

Kessler Foundation Podcast Transcript: John O'Neill on Employing People with Disabilities

Recorded August 2019. [Listen to it here.](#)

- AANOUNCER: 00:04 [music] Welcome to a Kessler Foundation podcast. The foundation is a global leader in rehabilitation research that seeks to improve cognition, mobility, and long-term outcomes including employment for people with neurological disabilities caused by diseases and injuries of the brain and spinal cord. In this episode, we are talking with Dr. John O'Neil. He is the director of employment and disability research at Kessler Foundation and has over 28 years of experience in vocational rehabilitation as a rehabilitation counselor educator, disability employment researcher, and adviser to state vocational rehabilitation agencies. He spoke with Rob Gerth, the foundation's communications director.
- ROB GERTH: 00:52 So I think I'm going to start with Jean Vanier. I think I'm getting that right. I want to start with it because you just taught me how to pronounce it correctly, and so I wanted to do it while I remember it. So that's why I'm doing it. Now, he's a guy-- One of the things I love about working here, John, in all seriousness is running into you in the hallway or you're on your way out or on your way in, and you say, "Hi." And the next thing I know, I'm in a conversation that I didn't expect to be in about who knows what, which I really enjoy. So Vanier is a guy who died at the age of 90 this spring. That's why it came up. And you got me interested in him. So tell me who he is, and how he relates to your life.
- JOHN O'NEILL: 01:33 Well, I never met him. I've always admired him from a distance and his work. He is a French Canadian, but he also spent a lot of time in France. And he has very strong religious beliefs which are very Catholic in origin. And he got engaged with disability by sharing his life with individuals with disability. And he brought them into his home and started something called the L'Arche movement, which is actually international at this point. And it's based upon his notions of life sharing, for a lack of a better term, but there are many L'Arche communities around-- particularly in Canada, but in the United States too where people in the community decide to share their lives with individuals, typically with pretty severe disabilities, often developmental disabilities. And instead of individuals being paid to care for people with disabilities, it's individuals without disabilities sharing their lives with people who have disabilities. Because it's voluntary and no one's getting paid and there's no government involvement and it brings a lot of value to the lives of people with disabilities because they're truly integrated into the community. And they're living with and sharing their lives with folks who really care about them.
- GERTH: 04:06 What a great idea. It must give those people that are doing that quite a different perspective. And that's kind of what we try to do here too is try to give a perspective. So he even said how much it changes people. And for him, when he first started doing it, how it changed just his whole outlook on life and how he was like, "Oh, I'm looking at life all backwards, how I'm doing it."
- O'NEILL: 04:32 Yeah.

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- GERTH: 04:33 And so how is teachings come into your daily work habits or your life stream? How has it directed you or focused you?
- O'NEILL: 04:44 Well, I'm not sure it focused me. It just sort of emphasized some notions that I had about disability and the place of disability in the world. I was also very influenced by some of the literature that is out there. And it's not academic literature, necessarily. It's more historical and how vulnerable disability communities are. And it is a known fact that during the Weimar Republic, prior to the rise of Nazism, people in institutions who had disabilities were really the final solution was piloted on those individuals. And there was historically, it's a historical fact that there was a committee in Germany of health workers and physicians who were sent documents from institutions and they were given the task of deciding whether individuals would be killed or not. And so that historical fact kind of influenced my life in terms of wanting to be part of a community that was advancing the well-being of individuals with disabilities.
- GERTH: 06:35 Was it always to be a researcher or did you start somewhere else?
- O'NEILL: 06:39 Well, my work as an undergraduate, I was focused on experimental psychology. And I had assumed that after my undergraduate degree, I would go and move on to graduate work in experimental psychology. But I had to do alternative service because I was a conscientious objector during the Vietnam War. And so I was placed. Well, I had to find a place to work that was in the public service where I would be earning what a private would be earning in the military. And so I found a psychiatric hospital in western New York State, go on to state hospital. Or I worked as a therapy aid on the wards there. And that got me engaged in, I guess you would say advocacy, but just recognizing the kinds of very bias negative kind of treatment that folks, in this case with psychiatric disabilities, experienced in a congregate care setting.
- GERTH: 08:10 And at that time I guess the settings were not good. That was before sort of the mini-revolution that cleaned up some of those places. Is that--
- O'NEILL: 08:20 Well, I'm not sure-- Yes. It really wasn't before, but there was the community mental health programs that John Kennedy wanted to put in place. They never really took hold in a very comprehensive way. But the institutional movement was occurring at that time. But this was a congregate care facility and there wasn't a lot of movement out of the facility back into the community. And so I also saw some harrowing treatment of individuals that lived in this hospital and it kind of energized me into want to do something about it.
- GERTH: 09:23 So you went to Syracuse for your undergrad and graduate work.
- O'NEILL: 09:26 Right. Right.
- GERTH: 09:27 So what trajectory did that put you on then? Did that change what you were talking about?
- O'NEILL: 09:33 Being I go on to state hospital, as far as I could see, the only people there that were doing anything constructive was the rehabilitation unit. And they had, oh, psychologists, rehabilitation counselors, occupational therapists, teachers who were

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working with the population at the hospital. It was a small group of individuals, but I admired what they were doing. And their director happened to be a person who was, by training, a rehabilitation counselor. He had a PhD and was a graduate of Buffalo University, and so I admired what they were doing. And so I decided that I would take that track, more applied than research. And I applied to several schools and was accepted at Columbia and Syracuse, so I went back to Syracuse.

