

# Quest

## PODCAST



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### Episode 6: Talent for Hire!

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**Mindy Henderson:** Welcome to the Quest podcast, proudly presented by the Muscular Dystrophy Association as part of the Quest family of content. I'm your host, Mindy Henderson. Our mission with this podcast is to bring thoughtful conversation to the neuromuscular community and beyond about issues affecting those with neuromuscular disease and other disabilities and those who love them. We'd like to acknowledge BMD awareness day and Disability Employment Awareness Month, which we join you in celebrating this October. We are here for you. To educate and inform, to demystify, to inspire, and to entertain. We are here shining a light on all that makes you you. Whether you are one of us, loves someone who is, or are on another journey altogether. Thanks for joining.

*(Music fades)*

**Mindy:** Today we're talking about employment. And with me now, I have Charlotte Dales and Annie Moore of Inclusively. Inclusively is a professional network and employment platform driving inclusion and opportunities for people with disabilities in the workplace. Charlotte is the Cofounder and CEO of Inclusively. Her experience in technology and start-ups has allowed Inclusively to provide a new technology solution to drive authentic diversity and inclusion in the workplace. Helping companies and employers acquire and retain top talent through human centered algorithms designed to optimize the success of job seekers based on their need for accommodations to build sustainable livelihoods and careers. And Annie is the VP of talent operations at Inclusively. Her experience in recruiting professionals ranges from entry level to the C suite across most industries and company sizes. I am so excited to have you two powerhouses with me today and just want to thank you both for being here.

**Charlotte Dales:** Thanks for having us. We're excited to be here, too.

**Mindy:** Absolutely. So, let's jump right in! I would love for you to tell me how, when, and why Inclusively was created. Where did this come from?

**Charlotte:** So, about 4 years ago, I was selling my first start up, which I co-founded in London, to American Express. And at that same time, my cousin became the first licensed aesthetician in the state of Florida with Downe's Syndrome so she could give facials at a local salon. And after getting my first facial from her, I kind of knew this would be my next company. It was just incredibly clear to me that what she'd been told her potential was in terms of career and what she was actually able to achieve was far different. And so how can we use technology to bridge that gap?

**Mindy:** I love it. That's so good. So, describe for me the process for an employer to work with you and to be listed on your site.

**Charlotte:** So, it really varies by employer. Depending on how big or small they are, if they want to focus on all their jobs, if they want to start within an organization, and how much work they've done in this space ahead of working with us. Typically, what we do is we start with a focus area in maybe their most high volume, high turnover jobs. Maybe they want to start within the technology space. And we really try to be very targeted so that we can demonstrate success in one area that then we can easily replicate across their organization. So, once we've kind of identified what our scope is in terms of the roles that we will be hiring for – we then work with the employers, their talent acquisition team, and the hiring managers to train them up on sort of what will be different in the process, how to handle accommodations – both for the interview and on the job, and really just how to remove biases from preexisting and sort of traditional processes. So, a lot of - you know, a lot of things that companies do now inadvertently screen out people with disabilities. And so we work with them to identify those bottle necks and sort of create an interview process that is inclusive to everyone.

**Mindy:** That's really interesting. So, when you're working with one of these employers - you know, clearly they are interested in being proactive about this particular issue and are open to hiring talent from the disabled community of individuals. Do they get specific with you about how far they can go with their accommodations, what they can accommodate and what they can't, or is it really a situation where they need to be open to be? Because I was looking at your website and it's a huge list of accommodations that are represented on your website. So how do they work from all of that?

**Charlotte:** So, what we do is we try to get employers to identify what accommodations they've made progress towards for different roles within their organization. But it's definitely not black and white. We encourage them to be open to a conversation about any accommodation because there's going to be a lot of things that they maybe they haven't done yet but that they definitely can do. So, what we are trying to do is drive – if a candidate is essentially self-disclosing to the employer that they have a disability ahead of an interview, we are asking the employers to do the same. To be transparent about where their progress is in this space, where they think they can make accommodations, so that candidates can look for companies on that basis. But it's not a sort of black and white, they're ticking off certain accommodations and then that's all that they'll do. It's trying to guide the candidate to the positions where the role will be most aligned to accommodations that they need.

