



ADA Live! Episode 112: A Successful Path to Employment with the Innovative Supports for Autistic Workers (ISAW) Project

Broadcast Date: December 7, 2022

Guests:

- Bev Harp, Principal Investigator, Innovative Supports for Autistic Workers at Human Development Institute - University of Kentucky

Host: Beth Harrison, Director of Knowledge Translation at the Southeast ADA Center

Recording: adalive.org/episodes/episode-112

Bev Harp:

Hi, I'm Bev Harp and you are listening to ADA Live

4 Wheel City: Yo. Hi, let's roll (singing)

Beth Harrison:

Hi everyone. On behalf of the Southeast ADA Center, the Burton Blatt Institute at Syracuse University and the ADA National Network. Welcome to ADA Live! I'm Beth Harrison, director of Knowledge Translation for the Southeast ADA Center. Listening audience if you have questions about the Americans with Disabilities Act or ADA, you can use the online form anytime at adalive.org or call the southeast ADA Center at 404-541-9001. All calls are free and confidential.

So to get us started, let's consider that some autistic adults have difficulties in finding employment opportunities that match their interests, gifts and talents, and many autistic adults experience substantial unemployment or underemployment. Autistic adults and youth also have barriers to completing post-secondary education and training opportunities, accessing healthcare and attaining and integrating in community living to discuss these topics relevant to autistic adults, we welcome as our guests today, Bev Harp, an autistic and the principal investigator of the innovative supports for autistic adult workers in Kentucky or ISAW I-S-A-W project at the University of Kentucky Human Development Institute. And we also welcome Squawker McCaw, Bev's assistant. Squawker And Bev, welcome to the show.

Bev Harp:

Thank you.

Beth Harrison:

Bev. What is the autism spectrum and what does it look like in adults?

Bev Harp:

Thank you for this question, Beth. The idea of a spectrum I think has started to fall out of favor with some of us in the autistic community, not because there isn't a spectrum, but because the concept is so poorly understood and represented that it may have outlived its usefulness. Many people when they think of the autism spectrum will visualize like a line leading from the most affected to the least affected. So already this is a mistake because so many of the ways autism shows up are invisible to others. So there's this idea that people at one supposed end of the spectrum are more disabled than those at the other end. When you're a person who can almost pass for "normal" on a good day, then a lot of is expected of you. If you look and behave mostly like everyone else, then it's generally assumed that you can do most of the things in the same ways that most people do.

People with higher support needs those who may have an intellectual disability or other conditions that commonly co-occur with autism. People who don't speak and haven't

found a reliable means of communication with others face a lot of barriers, and these barriers are fairly obvious and easy to identify. For those of us that speak, attend college, work full time, all of that sort of thing, people don't see our struggles. So my friend can't understand why I can only stay at her party for half an hour because she can't really imagine how exhausted I am from trying to play a role all day, from the constant sensory bombardments that come with being autistic. My coworkers might not recognize that I'm trying really hard to be included in a conversation but can't tell when it's a good time to speak. So I can only choose between interrupting or not participating at all, or my boss might be irritated by me asking the same question repeatedly.

So we are called antisocial and rude and annoying, whereas someone with a more visible disability wouldn't be held to that same standard. Meanwhile, we're working so hard to keep our heads above water that we burn out or our mental health suffers. So back to the spectrum concept. I recommend Matt Lowry's spectrum model that can be found at his website. That is Matt Lowry LLP or M-A-T-T-L-O-W-R-Y-L-L-P.com.

Also, Rebecca Burgess did an earlier but not quite as detailed version, which can be found on the art of autism website. Each of these models depicts a spectrum that is multidimensional and nuanced. You can use them to map anyone's strengths and needs in a very detailed sort of way. Looking at Dr. Lowry's model, there are nine areas of interest noted, and you can take each one of these and it breaks down each category. For example, under communication differences, you have echolalia, scripting, eye contact, body language, and a few others, and each one of these points can be graphed to show you how strongly each one manifests in this particular person. You can ask where are they on the spectrum of using eye contact, how far from the norm is their body language? And by thinking about each trait individually, we now have useful information to understand this individual.

This view of the spectrum lets you actually see the person's needs. Instead of assuming, for example, that since Joe has an intellectual disability in addition to autism and he doesn't speak yet at six, well that means that he should receive this particular type of therapy. Right? When you compare the two approaches, it's obvious how little sense it

makes to form decisions based on just a few factors like someone's measured IQ and speaking ability or just based on certain behaviors you can observe from the outside. So when someone asks "Where on the spectrum is Joe", because people like to ask that question as if the spectrum were a physical place, but I can show you that "Look, he's really strong here and here and he needs some support here and he needs a lot of support in these specific areas", so it's actually useful.