- GERTH: 10:37 Something about the cold must have attracted you. Did you have any family that were in the same direction? Did that influence you at all, what your family was doing?
- O'NEILL: 10:48 No. No.
- GERTH: 10:50 Were they caregivers or they were totally not-- It was just you. You picked this path all on your own.
- O'NEILL: 10:57 All on my own.
- GERTH: 10:58 Isn't that funny. Well, it's not that funny. My dad was a mailman and I'm not a mailman, so I guess that makes a lot of sense. But he was a good mailman, and so I try to be good at what I do. So I did learn a lot of lessons. How about mentors? Did you have any mentors then at Syracuse that influenced you?
- O'NEILL: 11:16 I did. I had one mentor in particular-- Well, actually, two. But one in particular who was a researcher in the field. And so I did get interested, very interested in applied research, which was his area of specialty. And he was entrepreneurial in terms of seeking and being awarded grants to fund his research. And so he was one mentor I had for sure. There was another mentor I had at Syracuse who was a fellow by the name of Burton Blatt. He was the, eventually, the dean of the school of education. And he was very much an advocate for people with disabilities. And he did a photo essay of the treatment of particularly folks with developmental disabilities, intellectual disabilities, the abuse that was occurring in large congregate care settings all over the Northeast. And he did a photo essay of that. There was a book called Christmas in Purgatory. And he actually, he tried to get funding to publish the book from the Kennedy's. And Bobby was running for senator in New York State. And they, both Bobby and Jack said, "Well, we'll pay for the publishing your book as long as you reveal to us where these institutions are so we can probably make them into some sort of political hay." And Burt Blatt said, "No." And so they didn't publish his book. But he ultimately got it published [laughter].
- GERTH: 13:42 That's funny,
- O'NEILL: 13:43 And he had promised the directors of these institutions that allowed him access that he would keep the information anonymous, so.
- GERTH: 13:57 So a lot of your-- It's sort of happenstance that you were a conscientious objector through the Vietnam War and that kind of pushed you in a direction then, an unexpected direction.
- O'NEILL: 14:06 Right.

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- GERTH: 14:08 Did you do one-on-one counseling at some point in your career then? Did you do that or did you go right into research and--
- O'NEILL: 14:16 Well, I did. It was the graduate degree, the doctorate, at Syracuse University and rehabilitation counselor education required clinical work as well as research. So it was modeled after the clinician-researcher model. And so I worked in the VA as a counselor for some of my fieldwork and did other counseling practica during my graduate work.
- GERTH: 14:53 And then, how'd you end up at Kessler Foundation? You've been here, how many years?
- O'NEILL: 14:57 Seven years.
- GERTH: 14:58 Seven years.
- O'NEILL: 14:59 Well, after I graduated from Syracuse with my PhD, I was looking for work and I saw a job that was available at the Rusk Institute for Rehabilitation in New York at New York University Hospital. So I applied for that job and it was a job where I was involved in field testing something called the rehabilitation indicators, which were indicators of rehabilitation outcomes in terms of skills, activities, etc. And this particular job was with the United Cerebral Palsy of New York State. And they were very involved in the deinstitutionalization of Willowbrook State School, which was a large congregate care facility on Staten Island, and so lots of people were being moved out of that snake pit and into the communities where they came from. So I was field-testing the rehabilitation indicators on that population as they moved from the congregate care facility into apartments that were more integrated into the community.
- O'NEILL: 16:34 And so that's how I got connected with medical rehabilitation was because Wayne Gordon and Margaret Brown who were, at the time, they were at Rusk. But they had this grant from the federal government to develop these instruments. And they were field- testing them around the country. And so one of the jobs they had available was at UCP in New York State to field test these instruments. So I was back in a setting where good things were going on. People were being taken out of these congregate care facilities where they were at risk for abuse. And being moved back to their home communities, which I valued that. And I was conducting research on that. As a matter of fact, I think it was the only quantitative research that was done on the deinstitutionalization of that facility.
- GERTH: 17:44 Wow. And how did that then take you into Kessler Foundation then? Or was there--
- O'NEILL: 17:50 Well, I was working for UCP. I had always wanted an academic job, and so.
- GERTH: 17:57 Like a university professor teaching? Yeah.
- O'NEILL: 17:59 Yeah. Yeah. And I was adjuncting at New York University during the time I was at UCP. But a position came available in 1984 at the Hunter College which is part of the City University of New York. And I applied for that position. And ended up there as an academic for 28 years or something like that.
- GERTH: 18:26 You're still there, right? You're still doing some teaching there?