**Mindy:** Yeah. That's really great. So, let's talk about the candidate experience for just a second. Would you describe the process for a candidate then to use your website? And how it's different maybe from working with another job search website?

**Charlotte:** The onboarding process is very similar to a traditional job platform. They can upload their resume, input information about themselves, and then they're able to tick off the accommodations that they would need for on the job and also for an interview. So, that sets that to their profile so that any employer picking up their resume can be really prepared to offer an inclusive interview for that person based on the accommodation request. And I would say how we're different from traditional job platforms is by using a lot more inputs into our matching criteria that are based more on the human

and not just on your background and experience. So, creating better matches and essentially more personalization for candidates with disabilities. In addition to a lot of the job platforms out there that exist that do cater to people with disabilities now, they are essentially marketing to this demographic, but they don't actually have a user experience that maybe adheres to some of the needs on top of a traditional job platform. In addition to, we don't list jobs on our site unless we have a process and a partnership in place with the hiring manager and talent acquisition. So, a lot of sites where they're just pulling API feeds of a ton of different jobs, they don't have enough of a strong enough relationship. So, a lot of times these candidates apply to those roles and traditional applicant tracking systems – their algorithms are trained to screen people out for different reasons. And some of those reasons could be things like having a gap in your resume – which could be inadvertently screening out a lot of people with disabilities where that might be a bit more common.

**Mindy:** I see. I think this is so fantastic and it's so exciting to hear that there are people out there like you that are doing this work to try and get more individuals with disabilities onto the workforce. Charlotte, I heard you say in another interview that only about 29% of individuals with disabilities are employed in the US. Why do you think, as a country, we are still so far behind in terms of employing individuals with disabilities?

**Charlotte:** I think a major reason is that currently this population exists amongst hundreds of thousands of different nonprofits and government agencies. And so, there's no real efficient way for employers to access the demographic at scale without having to make a lot of disparate, localized partnerships – which is really time intensive and usually only results in a couple of hires a year. So, I think there's a lot of efficiencies that don't exist. And I think another piece is just that the average hiring manager isn't going to have the knowledge about what they should be doing to interview someone more efficiently, for example, with Autism. And so, a lot of people are getting screened out from the process just by the fact that the cultural shift in the knowledge isn't widespread yet. So, one of the things we work on is, how do we sort of “scalably” change the culture of some of these companies.

**Mindy:** Let's talk just a little more about that. Because clearly, you all are doing some great work to try to make a shift to that world. But what specifically do you think really needs to happen to make a significant change to this statistic?

**Charlotte:** I think that employers need to start to think about accommodations they can make and really look into – you know, I think there's a myth that people believe it's really hard, that it's really expensive. The average accommodation is free or under \$500. And the number one accommodation that people ask for is remote work. So that's obviously something that people have all been granted over the past year or 18 months.

**Mindy:** Right.

**Charlotte:** So, I think it's really – there's a lot of education that needs to happen on the employer's side for them to understand why they're not attracting or retaining this talent. And I think one of the things Annie works on with employers is when there's an interview process that's set up, can we identify ways in which that interview process is actually uninclusive. And she can give you a bit more info on how she works with employers from that perspective.

**Annie Moore:** Yeah, I would say that one of the biggest impacts that we make in making sure that candidates are set up for success in an interview is to make sure that that interview process is as inclusive as possible. You know, a lot of times companies are used to conducting an interview process in a certain manner, such as just panel interviews. However, by allowing candidates to select

which accommodations will help them to perform their best in an interview – and on the job – right from the beginning of registering with Inclusively, we are able to kind of hit that head on. You know, we can connect with every employer to make sure that the candidates are set up to be able to highlight their experience and interests in the most effective way.

**Mindy:** I love that you're talking about the interview process. Because, you know, I was going through a job search process myself not too long ago. And, you know, there's so much anxiety about asking for accommodations. And I would get to the point where I was granted maybe an onsite interview and then I would need to go back to them and ask about things like accessible parking and access to the building and things like that. And it's such a double-edged sword because you want the access, but you also don't want to say something that's going to put you at a disadvantage. So, it's so hard for a person with a disability to know what to say and when – and I guess that's really the beauty of what you all are doing is there are no surprises, right?

