to make a request and never come back again to change that accommodation. And adjust it so that it will work better for them. And of course, many people have conditions that change over time and really do need to be actively managing their accommodations.

So even if your request is approved, there are things you can do to collect information about how that accommodation is working or not working and how things have changed. We also recommend people really just track how their coworkers and others are responding to them with their accommodation, to make sure that there is no ongoing harassment or discrimination that's occurring because of that accommodation.

Then, the other possible outcome is that they might be offered an accommodation, but not the one that they requested. So the employer says, I'll give you an accommodation, but not what you want. And in that situation, the same kinds of things apply, you need to, you know, try that accommodation, do your best to see if it works. But if it doesn't work, then you need to have the data to come back to the employer and explain why you need a different accommodation.

And then the third possibility is that your request could just be denied. And so if that's the case, then you have to make a decision about whether you want to fight that and bring more information, how you could fight it. If you think you're being discriminated against, do you want to bring up a formal complaint? How do you do that? And so that's all kind of wrapped into that section.

And then we do have another section that really is specifically about what do I What happens if I need a different or an additional reasonable accommodation at a later time. And so it gives them some additional steps to think about if they come, you know, they've used their accommodation at work, but now they need something different.

All of those sections are there not necessarily intended for them to go through sequentially? Right. These are just things for them to come back to if they need those resources at a later time.

SHARON:

I understand that this decision aid is web based, what was the thinking behind putting it online versus having say, a PDF that people could print out and use?

MARK:

Yeah, you know, it's, it's not impossible, that we might provide something that's more static. But the nice thing about having it on the web is that we were able to have an opportunity to capture user generated information. So in those reflect and apply sections, almost all of them have spaces where people can write out notes, or make decisions or identify next steps that they want to take. And all of that information then gets accumulated into a series of reports that they then can print out at a later time. And so that's kind of the beauty.

The other nice thing about having it on online is, it's just a lot easier to bounce around through the tool. And we expect this, some people may want to go in a very, very linear path through the tool, but other people may really just be kind of poking around, they may look at a section and say, Oh, I know this information and then jump on. So it allows for a bit more flexibility, a little bit more interactivity.

SHARON:

And I know that it's probably different for everybody who uses it, but about how much time does it take to get through it. I mean, people reflecting over several weeks, or some people might go through it a lot faster?

MARK:

That's a great question. And we haven't really timed it out, it is not a small amount of effort to work through the tool, there's a lot of pieces to it, we had thought that there would be different ways people would use the tool, some people would use it independently, so they just come to it sit down and use it by themselves. But we also thought that there

probably are people who would use it with their voc rehab counselor, for example, where they would maybe work through a section every time they have a visit or work through a couple of sections. And, and so I imagined that is the kind of thing that would be best done over several weeks, at least, where you, you can learn something, reflect on it, and then come back to it after you've had a little bit of time to digest that. Heather, do you have other thoughts about that?

HEATHER:

I absolutely agree. And the two things about kind of moving through it is one, you know, people, people process information really different paces. So you know, that's a consideration. And again, I think we created this not to be a book, a booklet that you go through with checkmarks, right? It's not really meant to be linear.

It could be you're someone like myself, who's requested accommodations on a job a few times. And so you come in and you don't need all of the beginning or even part of the middle. You just want to know, for example, will you know this recent time? Let's say I had a request denied, what are my options? What can I do? And so that that's why it's tough to say well, it should take you, you know, an hour and a half to go through.

But getting back to not just the legal and factual information but for example, thinking through risks and potential benefits. That is so individualized.

The amount of time that it will take someone to really think through what their support systems are, their professional support systems, their personal support systems, is really going to be variable, it's really going to depend person to person.

But to Mark's point, having it online, the way we've set it up, is that that's kind of our next phase is to try to get our arms around well, you know, how, how long does it take someone to go through each decision phase, and are there ways that we can make it shorter or more efficient, so it's still very much a project that's in progress, we're just we're excited to get it up and get it available to folks so that we can all start to learn together and improve where we can.

MARK:

And I'll add one more thing about having it online. So we're able to have user accounts. So people can set up an account can log in, they can begin with a couple of sections, fill in their information. And then when they come back, and log back in again, all of that information will still be there. And so that that way, it's more of a permanent, you know, a permanent product for them. And then if they work all the way through it, and they have a couple of years with an accommodation that's working and then need to come back, there's a way to come back into the system and reset it so that you can work through it again. So I think that I think that's a valuable aspect of having it online as well.

SHARON:

So the decision tool is still in development, do you need to recruit people to come and use the decision aid?

MARK:

Absolutely. So we're, we're currently having some folks who are internal to our project, review it, the next stage is to do what we call proof of concept studies. And where you plan to run two small studies, one of them is really going to be about independent use. So we'll be looking for people who want to use the tool by themselves without a lot of support. And we'll ask them to give us a little bit of demographic information, and then to use the tool and then to fill out a survey about their experience. And then we'll try to reach out to a subset of people who use the tool to have a more in depth interview with a few people and just see how it worked for them. How do you know how did it work for somebody who was using it independently. And then we also want to have a small study where we identify some vocational rehabilitation counselors who are working with clients who are in the process of requesting accommodations. And those individuals would work together in a shared kind of process. And similar kinds of kind of low-cost data collection, we would ask them to give us a little bit of demographic information then to use the tool and then to participate in a survey or interview. So we hope to get those studies started pretty soon.

SHARON:

Is there a way that people can register to be participants in these studies?

HEATHER:

Absolutely. We're still in the early stages.

So if any listeners would be interested in engaging in this, you can reach out to me directly. Heather Evans, my email address is H, D, as in Don, E, V, A, N, S @uw.edu. If you send me an email, I would be happy to put you on our list. So as soon as we have open recruitment, we'll come we'll contact you and we'd be glad to have your participation in our study.

SHARON:

Thanks to both of you for being on the podcast.

HEATHER:

Thanks so much, Sharon. It was a pleasure being here.

MARK:

Thanks so much.

SHARON:

This has been INside the OUTcomes: A Rehabilitation Research Podcast. This podcast is supported by the National Institute on Disability, Independent Living and Rehabilitation Research. This is your host Sharon Parmet, signing off.