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- O'NEILL: 18:27 I'm a professor emeritus there, so I still-- I teach one course a semester.
- GERTH: 18:34 Oh, good. That's great. What's normally the course? Is it the same course or is it--?
- O'NEILL: 18:39 It's almost always the same course. It's the basic foundations course in rehabilitation counseling and vocational rehabilitation.
- GERTH: 18:54 What majors usually take that, just out of curiosity?
- O'NEILL: 18:56 These are graduate students who are getting their degrees in rehabilitation counseling.
- GERTH: 18:57 Graduate students. Cool. So you've been around the business 30 years. Is that about right?
- O'NEILL: 19:08 Well, depends on how far back you go. I started my conscientious objector work in 1970, so.
- GERTH: 19:14 Okay. Yeah. Well, there you go. So you have a perspective. I just want to get your perspective. Has it progressed? Because it's a really tough field. Has it progressed at all in that time?
- O'NEILL: 19:29 Has the field progressed?
- GERTH: 19:30 Well, has the vocational rehabilitation, how it's being dealt with, how things are done, is it the-- People aren't being institutionalized anymore, for the most part, so that's good. But what have you seen during your 30 years? We've got plenty of time. Go ahead.
- O'NEILL: 19:49 From my perspective, I'm not sure there's been-- There have been advancements, improvements, but I still think there's a strong need for continued vigilance in terms of the treatment of individuals with disabilities. Just because they've moved into the community and they're more integrated does not necessarily mean that they are immune to abuse. And I think some of the-- I'm thinking of New York City and New York State. In particular, there's been quite a bit of press on the abuse and mistreatment of folks who are living in the community. And there's been quite a bit of concern about that. And I know that one of Burton Blatt's nightmares, as he was advocating for the deinstitutionalization of people with disabilities, was that once everyone was back in the community that, eventually, they might end up back in congregate care facilities because their treatment was so bad in the community, so.
- GERTH: 21:19 Right. Right. So that's a danger still in your mind then?
- O'NEILL: 21:24 Well, it could be. I mean, it's interesting to know that in the 1900s there was these institutions which eventually became warehouses for people with disabilities. They were originally established in order to protect people with differing disabilities from the community because people with disabilities were being mistreated in their communities. And these advocates like Dorothea Dix and Samuel Gridley Howe, amongst others, were creating congregate care facilities where there was going to be better treatment. Or they were going to take an educational approach. So these were safe havens, initially. But towards the turn of the century, into the twentieth century,

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because of various societal perspectives, these institutions were considered to be places where folks with disabilities would simply be ignored or abused because they were-- Because of the public's concern about being exposed to people with disabilities, about the eugenics scare, etc. Now these institutions that were supposed to be havens or asylums, places of safety, became warehouses where folks were basically being neglected. So that was one of Burt's nightmares that we would return to taking people out of communities and putting them back in congregate care settings for their own protection.

- GERTH: 23:45 Right. Is there a bright side anywhere along in the history here that you've been involved? Is there progression that you see?
- O'NEILL: 23:55 Yeah. I think there is. There's been a lot of work to improve community-based care. And to shift funding from these hospitals, congregate care settings, back into communities. There are very strong advocacy groups, many of them. And I think that is all for the good. Just thinking of the ARCs and APC and other organizations. There are quite a few organization that are advocating for folks with psychiatric disabilities as well. Very grassroots organizations, initially, but they have grown and they have quite a bit of clout and influence.
- GERTH: 25:02 Getting people out of these?
- O'NEILL: 25:05 Getting people out of congregate care settings. But also improving the community-based care that exists. Finding ways to keep people safe and thriving in the community.
- GERTH: 25:21 And there's some resistance to that, right? It's not all, like, everybody's agreeing that this is what we should do.
- O'NEILL: 25:27 Yeah. That's true. There has been some resistance. But I think that has even waned quite a bit, so.
- GERTH: 25:39 So let's switch gears for a second then. Let's talk about some things that you're doing here at Kessler and one of them is what I was introduced early on is this first Friday of every month, we all wake up early and come to the office, and we wait for-- Us here and at the University of New Hampshire, there's a group that's doing the same thing as we work on this project together that we call nTIDE, and we wait for the jobs report to come out, which comes out, I think, at 8:30, 8:30 AM. And then we interpret those numbers from the jobs report and apply them to people with disabilities as far as the workforce goes. Tell me about what that is supposed to be doing for us.
- O'NEILL: 26:25 Keeping the employment situation amongst people with disabilities front and foremost in the public eye I think is the intention of that. Back in, six years or so ago, we decided to plant our flag in the sand. And it's not a particularly complicated process to customize the data when it comes out. But doing it every month and connecting it to a webinar which we, the University of New Hampshire and the Kessler Foundation co-sponsor, connecting it to an educational webinar the same day and doing it every month, 12 times a year.
- GERTH: 27:35 Rain or shine.