**Annie:** Yeah. We are trying to drive transparency on both sides. Ultimately the solution to this problem is to create interview processes that screen in people with disabilities. And one of the ways to do that is to have the transparency on both sides so that they can make those accommodations for you for the interview. And they can make sure they're setting up the interview in a way where you're going to succeed no matter what disability that you have.

**Mindy:** That's great. I'm also seeing an uptick in a lot of articles and social media posts and things about – like, it's kind of an uptick in companies that are hiring for specific DEI roles. Is that a trend that you all are also seeing? And how optimistic do you feel like that is going to perpetuate progress in this area?

**Charlotte:** I think definitely since four years ago when I started this company, it was very much, you know, "Oh, we should be thinking about this." Whereas now, disability is completely included in a company's overall diversity and inclusion goals. There's also federal regulations, that I think are going to get a bit more enforceable over the next year around, if you hold a federal contract you need to be demonstrating you're working towards having a workforce of 7% people with disabilities. And then I think also, having the FCC ruling last year, where publicly traded companies need to start reporting on their EFG goals in actual numbers not just that they're going to do it, has – honestly on our end, we've seen a huge wave of inbounds from those large organizations as it's clearly trickled back down to the partners that need to execute on it. So, I think this might be altruistic and optimistic, but I think companies genuinely want to do this, but they also need to do it now. So, the combination of that and companies like ours, that are making it a lot more efficient to do it – I think is hopefully going to be a really good next couple of years in really making a dent in this unemployment rate for people with disabilities.

**Mindy** – Yeah, and I think I would agree with you. I think that companies and people are going into this with really good intentions. Do you have any specific advice for individuals who may be working in these diversity inclusion roles to help them do it well? Because I wonder if part of the issue is that maybe they don't necessarily know how to – know what all of the issues are – or know how to create real true inclusion. Does that make sense?

**Charlotte:** Yeah! So, I would say my advice to any company, whether it's a huge organization or a small one, is that no one really knows how to do it perfectly. And if you're sitting around and waiting for that to happen, you're never going to be actually actively trying to hire this demographic. So, I think you really have to stick your neck out and just start to hire people with disabilities and with that, you're going to learn what is working, what is not. And people with disabilities always say they would rather come into to a company and maybe a couple mistakes happen but be part of the solution than

just not be let in at all. So, I think one of the big things that employers of all sizes, they want to make sure they have it perfectly right before they really start going after this. But proximity creates empathy. If you just start hiring people, it's going to spread throughout your organization. And it will be a lot more organic than setting up big companywide initiatives.

**Mindy:** I think that's such good advice. And the other thing that I would say, just from my own perspective and experience, is that you know I think most individuals in this situation – an individual with a disability, usually, we're pretty good at advocating for ourselves and communicating what we need and how we need it. Not necessarily in a demanding way, but I think that typically individuals are more than happy to work through a solution on something with their employer.

**Charlotte:** Yeah. I think that's one of the things we always hear at the beginning is that they don't feel like they're ready. But that "being ready" is just hiring people.

**Mindy:** *(laughter)* Yeah. So true. So true. I want to go back – I don't mean to give you whiplash – but I want to go back to what we were talking about a few minutes ago with respect to individuals with disabilities going into an interview and being unsure about when to disclose what information. You know, telling the person that they have a disability or what accommodations they might need. For individuals out there who may not be going through your website to kind of prime them to be set up for success in that area – is there anything that you would tell candidates about when the right time is and what the right information to disclose is?

**Annie:** Well again, you kind of touched on the Inclusively part and we really do want to be a hub for employers and candidates to use to find employment. So, again, we address this head on. It's part of the on-boarding for employers and candidates. So, I really can only – I feel comfortable speaking about Inclusively. But for other candidates, I think honesty is the best policy. You know, if you are comfortable requesting accommodations, anything that would help you to do better in an interview or a job. You only want to take an interview or a job that you are going to be able to perform your best in.