Beth Harrison:

Thank you, Bev. I did not know about that model and I had never thought about looking at certain characteristics individually, but that makes a whole lot of sense. Why do autistic adults have trouble finding employment?

Bev Harp:

A lot of it is just that autism is so very poorly understood. Stigma plays a big part in it, and some of that has come from intentionally negative portrayals presented by autism charities over the past couple of decades. There are organizations that have done a lot of damage by promoting the idea that autism is a burden and it would be better if there were not autistic people at all. Then there are organizations too that are determined to separate us using functioning labels because there's this belief that autism is only autism if it looks a certain way. So some people would not count it as autism unless it was like all the traits that I know of as autism plus a few additional disabilities, maybe intellectual disability, seizures, something like that, and the person would be usually minimally speaking to non-speaking, right?

In my view, it's not their autism that's different from mine. It's the types of co-occurring conditions we have, and I have quite a few of those, but they are not visible for the most part until I'm in a meltdown and they do make aspects of my life very challenging, but as long as I don't make things difficult for the people around me, they stay invisible. When people talk about someone being high functioning, low functioning, level two, whatever, they're talking about how the person's autism is experienced by others, not how it affects the autistic person's quality of life. And sometimes when I say this, people take it to mean

that I don't understand or respect that some people have more urgent and widespread support needs, that there are people who need supports 24/7. Of course, I do understand this, and I fully support all autistic people having all of the resources they need to thrive. I just don't believe that the differences can be attributed to a different type or brand of autism.

There are many, many ways for an autistic brain to be configured, whereas neurotypical brains are all pretty similar to one another. It might even be more reasonable to say that there are hundreds of thousands of types of autism than to say that there are two or three types. Anyway, I'm off track again.

Finding employment is hard because autism is poorly understood, and this is the same story that you'll hear over and over again from job seekers. They have a good solid resume. They get interview fairly easily, but then they never get called back for that second interview after 10, 20, 50, 100 interviews. They never get a call back. In spite of the fact that they might even sometimes be the most qualified candidate. And the reason is that in the interview, they might not make eye contact or they may not know how to answer an ambiguous question or just in the interviewer's eyes, there's just something a little off. They're not sure what it is, but they're not entirely comfortable with us.

So we lose out on employment and on yet another opportunity for people to get to know us, to interact with autistic people and discover that yeah, we are different in some pretty cool ways too. And to see that we can bring something to the table that they maybe didn't even realize they were missing. The way kids with disabilities are separated from non-disabled kids in school is another contributing factor for this. We grow up not knowing each other. Where are they going to learn that hey, autistic people are awesome, or kids with intellectual disabilities aren't dumb, they are intelligent, sometimes highly intelligent in ways that our society just doesn't value much. So to answer your question, I think it is a combination of not knowing on one hand and also maybe having taken in some misinformation about autism.

What we're trying to do with ISAW innovative supports for autistic workers is to make sure that employers have access to accurate information, that they understand what autism is

and what it isn't. They understand why we do some of the things we do and how to make communications easier. We talk about better interview strategies and how to help autistic employees understand the unwritten and unspoken rules of the workplace without shaming them or demanding compliance with things that don't really matter to the job. I want employers to know that we are here to support them and the employee. We love doing consultations and troubleshooting. Helping autistic and non-autistic people understand each other is one of my favorite things to do.

Beth Harrison:

Thanks, Bev. Your comment about it being a combination of not knowing and misinformation, and that's a bad combo that keeps us really from getting to know one another. I've heard the term masking. What does that mean in terms of autistic adult employees and what is the impact of it?

Bev Harp:

Well, first of all, it doesn't have anything to do with masking up for a virus.

I had one person contact me because we did an infographic on masking, and this person was very concerned that we were encouraging people not to wear a physical mask during the worst of covid, which they just didn't really read the infographic. And so there was a little confusion. But masking is when we act as neurotypical as possible in order to avoid criticism or bullying or to keep a job or whatever it is we're not allowed to do as our autistic selves. The mask is constructed over years as a response to repeated rejection. It can be conscious or unconscious or a combination of both. Like if I'm in a situation where I know it is extra dangerous to be different, then I might pay more attention to the way that I move. Be sure not to squawk or make other animal sounds. Try not to fidget, fake eye contact, laugh at the joke that isn't funny.

But there's also the things that were trained out of me long before I understood I was autistic, because autism is so misunderstood and has been so vilified. Many autistic kids are sent to therapies where they're discouraged from things like hand flapping and echolalia, which is repeating the same phrase over and over again. That's not a good

thing because stims, we call them stims short for self stimulatory behavior, which is the clinical way of saying that flapping your hands or rocking in your seat, pacing, those sorts of things. But those are the things that we do to self-regulate. So now I might be able to stay at the party a little longer if I can get regulated. So echolalia is real communication, and sometimes it's the best we can do. And if a person keeps doing their best and giving you the communication in the way that they can and you're not accepting that, you're not paying attention to what is being communicated, then it becomes much harder for that person to continue making efforts to do it the way that you would like them to do it.