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- O'NEILL: 27:36 Rain or shine. And then the good work that the University of New Hampshire as well as the Kessler Foundation does in terms of getting it out to the public, I think is-- Our intention was that it would make a difference.
- GERTH: 27:54 And this is about letting people know how many people with disabilities-- So the employment numbers are about how many people that are looking for work. How many people that are looking for work or finding jobs. That's what the employment numbers, in general, are about. And what we focus on is the number of people that are living with a disability that are looking for work. What percentage of them are actually finding work month to month, right? That's what we're talking about.
- O'NEILL: 28:22 Well, yeah. Yes. We're looking at workforce participation which includes looking and having a job. And so we emphasize having a job because that's the ultimate outcome, so. And certainly, we also look at those that are looking and working.
- GERTH: 28:45 And then over the six years, does the employment of people with disabilities rise and fall with the job numbers or does it go counter to the-- Like, if the unemployment rate is good for people that are living without a disability, is it also good or bad for people living with a disability?
- O'NEILL: 29:04 Well, we've been doing this since the beginning of the Great Recession. So for people with and without disabilities, we were tracking downturns. And while we weren't doing it from the beginning of the Great Recession, but we were several years into the Great Recession. And what we saw was there were downturns for people with and without disabilities. And the upswing was started for people without disabilities sooner than it did for people with disabilities. The employment situation continued to deteriorate for a couple years past when people with disabilities were getting jobs or were returning to the same job, right, they had at the beginning of the Great Recession. We did begin to see some improvement. And I think it was about 2016, for two years there was a steady uptick amongst people with disabilities. And that's kind of plateaued at this point. And we're, obviously, hoping that there'll continue to be an uptick. But the discrepancy between people with and without disabilities has always been great. And it's a--
- GERTH: 30:50 And by great, you don't mean good. You mean big.
- O'NEILL: 30:51 Big. It's been big. Yeah. The discrepancy has been as high as 40%.
- GERTH: 31:00 Wow.
- O'NEILL: 31:01 So it's a big discrepancy. And much of the work that the foundation does in terms of its grant-giving is focused on trying to lessen that gap.
- GERTH: 31:16 Yeah. Effect that number. That would be the ultimate goal is to be able to take some credit in having some effect on that number.
- O'NEILL: 31:23 Right. Right.
- GERTH: 31:24 Yeah. I know you don't really like to speculate, but I'm going to ask you if you would. Because I know on the webinar we do on the first Friday, we don't really talk about, "Oh, it could be this, it could be that." But do you have any feel, after doing this nTIDE

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for six years, do you have any feel for reasons for the ebb and flow? Is it just the economy or-- And that gap that we're talking about. Is it just people's attitudes? Are we fighting the same thing that we've always fought that people living with disabilities just they're too much trouble, probably can't do the job anyway, so why should I bother? It's hard enough hiring people as-- Give me some insight to that. Speculate for me if you would.

O'NEILL: 32:15

I think, certainly, amongst employers-- Well, let me back up a little bit.

GERTH: 32:23

Sure.

O'NEILL: 32:23

Most employers, they've been very forward in pushing the diversity agenda. But that diversity agenda has primarily focused on race, religion, gender, ethnicity, and not on disability. And as a matter of fact, the supervisors' perspective survey that we recently did, it was a 6,000 plus supervisors across the country, asking them about their employers' practices. We found that there is a very small proportion of those companies that they work for that included disability in their diversity agenda. Okay.

GERTH: 33:22

So it wasn't on the table even when they were talking about diversity.

O'NEILL: 33:23

Wasn't on the table. Yeah. About 12% of those corporations included disability in their diversity agenda. So I think that gives you some insight into why people and why that gap still exists.

GERTH: 33:44

Just sort of a lack of awareness? Do you think that or just they lack--

O'NEILL: 33:46

Yeah. I think it is lack of awareness and yeah. And even that's beginning to change, I think, somewhat. And I don't have any numbers to support that, but I have a sense that it's beginning to change. There's a lot of-- There has been an effort to connect programs in the community that focus on employment and disability to corporations. And much of the work-- Some of the work that the foundation has funded has focused on workforce intermediary work where there is a person or a group that brings the employment programs for people with disabilities and employers together. And so that workforce intermediary activity has increased. And more people are getting involved in that, being the intermediaries.

GERTH: 35:05

And the intermediary can help the company adjust and help the people adjust. And the company, they don't have to figure out how to do it on their own.

O'NEILL: 35:09

Right. They do not have to figure out how to do it on their own. Because employers typically have said, "Well, where are these people with disabilities? We'll hire them." And the people with disabilities are saying, "We're here!" But they don't seem to know how to--

GERTH: 35:32

And they're never in the same room.