**Mindy:** Right.

**Annie:** So, I always just encourage candidates to request the accommodations that will empower them to perform their best.

**Mindy:** Fair enough, fair enough. And I think that that's good advice. So, let me ask you, just to get an idea of how vast the Inclusively universe is, how many employers on average do you have with listings on your website? And what sorts of jobs do you place candidates in?

**Charlotte:** We have about 30 large enterprises and logos on our site right now. And then we have a number of other smaller organizations that we're starting to test - kind of, how can we make this model work for smaller to medium sized businesses. And we also have a number of organizations on our platform that we source candidates for free, that are disability owned companies. And yeah – so that's sort of the makeup right now. We have 30 large companies, but thousands of jobs amongst those because they're all quite big organizations.

**Mindy:** Wonderful. And what's on the horizon for Inclusively? What's coming next for you?

**Charlotte:** So, we're building out – we just launched our community portal, which allows people to connect and engage and obtain resources about training programs and best practices on interviewing, etc. So, we are really excited about that. It launched last week. And getting people, sort of, outside of just looking for a job but looking for resources to help them in many different processes that kind of are adjacent to their career. And after that launching, our advocacy portal, which allows all

the hundreds of thousands of organizations across the US that are already doing a lot in this space to help candidates find jobs – we're launching a portal for them, to be able to manage their candidates a lot more efficiently. And hopefully, with better access to employers. So, creating, as Annie alluded to earlier, a hub for people with disabilities and aggregating all of the different resources that exist in this space into one place. So that people are able to efficiently route themselves to training programs, support programs, and sort of anything that maybe even kind of leads up to you even being ready to start interviewing and looking for a job.

**Mindy:** Wonderful. Actually, I have one more question that I would love to ask you on the remote work front. You mentioned that a little while ago, and obviously we've all seen everybody's been working remotely for the last year or so. Do you see that sticking around permanently? I've heard sort of conflicting views on how permanent that change is going to be in the world. What are your thoughts? What are you hearing?

**Charlotte:** Yes. It's definitely conflicting. I think a lot of organizations want to go back into the office. Going remote for the whole world essentially was great for people with disabilities, given that it's the number one accommodation they asked for. However, I'd say it's also a bit of a curse because now employers view this as sort of a preference. But when someone with a disability is requesting this as an accommodation it shouldn't be treated as a preference. So even if the company would like to go back to work all in the office, if a person with a disability is requesting it as an accommodation that they've reasonably made, before, for a very long time – it shouldn't be a reason that they're not giving someone a job. I do think it's been a great thing in terms of bringing awareness to the fact that an accommodation like this can open up the talent pool for people with disabilities incredibly. But it's also been – we've had a lot of discussions with our partners around them saying, "Well this role isn't going to be remote after the pandemic". But it's different if it's a preference of an employee wanting it to be remote versus an accommodation. So, I think that's one of the things that we are constantly trying to drive home with our employers.

**Mindy:** Yeah, well, and I think that it's been great also in terms of just sort of proof of concept of working remotely.

**Charlotte:** Yeah! (*laughter*)

**Mindy:** Yeah, I think that everybody has seen how effective workers can be working from home. You know, they're productive, they're work life balance is good, all the things that have been sort of scrutinized over the past year. And I think that there is a lot of data probably out there for employers to show just how effective their employees can be from home.

**Charlotte:** Yeah. Definitely.

**Mindy:** Yeah. Is there anything else that you all would like to leave us with? Either on the candidate front or the employer front? Just in terms of, you know, how we can all work together in terms of making workplaces more inclusive, to get people into jobs. What are your parting thoughts for us?

**Charlotte:** I think that it's an incredibly altruistic effort to want to create a dent in the unemployment rate. You know, it's initially thought of as something you should be doing to do the right thing. But I think that my parting words are that it's not just the right thing to do. That this demographic of talent is incredibly valuable. It's untapped. And I think that employers have a lot more to benefit, than just doing the right thing, by accessing this talent.