Also, not everyone can mask. If you show that you can, then you are expected to do it all the time. And this can lead to a very hollow feeling life. The feeling that, "Oh, nobody really knows me, and if they did, they would judge me as unacceptable." Some of the consequences of long term masking are increased depression and anxiety and decreased self-esteem. We need to think about this seriously before deciding that autistic kids would be better off if they acted more neurotypically. Sometimes we can't unmask at work or school, and we have to weigh these potential mental health consequences against the possibility of losing a job, and it can feel so hopeless because even with these efforts, a lot of time the autistic person is still being judged because you know what? We are still autistic and no matter how we may try, the mask is going to slip. It's not going to cover everything. People instinctively know that something is different, and sometimes it's worse if they can't put a name on it or relate it to something they know.

Beth Harrison:

This reminds me a little bit about of code switching, just not allowing people to be their authentic selves and how sad that is, really.

Bev Harp:

Yeah.

Beth Harrison:

And you've mentioned neurodiversity and neurotypical. Could you talk a little bit about what neurodiversity means?

Bev Harp:

Neurodiversity is at the core of it, just the simple fact that there are different types of brains that need different approaches to learning and to working, and this is actually a good thing. When you hire autistic workers, you're bringing in new ways of gathering and processing information, not to replace the ways you're used to, but to add the kinds of depth and possibility that you can only have with diversity, appreciating the diversity of abilities, diversity in ways of thinking. We are really behind on this as a society, but we don't have to stay there. Most of the time when people talk about autism, they're using some sort of a clinical or medical lens in their thinking. In other words, they're talking about deficits. They're seeing autistic traits as abnormal and undesirable, but there are other ways to look at disability that take into account our full humanity and value.

So ISAW uses more of a social model and a neurodiversity lens in our discussions of autism, which means not only do we have different kinds of brains, that's a strength and not a weakness. That applies to the neurotypical person, the autistic person, the person with ADHD. Pretty much anything in the DSM, it's all neurodiversity. And if you take out the neurotypical people, then these are what you call neurodivergent people. So neurodivergent is the category that covers autism, ADHD, and then pretty much anything else that's considered a disorder or condition. And neurotypical is people who are more fit the norm. We look at strengths and support needs of each person to try to work out ways that meet both the worker and the business can have their needs met. So for example, say an employee keeps getting in trouble for leaving their desk too frequently and the employer doesn't know much about autistic neurology, so thinks that the worker is just slacking.

The first thing I'm going to do is to explain why an autistic worker might need to do that. The person might need to walk around once an hour to feel calm and regulated. It's not a choice, it's a necessity for this person. Maybe this employee could have a shorter lunch break and that time can be split up so that they can get in their movement breaks as

needed, or maybe a standing desk would be better for this person. Quite possibly there is something in the environment that's causing the worker pain, fluorescent lights, noise, maybe a smell that no one else is aware of. What we're not going to do here is to coach that employee to remain in their seat regardless of their own needs. That is something that's just going to create more problems down the road because the solution doesn't fit the person. It doesn't fit the person's neurologically based needs.

Beth Harrison:

Thank you, Bev. ADA Live! listening audience. If you have questions about this topic or any other ADA Live! topics, you can submit your questions online at www.aadalive.org or call the southeast ADA center at 1-404-541-9001, and now a word from this episode's sponsor, Innovative Supports for Autistic Workers.

Voice Over:

Innovative Supports for Autistic Workers, ISAW is a collaborative project funded by the Office of Vocational Rehabilitation and the Kentucky Office of Autism, and administered by the University of Kentucky Human Development Institute. The project provides in-person trainings, online modules, and ongoing technical assistance to Kentucky Career Center business service teams, as well as human resource professionals across the state of Kentucky. The project mission is to advance the understanding of the benefits of inclusion and of the needs and strengths of autistic workers. For more information about this important project, please visit their website at isaw.hdiuk.org.

Beth Harrison:

Welcome back. We're talking with Bev Harp, principal investigator of the Innovative Supports for Autistic workers, or ISAW, I-S-A-W, administered by the University of Kentucky Human Development Institute. And before the break, Bev, we were talking about neurodiversity and how some of the things that neurodiverse workers use to be successful are looked down upon by typical employers. Maybe you could tell us a little bit about the supports that are available to autistic adults that are seeking employment.