O'NEILL: 35:34

They're never in the same room, so. This particular model is being used extensively within the community across the country. I think it holds promise.

GERTH: 35:48

I don't want to handcuff you here, so let's talk about the surveys, what we call the national employment surveys. You mentioned the one that was for supervisors. That was a 2017 one. But you did one in 2015. And then you're doing one for 2020. So let's

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take a minute and just talk about each of those. So the one in 2015 is the first national survey to look at the workplace experience for people living with disabilities. Is that a good encapsulation? Or give me your own.

O'NEILL: 36:18

Well, it's not the first survey to do that.

GERTH: 36:22

No.

O'NEILL: 36:23

Well, first of all, it was a nationally representative survey. But it's innovation was that it didn't only delineate the barriers that people with disabilities face in terms of finding work, getting hired, and onboarding. It also looked at how those barriers were overcome by people with disabilities. What did they do? How many of them felt they overcame those barriers? And if they did, what did they do? So that was an innovation. And it was really focused on striving to work. So the employment rate amongst people with disabilities is what, 30, little under 32%, right. While in this survey, we found that over 64% of individuals with disabilities were striving to work in one way or another. They were either looking for work or they actually held a job after the onset of their disability. And people were working, most everyone was working more than 35 hours a week. And if they weren't, they wanted to. And if they were working 35 hours a week, a good proportion wanted to work more hours. So it was trying to change the dialogue to, "Oh, look at how bad it is. Look at what all the barriers are that people with disabilities face." And it tried to change the dialogue and make it more of a striving to work as opposed to, "Oh, wait, all those poor people are unemployed."

GERTH: 38:22

Right. Right. Right. I'm going to make an edit point here. You're banging is--

O'NEILL: 38:31

Oh, sorry.

GERTH: 38:31

I'm hearing it, so. That's all right. You didn't bang the whole first 30 minutes. And suddenly, you're making points. It was good.

O'NEILL: 38:39

You need it bigger.

GERTH: 38:45

So this survey was really about talking to people living with disabilities, not their employers or-- It was going right to them. Is it hard to find that group for you? How did you go about identifying them?

O'NEILL: 39:03

Well, it was a random-digit dial survey. And that particular methodology is very expensive and time-consuming. It was a household survey. So we were randomly calling households. And we had to-- We were trying to get about 3,000 folks into the survey. And we probably had to call, randomly call, 50,000 homes or more to get that many folks. And so, yeah. It's effortful because the incidents of disability depends upon the survey. But it's not a high incidence population. Except that some surveys show that it's the largest minority group, but it still is a minority group.

GERTH: 40:15

And then the 2017 survey we touched on was for supervisors. So tell me more about that.

O'NEILL: 40:19

Correct.

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- GERTH: 40:21 What was the point of that?
- O'NEILL: 40:22 Well, the point of that survey was to-- Surveys that have been done of employers in the past have used Dun & Bradstreet listings in order to identify corporations that they would call. And that the surveyors would call and they would be put in touch with either a CEO or some human resource person or a vice president or someone who was in the C-suite, who was in leadership. And we always felt that-- Well, first of all, the people who were being talked to knew that the surveyors knew the company they were working for. So there's kind of a social desirability built into their responses in the sense that they're not going to want to make their company look bad. Doesn't mean they would exaggerate or lie, necessarily, but there would be that social desirability factor.
- GERTH: 41:36 Right. Yeah.
- O'NEILL: 41:38 The surveys were done by some of my colleagues. But they were kind of rudimentary. And they would ask about barriers, but they would have a list of barriers that through experience and anecdotal information, they had developed this list of barriers. And they never asked about how these barriers might be overcome. And there was very little qualitative information. The past surveys had also asked about practices in terms of recruiting, hiring, and onboarding people with disabilities, but they never got at the effectiveness of those, perceived effectiveness of those practices. So we wanted to conduct a survey that would avoid the social desirability and ask about the effectiveness of the practices they used. As well as collect qualitative information on how the barriers might have been overcome. And so we developed this. So we decided to talk to supervisors. Well, another factor was when you're asking someone in the C-suite or leadership, they don't know what's happening on a day-to-day basis.
- GERTH: 43:30 Right. Right. They're not in the loop.
- O'NEILL: 43:33 Yeah. Yeah. They're not--
- GERTH: 43:35 They're not walking the floor.
- O'NEILL: 43:36 Well, they're not there, right.
- GERTH: 43:37 Right. Yeah.
- O'NEILL: 43:39 And even the information they're getting is filtered. So we wanted to go to someone who was closer to the lived experience. So we wanted to interview supervisors. We did it through a company that keeps a large national sample of all kinds of people including they have a business to business sample. And so we use that sample to reach out to supervisors. But the supervisors knew that we didn't know who they were working for. So that took out the social desirability piece. And then we asked them about all the practices and whether they felt they were effective or not generally, and were they as effective with people with disabilities. So we asked them about that as well. So it was leaps and bounds beyond what the other surveys had been in the past.