**Mindy:** So true. So true. You know, I think that there are some really unique and specialized skills that people with disabilities acquire over the span of their lifetimes. And I know that there were a lot of

things that put me at an advantage when I was working in the corporate world. Things like creativity and problem solving and loyalty and compassion. And so many other things. I could list a lot more things that are, I think, kind of unique to this community of people that I think brings a lot to a company in terms of making you successful and making you competitive.

**Charlotte:** Definitely. I think that we all want to believe that we want to do the right thing. But I think it's also important to not just count that as the reason why you're doing it. There's incredibly talented people.

**Mindy:** Absolutely. Well, Annie and Charlotte, thank you so much for your time. I commend you for the work that you're doing. I think it's incredibly important to this community. And I just thank you for spending your time and sharing your expertise with us today.

*(Music playing)*

**Mindy:** Today we're talking about employment. And with me now, I have Sarah Schwegel. Sarah is the Organizing and Advocacy Specialist at Paraquad. In 2015, Sarah graduated from Maryville University with her Bachelor's in Rehabilitation. In 2018, she graduated from Saint Louis University with a Master's in Public Administration. Before she started working at Paraquad, Sarah worked in Diversity and Inclusion at Nestle Purina PetCare and as a Youth Transition Coordinator at Starkloff Disability Institute. She is passionate about helping people with disabilities become as independent as possible through self-advocacy and policy change. Sarah, thank you so much for joining me today.

**Sarah Schwegel:** Yeah, thank you for having me. I am so excited to be here.

**Mindy:** Oh, thank you, I am excited to talk to you. So, I'm just going to jump right in. If you want to tell us about yourself, your disability, and maybe how you became so passionate about the topic of employment and independent living for individuals with disabilities.

**Sarah:** Sure. So, my name is Sarah Schwegel and I have Spinal Muscular Atrophy. So, I got my first powerchair when I was two and half years old. And I have been doing a lot of self-advocacy my entire life. I am incredibly passionate about employment and self-advocacy because all people with disabilities deserve to live their best and most productive life. And I just think it's so important for folks to know all of the options out there. And know what questions to ask to make sure that they can get all of the services and supports they need so that they can be productive and independent.

**Mindy:** I love it. I could not agree more. And you know, honestly, employment, independent living, all of it - there's a little bit of an additional layer of complexity, I think, when you have a disability. And so, I am all for people who are out there, on the front lines, helping to educate all of us about how to do this well. So, like I said, when you have some type of a disability it adds that additional layer of complexity when you're interviewing for jobs. Tell me what your interview experience has been like when you've been on the candidate side of the house.

**Sarah:** Of course. So, job interviews are always incredibly nerve-wracking and can sometimes be a little bit scary.

**Mindy:** Yeah.

**Sarah:** So, something that I like to remember when I'm interviewing is that not only are they interviewing me to see if I'm a good fit for the company, but I am also interviewing them to make sure their company is a good fit for me. I think it's really important that you are honest, you are your true self, and you ask any questions that you have. The interview is a great time for you to really

understand what that company is all about. And it's a good time for you to showcase yourself and all of the incredible things you can do as a disabled person.

**Mindy:** Exactly. And you know, I've been on the candidate side of things a ton of times – and it's funny, I kind of equate interviewing for jobs a little bit to dating. It's kind of that same kind of scenario where you're trying to put your best foot forward and get to know each other, and then you're waiting for the phone to ring, and all of those things. But, of course, you know interviewing for a job is a little bit different because you don't have the luxury of time. You know, sometimes you talk to employers one, two, three times. And I think you made a really good point about being yourself and really putting your best foot forward - but being yourself, being true to who you are – because that's the only chance you're going to get to see if you're going to be a good fit for them and if they're going to be a good fit for you.

**Sarah:** Yeah. And I think, personally for me, it's always been really important to bring up my disability in the interview process just because it's so much a part of who I am. I feel like I would be doing myself a disservice if I didn't talk about how my disability has given me so many strengths. Like being able to manage attendance and just being able to organize my life – you know, you have a disability as well, Mindy. You know that it is super crazy and things are always really difficult. So, using your experience, as a real-life human with a disability, can translate really well to some experience in the job world.