Bev Harp:

Our main focus with is on employers and employment support specialists, but we do offer some services for job seekers. For example, we'll work with a job seeker to review and edit their resume and make it look really sharp, advise on cover letters, conduct practice interviews, and we provide counseling on subjects like disclosure and accommodations. We also offer supports over a longer time period when we're able to. For example, we have a couple of employed workers who check in regularly for advice on navigating issues at work. And just as with our employer consultations, these services are provided free of charge. A lot of autistic adults will also qualify for support from the Office of Vocational Rehabilitation. They might be assigned a support specialist or a job coach to help them find work, learn the job, and stay employed.

Beth Harrison:

I was thinking back many moons ago when I was a job coach, and oftentimes the folks that I was working with would want to come back in when there was a new employer or a supervisor changed or that kind of thing. So having that ongoing consultation and being there for the worker when those changes are inevitably going to occur is very important.

Bev Harp:

Yes.

Beth Harrison:

What kinds of supports are available to employers looking to hire autistic adults?

Bev Harp:

Innovative supports for autistic workers provides both training and consultation services at no cost to businesses. We'll meet with you and your employee to work out solutions to problems autistic workers might face. Usually this could be a conversation or two or three on Zoom. In some cases, we will also go to the business to check out the suitability of the environment if that employer wants us to.

We'll look at everything from lighting to types of seating procedures and relationships with colleagues, and sometimes we're able to suggest relatively minor changes to save somebody's job and save the company from the headache of unnecessary turnover. We're also working on coming up with more written materials for managers who might not have time to meet with us. At our website you can find infographics covering the most common accommodations, ask for executive functioning differences, best practices for including autistic employees in meetings and many other topics. Any employer interested in hiring autistic workers can contact ISAW and we'll share your job posting on our website and social media. We will probably reach out to OVR counselors and employment specialists that we know to see who they might know that would be a good fit for that position.

Beth Harrison:

Those are a lot of great supports that you all are providing. Is there anything new going on with the Innovative Supports for Autistic Workers? Are there other projects like yours, Bev in other states?

Bev Harp:

There are very few projects similar to ISAW. I don't think that there are any quite like this that are being backed up by OVR and the States University Center for Excellence and Developmental Disabilities. There are actually more for profit types of programs out there that will help you with these things for money. So as far as what we have new going on, we are working on an initiative to make it easier and more attractive for employers to take advantage of our trainings, and we're going to call this the Autism Informed Employers Initiative. Our hope is to create a network of employers who have sufficient understanding of autism. That we can be sure they know how to communicate with their employees. They know what kinds of accommodations might be requested or what might work. The employers can be certified after completing online modules rather than having to come to an in person or synchronous training. They can earn a certificate and we will promote those businesses on our website and social media and in podcasts like this, and we may feature them in a newsletter or conference presentation. We'll do our best to help to

support that business as they become an autism informed employer. If an employer is interested in hiring an autistic worker, we'll do our best to connect them with good candidates.

Beth Harrison:

You're kind of doing the education or the get to know you that folks have not had growing up, as you mentioned earlier in the episode, because of how we segregate typical from atypical students. I applaud you all for that. As we're wrapping up Bev and Squawkers are there any resources you would like to share with our listeners who are looking for work or those looking to hire an autistic person?

Bev Harp:

A good resource for understanding accommodations is the Job Accommodation network at askjan.org. They have extensive lists of recommendations for accommodating all different disabilities. So even if you don't find what you're looking for, either as a job seeker or employee who is going to be asking for accommodations, or as an employer who's just looking for to see what people have done in the past, you're probably going to come away with some good ideas that might work for you or for your business. Looking for work one thing that I recommend for job seekers to do is try to get a handle on the culture of any business you think you might want to work for. Because really that is what's going to make or break the job, the business culture and your relationships with the people at your workplace.

So I would first look at the website. Are there any people with disabilities in the pictures? Is there a diversity statement and does it mention disability? If it's a public place you can visit, you might even observe how things generally work there. Do the workers seem reasonably happy? If you see a manager or a supervisor, are they being respectful toward the staff? The last thing you want is to get the job and then find out that it's not really a good fit for you. For employers who would like to hire autistic workers, it wouldn't be a bad idea to contact Innovative Supports for Autistic Workers or ISAW. We're not an employment agency, but we do have a network of contacts who will help spread the word

that you're hiring. So be sure to visit isaw.hdiuk.org to start learning all you need to know about hiring autistic workers as well as better ways to communicate with and supervise them.

Beth Harrison:

Bev and Squawkers, thank you so much for sharing this valuable information. Really, there are a lot of supports out there for those seeking employment and those wishing to hire, and I'm so excited that you all have this project because it's doing very, very important work. So Squawk on Bev and Squawkers and thanks again.

Bev Harp:

Squawk.

Beth Harrison:

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4 Wheel City: (rapping)

[End of Transcript]

Disclaimer: The contents of this publication are developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant #90DP0090-01-00). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this publication do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

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