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- GERTH: 44:51 And then what are some of the takeaways then from the survey? What did the supervisors tell you?
- O'NEILL: 44:54 It was much more positive than what I thought it was going to be. Many supervisors felt that the-- For example, the accommodations that they were using, generally, were also effective for people with disabilities. Such as, working from home. Okay. Not all the time, but sometime. Okay. That's a common accommodation that's provided by many corporations to any employee. And the supervisors felt it was working, generally, and working for people with disabilities. So there were those general kinds of accommodations that were also being used with people with disabilities. I thought that was a positive finding. We found that some of the practices that weren't used very often, but when they were used, the supervisors felt they were extremely effective for people with disabilities. For example, collaborating with organizations in the community that have employment programs for people with disabilities. About 19% of the supervisors said that their companies were doing that. But almost 100% felt that it was effective if they were doing it. So we were confirming some of the suspicions we had about these practices that are currently being used. There's also something called a centralized accommodation fund. Many supervisors are hesitant to provide accommodations because it's going to come out of their budget, right.
- GERTH: 46:55 And accommodations, we're talking ramps or--
- O'NEILL: 46:57 Ramps. Bathroom modifications. Equipment. Whatever. And the companies that had centralized accommodation funds, so the supervisors-- wouldn't be coming out of their budgets. Very few companies were doing that. Maybe 10%. But almost 100% of those who had it felt it was very effective. So we were beginning to confirm some of the-- We were thinking these practices were good, but now we have some evidence that they make a difference.
- GERTH: 47:35 Through these two surveys you've done so far, the 2015, 2017 survey, what do you do with that information then? How do you get some of that out to the people or implement some of it? Tell me about that.
- O'NEILL: 47:54 Well, we write papers. We get them out into the journals that are targeted toward people working in the employment and disabilities space. Through our webinars that we-- The lunch and learn webinars that are attached to the nTIDE that comes out every first Friday of the month. We report the results there. We go to conferences. I've maybe presented on the-- In the last year, I presented on the supervisor's perspective survey maybe at seven conferences. So that's how we get the word out.
- GERTH: 48:51 So two years later, you're still using that data.
- O'NEILL: 48:53 Oh, yeah.
- GERTH: 48:54 Yeah. You're still making the pitches.
- O'NEILL: 48:57 Yup. And there's also additional research we can do based upon the data we currently have. We ask the supervisors if we could come back to them with additional

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questions. And about 1,700 of the 6,000 said we could do that. So we can apply for additional research dollars in order to begin to mine that opportunity.

- GERTH: 49:25 Yeah. Some of it I just see as a marketing problem. To get awareness, you need a Coca-Cola kind of budget to really make an impact. I'm not taking away anything, mind you, I know what you're doing. And I know how hard you're working, but.
- O'NEILL: 49:41 Also, there are others that are working on this issue is American Association for People with Disabilities which is a fairly large advocacy organization in Washington. They have their-- It's not really a-- I guess it's a survey, but they have a bunch of best practices that they ask companies to benchmark themselves on. And many of those practices are in our survey. And it's just that we have some real data on their effectiveness. So there's a crossover there. And so it's not just us. There are others that are doing that as well.
- GERTH: 50:34 It being based in Washington is also going to be talking to the right people.
- O'NEILL: 50:39 Right. Right. Right.
- GERTH: 50:40 Yeah. That's great. No, that's good.
- O'NEILL: 50:41 And there's the National Organization on Disability, NOD, and they have their own benchmarking, and so we actually-- And their board is made up of CEOs and people with disabilities, but primarily CEOs. And we've presented to their board about these results and they were very interesting. So it's not just us.
- GERTH: 51:08 That's good. That's good to know. So tell me about the 2020 survey then. So what's the focus of that then?
- O'NEILL: 51:15 That survey will focus on the employment of people with disabilities who have received post-secondary degrees of one sort or another. Either an associates degree or a bachelors degree or even a graduate degree and employment. There's been some research that's been done by individual universities showing that people with disabilities who get post-secondary degrees are not getting employed as readily as people without disabilities. And in some ways, if folks with disabilities who are getting graduate degrees from Berkeley--
- GERTH: 52:08 Right.
- O'NEILL: 52:10 --can't get employment after graduation, something's wrong with that picture. So on the other hand, some of the national surveys done, some of the census surveys have shown that the benefit that people with disabilities get out of having a graduate degree, even though there's this-- In earnings, for example, even though there's a discrepancy between people with disabilities and people without, the bump-up that people with disabilities get from increasing degrees is greater than the bump-up that people without disabilities get. So the benefit is greater. And so let's find a way to lessen that gap between people with and without disabilities who have post-secondary degrees. Let's lessen that gap because it is definitely a benefit. It raises all boats. It's a tide that raises everyone's boat. People with and without disabilities, but those discrepancies still exist, and let's see if we can close that gap even more.