**Mindy:** Yeah. And I am a firm believer that living with a disability really instills skills in you that can make you a really valuable employee. So, let's talk about that for second though. Because it can be hard to know when to disclose that you have a disability. You know, when I've been interviewing for jobs, I'm never really sure when exactly to bring it up or to mention it. And I tend to bring it up, I guess, when I am getting ready to go on site for the first time if that's a factor in the interview process. But what is your best advice to somebody? As to when the right time is to bring it up? Or should you?

**Sarah:** Yes. Yeah, no, these are great questions. So, remember that disclosing your disability is an incredibly personal decision. And every person that you talk to might have an answer that is completely different from another person that you talk to. And it might not feel right for you. So, you really have to do what feels right for you, your level of comfort with your disability. I personally also like to bring up my disability right before I go on site. So, for me, the best way for me to disclose is just to mention with my recruiter, or whoever I am speaking to before my interview, while I am kind of scheduling and getting all of those logistics in place. And I just casually mention, "Hey, I use a wheelchair. What's the best entrance for me to use that doesn't have any steps?"

**Mindy:** Exactly.

**Sarah:** And then, based on their reaction, I can kind of gauge how welcoming that company is to employees with disabilities. And you know, that is something that I can hopefully factor into my decision-making process as well. As to whether or not I want to work at that organization.

**Mindy:** Right. That's very, very true. And it's funny. It sounds like we have a similar approach. For me, it always just felt kind of natural when you're going on site to ask questions about accessibility. Like where you park and what entrance you should use and things like that. So, it gives you kind of a natural opening to mention it and get some information that you need at the same time of course. But you also make a really good point in that sometimes being able to gauge their reaction to your question can be insightful as well.

**Sarah:** Yeah.



**Mindy:** In today's world though, with so many people working remotely – if you are meeting with the employers to interview over Zoom or some other platform, how do you feel like that changes the conversation? Do you still need to disclose that you have a disability? Or does it become kind of a moot point in that case?

**Sarah:** So, I like to think about whether or not my disability is going to affect the way in which I do the job. For me, if I am interviewing over Zoom and I know that I'll be able to work remotely and they will give me the tablet that I need and all of the accommodations that I need because that's just like the supplies they provide to all of the employees, then I might not bring it up. But if I'm interviewing over Zoom and I'm going to have to go into the office on a hybrid schedule or even full time and I don't know what kind of technology or equipment I am going to get – that's when I bring up that I have a disability, I often need a lightweight computer, sometimes it's really difficult for me to find transportation so I might have to work from home some days...and just kind of have that conversation and let them know what you need to be successful on the job. I think a really important part of disclosure is letting employers know that you have thought it through and have some ideas for how you'll be successful.

**Mindy:** Agreed. Because I think part of the problem sometimes is just the employer's - maybe their discomfort or their lack of knowledge about what you may need or may not need. So, I think that as much as we can advocate for ourselves and speak clearly and articulately about exactly what we're going to need so that – you know, I think in a lot of cases, it's a much less big deal - Is that proper English? (*laughter*) – than they may think it's going to be. And the accommodations that we need may be far less than what they could be anticipating. Would you agree?

**Sarah:** One hundred percent. I remember when I was interviewing for one of my first jobs. The hiring managers and HR team were all really concerned about making sure that my desk area was perfectly accessible. And they had so many questions. Which was fabulous. But I was able to go into the office on that first day and kind of give them a full run down of the things that work really well for me. And say, "I am willing to work with you guys and meet within your constraints of budget or whatnot", and we were able to come up with a really good system by just having a conversation and working collaboratively.

**Mindy:** Yeah, I had an experience where I was starting with a new company. And they made it so easy. They sent me an email, I think a week or two before my start date, and just asked me. You know, we're putting together your workspace and need to know what height your desk needs to be at, if there's anything else you need just let us know. And they made it very easy for me to tell them exactly what I needed. But again, I think that the more direct we can be about what we need, the more comfortable probably that's going to make the employer too. Because it takes the guess work out of it for them.

**Sarah:** Yeah, one hundred percent. I always try to provide employers with as many resources as I can. Just because I like them to know that I am on their team and I want to be a part of the solution. Some of the resources I really enjoy using are askjan.org - and it's the job accommodations network.

**Mindy:** Okay.

**Sarah:** And that has a list of all of the job accommodations you could possibly think of and a full list of disabilities and what some accommodations might be for them. And it's just a really incredible resource to help employers make sure their space is accessible and for disabled employees to kind of get thinking about what might work well for me. Especially if they've never been in a office setting and they don't necessarily know what would work. I really love askjan.

**Mindy:** So, what would you say to people who may be listening, who – you know, it's such a tricky thing because we need jobs. You know, we need to pay our bills, we need to put food on our tables, and all of that. And there can be so much insecurity around this topic when you are interviewing for a job. Because we don't know what biases and things the person on the other end of the phone or across the conference table from us may have. So, bringing up things like this can be really hard. What would you say to people who are listening to maybe get them a little more comfortable with the idea of having these conversations and sort of letting go of some of the insecurity around it?

**Sarah:** So, I think a really good place to start is start talking about your disability with your friends and family. You know, talk about the things that it allows you to do and the things you have done successfully because of your disability. Something that I know I've really gained a lot of skills in is time management and being able to create schedules. Because I have to work with personal care attendants. And I have a team of like 6 college students and 4 nurses that I have to schedule to make sure all of my needs are met. So, that's something you can take into an interview and bring in as a positive that your disability gives. I think a lot of times we think of our disabilities as well, we can't do this, we can't do that, we – you know, it's really hard, it takes forever to go to the bathroom or whatever. But it's - you know, while that is true, it is also a really cool thing because it's allowed us to have to think creatively. And make modifications to our lives that normal people without disabilities don't have to do. And I said the word "normal," and I hate when I accidentally do that.

**Mindy:** Yeah.

**Sarah:** Because really, disabled bodies are pretty normal. If you live long enough, you're going to be disabled.

**Mindy:** Yeah. It's true. It's true. And, so, because this can be a little bit of a tricky conversation to have with people, do you know what sorts of questions an employer is actually allowed to ask? And what they aren't? Because I think it can be important for us as candidates to know if we're being asked questions that are inappropriate. And sometimes that's going to be obvious, but you know, not always. And so, I am wondering what your thoughts are on that. Or if you know what questions are legal, so to speak.

**Sarah:** Yeah. So, Title 1 of the Americans with Disabilities Act protects employment. There are specific questions your employer is allowed to ask, which there are not many. They really can't ask about your condition or anything like that. They can just like barely skate around the subject. So really the ball's in your court. You get to choose when and how you disclose.

**Mindy:** Okay, perfect. Yeah. And I think it's important to know that there is actually very little that they're allowed to ask. Which makes it even that much more important for us to advocate for ourselves and tell them exactly what the truth of our circumstances are and what we need in terms of accommodations.

**Sarah:** Yeah.

**Mindy:** So, I know that sometimes people may also have concerns about going to work and losing their SSI or SSDI benefits. Which can be critical to your daily living. Are there programs that you're aware of that may be able to help offset that?

**Sarah:** Yes. And this is actually one of my favorite things to talk about.

**Mindy:** Alright!

**Sarah:** Many states will offer what is known as Medicaid “buy-in program” to people who are on SSDI. So, that’s for folks who became disabled after they were working. And that allows you to literally pay a premium every month and buy into the Medicaid program and receive services such as personal care attendants and coverage for doctors or hospital visits. And then they also have this other program called 1619B. And that is a program under the Social Security Administration. And that program is for folks who were disabled before they started working. So, a lot of folks with muscular dystrophy are probably going to qualify for this because of the time of onset of their disability. With 1619B, you can work and earn up to a state-determined threshold. So right now, for Missouri it’s about \$44,000. And when you are on that program, you can earn that amount. And until you make one penny over that threshold, you can keep your services. So, it’s really nice and it allows people to work and have full time jobs and meet those needs.