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- GERTH: 53:42 And so for this survey, what's your methodology to find the people?
- O'NEILL: 53:47 Well, we're going to use the survey service, Qualtrics, that maintains this large, very large national sample of people. Of people, period. And we're going to use them to find individuals with disabilities that are a couple years out from getting their degree and ask them about what their situation is, currently, in terms of employment. But also, what happened to them while they were getting towards the end of their degree? What kinds of services did they get? What kinds of supports? And we're going to try and figure out why this gap exists. And we are also going to have another sample, a matched sample of individuals without disabilities in the same situation, so we can begin to understand more about why the disparities exist.
- GERTH: 54:57 And this survey would be of interest to universities to improve their systems or is it a bigger audience than that?
- O'NEILL: 55:04 Yeah. I think it's bigger than that. I think it's really for the workforce development community which includes universities. Universities and post-secondary institutions, their feet are being held to the fire by many different groups in terms of the workforce outcomes that they are contributing to or not. And--
- GERTH: 55:31 And when you say many different groups are holding your feet to the fire, you're not just talking about disability groups, you're talking about other--
- O'NEILL: 55:35 No, no. I'm talking about, yeah. I'm talking about the US Department of Education and Congress and-- So we're spending all this money on loans for kids, youth, young adults with and without disabilities, and what's the impact? And there's a real problem with people not finishing their degrees and then not getting better jobs in general. And we know it's true for-- Probably it's also true for-- Well, we know it's true for people with disabilities as well.
- GERTH: 56:17 And the results of the 2020 survey will be in right around the time as we're celebrating the fiftieth anniversary of the ADA, is that--
- O'NEILL: 56:25 Yes, correct.
- GERTH: 56:26 So sometime in the summer.
- O'NEILL: 56:28 Yeah. And also, these folks that are just a few years out of post-secondary education at the time we do the survey, they're the children of Americans with Disability Act because they were born after, just after.
- GERTH: 56:51 Right. Right.
- O'NEILL: 56:52 And so if those disparities still exist, which they probably will, they'll be more impetus for movement forward because if anything should have improved their lot, the Americans with Disabilities Act should have.
- GERTH: 57:11 Right. So it's sort of a litmus test.
- O'NEILL: 57:15 Yes.

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- GERTH: 57:15 Yeah. And then, what's the-- What would it be? 2022, 2023 survey? Do you have any-- You've got a pattern here. I'm just curious if you thought ahead?
- O'NEILL: 57:25 I should live so long [laughter].
- GERTH: 57:29 Fair enough. There's another piece. I'm going to move ahead from the surveys if that's all right. There's another piece of work that you do here that we call the Kessler Vocational Research Facilitation Program. So tell me about that. Tell me about that. I'll just let you tell me.
- O'NEILL: 57:50 Okay. Well, when I first came to the foundation, and obviously, the foundation has this very solid historical and current relationship with the Kessler Institute for Rehabilitation, which is a acute rehabilitation hospital for folks who have just sustained some sort of disability and they're out of acute care and they're sent for medical rehabilitation. And when I first came, I recognized that there was very little being done within the hospital. Kessler Institute is one of the largest free-standing medical rehab facilities in the country. And over time, these stays at these acute medical rehab facilities have gotten shorter and shorter. One time, it wasn't unusual for people, for example, with spinal cord injury staying in these acute medical rehab facilities for six months, a year, even longer. And when that was the case, there was more connection to vocational rehabilitation. There were actually vocational rehabilitation counselors in the hospital working with individuals talking about employment once they're discharged and back to community life. But as the days got shorter and shorter, it's not unusual for someone with a spinal cord injury to be in acute medical rehab four weeks as opposed to six months or a year.
- GERTH: 59:45 And that shortness is not necessarily because, "Hey, we've gotten really good at this." Does it have to do with insurance money? Is that the bottom line?
- O'NEILL: 59:52 It has to do with insurance. Yeah. And the emphasis now is really on-- The emphasis now during that period is getting people up and moving and physically functional again. And there's been no room for focusing on employment because the hospitals are reimbursed for what they do medically, not for what they do socially.
- GERTH: 01:00:19 Right. Right.
- O'NEILL: 01:00:21 So I felt that there was a possibility for some early intervention on the in-patient unit, vocational rehabilitation intervention, but only if there was follow-up post-discharge. And there's a whole movement these days around early intervention and many kinds of issues related to healthcare. And also, in terms of employment, and so we applied for a grant from the Neilsen Foundation, Craig Neilsen Foundation, to try out vocational resource facilitation which is a model that had been used in traumatic brain injury. And originally was used at the Mayo Clinic where a resource facilitator, employment resource facilitator, would work while people were in-patients and then follow them after discharge. I don't think Mayo at the time was thinking about it as early intervention, but it was. And it was shown to be pretty darn effective for people returning to work or going to work. And had never been applied for SCI which is a very different ball of wax in terms of the issues and--