**Mindy:** Fantastic.

**Sarah:** It’s a very, very cool program that not a lot of people know about. I remember when I was back starting my job search and everything after college, I was talking to my Social Security Administration Case Manager and they were like, “The what B program?” And I was like, “1619B? It’s for individuals with disabilities...” So, you definitely have to like really advocate for yourself. And make sure you have done research on the program and everything like that. Because a lot of times, the individuals that you’re going to talk to with the State aren’t familiar with it. Because there is such a small percentage of people with disabilities that do use that program.

**Mindy:** Gotcha. And I think that you said that all of these things – all of these programs – vary from state to state. So, what would you say is the best first step for someone to look into whether those programs may be available to them in the state that they live in?

**Sarah:** I always recommend checking with your local Center for Independent Living. Which, Paraquad is one of. But Centers for Independent Living help individuals with disabilities of all ages and all types of disabilities. And they have an Information and Referral Department. So, that I&R Department is the place you can go and ask pretty much any question and they will get you connected to the correct people in your area. So, I always recommend reaching out to your local CIL. And then you can also do some research on your own, on your state’s Medicaid website. Depending on what state you’re in, those websites might not be super easy to navigate. So, it’s always good to get a Center for Independent Living behind you and be able to help you advocate and know what questions to ask.

**Mindy:** Great. And a lot of cities, I know, do have Centers for Independent Living, which is basically what your employer does. Would you tell me more about the work that your organization does in terms of helping people find employment?

**Sarah:** Yeah. So, Paraquad is unique in that it also has some employment services. In addition to the core services that all Centers for Independent Living have, we also have employment services that connect folks with job readiness classes and job coaches. So, job coaches and job readiness classes are often for folks who maybe don’t have those job skills and need a little bit extra help on the job with problem solving and coming up with those accommodations that they need.

**Mindy:** Great. So helpful. This is such a interesting topic of conversation and, you know, it can be an emotional one. It can be a tricky one to navigate. But it’s doable. It’s a process that can be figured out and can be worked through. Like I’ve been saying all along, people with disabilities do have some unique circumstances and things to overcome in the interview process, but I think that what I would want people to know – if there are people out there listening who haven’t sort of found their way

through the employment process - just to persevere. And keep asking questions. And follow the breadcrumbs. And I think a Center for Independent Living, particularly one with employment services, is a great place to start. Because there are wonderful people to champion for you and to answer your questions. Sarah, what would be your parting words to people out there who are either maybe looking for a job right now or maybe thinking about looking for a job?

**Sarah:** I think job searches are exhausting and difficult. But stay with it, because you will absolutely find the job that is a perfect fit for you. Know what questions to ask, do research about accommodations, and come into the interview with some solutions and ideas, and really talk yourself up as a disabled employee. And talk about the skills that you can bring to the table. And of course, just be – again, I'm going to say be patient and just take a deep breath. Because the job search is really difficult but it's definitely something you can do and there are resources to make sure that you can work and maintain all of your benefits.

**Mindy:** Absolutely. And the good news is, you only need one job!

**Sarah:** Exactly.

**Mindy:** *(laughter)* So, it can take some time to find that right one. But when you do, then you're all set. So, I think your advice is good. Just to be patient and be yourself. I think that people undervalue maybe the importance of going in and really being themselves and being proud of who they are. So, Sarah, again I just want to thank you for spending your time with me today and sharing your perspective on this topic.

**Sarah:** Yeah. Thank you!

*(Music playing)*

**Mindy:** Thank you for listening. For more information about the guests you heard from today, go check them out at [mda.org/podcast](http://mda.org/podcast). To learn more about the Muscular Dystrophy Association, the services we provide, how you can get involved, and to subscribe to Quest magazine or to Quest newsletter, please go to [mda.org/quest](http://mda.org/quest). We'd also love to have you as a member of our grassroots advocacy network. There are two easy ways you can sign up. Go to [mda.org/advocacy](http://mda.org/advocacy) or text MDAUSA to 504-57. If you enjoyed this episode, we'd be grateful if you'd leave a review, go ahead and hit that subscribe button so we can keep bringing you great content, and maybe share it with a friend or two! Thanks, everyone! Until next time, go be the light we all need in this world.

*(Music fades out)*