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- GERTH: 01:02:01 Spinal cord injury.
- O'NEILL: 01:02:02 Spinal cord injury. Correct. And so we applied for this grant and now we have funding from the state vocational rehabilitation program to continue this service. And it's being done at KIR and we hope to move it out to other acute medical rehab facilities. We've gotten some interest from some other acute medical rehab facilities around the country who would be interested in engaging in such an effort. And we found that the return to work rate is much better for people with spinal cord injury who are part of this model than the benchmark that the spinal cord injury Model Systems data shows. For example, the return to work rate one year after being discharged in the Model Systems. Overall, the Model Systems all--
- GERTH: 01:03:11 Just to interrupt, the Model Systems is a nationwide sort of collection of data from all over the country and there's a lot of statistics available to you, and that's what you're referring to.
- O'NEILL: 01:03:20 Right. That's what we're referring to. So their benchmark is at one-year post-discharge, about 12% of individuals with SCI return to work. And we're finding at KIR that's about 31%. So it's an improvement.
- GERTH: 01:03:39 Wow. Wow. Yeah.
- O'NEILL: 01:03:41 Considerable. I mean, if you just look at 31% and didn't have a comparison, you can go, "Eh, so what?" But, "Or compared to what?" as my father used to say [laughter].
- GERTH: 01:03:54 That's great. So that program is on a grant. How many years has it got to go yet and--
- O'NEILL: 01:04:04 Well, the grant is finished at the end of this year. But we already have state funding from vocational rehabilitation to continue it. So it's part of the service system now in New York. In New Jersey, sorry.
- GERTH: 01:04:19 And that's how other people will fund it?
- O'NEILL: 01:04:21 We're hoping. Yes. So we're going to work with the trade group for the vocational rehabilitation programs throughout the nation. We'll work with that group in order to interest the states that we're going to move into to fund such a program, as long as it's effective. And we have the benchmarks to use for effectiveness.
- GERTH: 01:04:52 So what do you think this rehabilitation area will look like in, say, 10 years? Again, excluding the fact that you may or may not be with us at that time [laughter] in one way or another. Who knows who's going to be here? But what do you see? What are the trends? Where do you see it going?
- O'NEILL: 01:05:16 Well, it's not where I see, where I hope.
- GERTH: 01:05:19 Okay. I'll accept that. Where do you hope it goes? That's a good distinction.
- O'NEILL: 01:05:23 Yeah. Well, there are opportunities. One opportunity is there's a trade group for all of these medical rehab facilities, acute medical rehab facilities around the country. And there are literally hundreds of them, into the thousands of these acute medical rehab facilities around the country that are working with people with spinal cord injury and-

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- GERTH: 01:05:53 Which is a growth, right? That wasn't always the case of the acute facilities.
- O'NEILL: 01:05:57 Well, I don't know. I don't know how long the trade groups been in existence. But yes, it's certainly growth. I mean, when you see for-profit companies coming into this space and wanting to buy these acute medical rehab facilities, you know it's a growth.
- GERTH: 01:06:15 Yeah. Okay.
- O'NEILL: 01:06:15 It's a growth industry. So there's an opportunity there to move these services, these collaborations between state vocational rehabilitation and acute medical rehab facilities. So there is that. And it sort of like we're Back to the Future, in a way, because at one time, when the days were much longer, there were many of these facilities that had vocational rehabilitation counselors actually who were working for the state program who were outplaced into these medical rehab facilities either full-time or part-time. But that went away when the medical rehab stays got shorter and shorter.
- GERTH: 01:07:11 And do you think technology's going to play a key role in this or?
- O'NEILL: 01:07:14 Technology definitely will play a role because spinal cord injury and returning to work and technology is key. It's a core element of returning to work in one fashion or another.
- GERTH: 01:07:32 And I'll give you my final question which is-- And we've already discussed your longevity, but what do you like about working at Kessler? What keeps you here?
- O'NEILL: 01:07:43 All the opportunities to engage in research. And there are just-- I'll compare it to an academic setting. I thought I always wanted to work in academic setting and be with my colleagues and be teaching and doing research and-- But many academic settings, they value research, but they don't promote it to the degree that an organization like Kessler Foundation does. And there are always-- You're always in an academic setting if you're-- That's not true, necessarily of medical academic settings. Medical schools, there you live or die by your funded research. But in most academic settings it's not that way. You need to publish. But you're often buried in a large institution and you don't get much recognition and there's no one there pushing out your results to the public. And here at Kessler, that is just all-- It's very different. And you're given lots of opportunities to be creative and to follow your best instincts on research.
- GERTH: 01:09:35 Great. Well, thanks. Great. Thank you, John. Appreciate it.
- O'NEILL: 01:09:41 You're welcome.
- ANNOUNCER: 01:09:43 For more information about Kessler Foundation, go to kesslerfoundation.org. Follow us on Facebook, Twitter, and Instagram. Listen to us on Apple Podcasts, Spotify, SoundCloud, or wherever you get your podcasts.