



## **ADA Live! EPISODE 44: WHY YOUR ADVOCACY MATTERS: WHAT'S HAPPENING AT THE STATE AND FEDERAL LEVEL IN DISABILITY POLICY**

**Event Date:** May 3, 2017

**Presenter:** Allison Wohl, Executive Director of the Association of People Supporting Employment First (APSE)

**Host:** Barry Whaley - Project Director, Southeast ADA Center

**VOICE-OVER ANNOUNCER:** Blog Talk Radio. (Music) Welcome to WADA ADA Live! Talk radio. Brought to you by the Southeast ADA Center, your leader for information, training and guidance on the Americans with Disabilities Act. And here's your host.

**BARRY WHALEY:** Good afternoon and welcome to WADA ADA Live! On behalf of the Southeast ADA Center, the Burton Blatt Institute at Syracuse University and the ADA National Network, welcome to the 43RD episode of ADA Live. My name is Barry Whaley, and I am the Project Director for the Southeast ADA Center. The topic of today's show is Why Your Advocacy Matters: What's Happening at the State and Federal Level in Disability Employment policy. As a reminder, you can submit your question about disability employment policy at any time at [employmentpolicy.org](http://employmentpolicy.org) at any time on [ADALive.org](http://ADALive.org).

Now I would like to introduce today's speaker, Allison Wohl. Allison is the Executive Director of APSE, the Association of People Supporting Employment First. APSE is a national membership organization that promotes the full inclusion of people with disabilities in the workplace and community. In 2009, after her youngest son, Julian, was diagnosed with Down Syndrome, Allison knew it was time to leave her busy life as a management consultant for the even busier but more rewarding world of disability advocacy. Allison received her MBA from the College of William and Mary and her undergraduate degree from SUNY Binghamton. In addition to Julian, she is the mom of two other boys. Allison, welcome to our show.

**ALLISON WOHL:** Thank you so much.

**BARRY WHALEY:** Today we are talking about disability employment policy at the state and local levels. Allison, I'd like to start by asking you to talk about what have been the national trends in disability employment over the past 5 10 years.

**ALLISON WOHL:** That's a great question. Other groups have been involved in promoting employment for 30 years, really we just started seeing substantial movement just over the last six years or so. There's been a national shift, which some states have moved further along this path than others, but the primary focus has been an emphasis on systems change. We're really seeing shifts away from congregate settings where people with disabilities are just with people with disabilities and their staff that support them. The system is focusing more on supporting people in community settings. We're also seeing a shift away from sub minimum wage work. It's interesting. When I got into this work in 2011, there was a proposal and a big bill to set below minimum wage and the outcry was so fierce that they pulled the language from the bill. Now it's not just a question of if but when. We really have seen enormous progress over the last several years.

Another focus has been on people with disabilities making decisions for themselves both on their own and the support from trusted people in their lives. From opening bank accounts, paying taxes, and building assets. So obviously, this is just another part of that. If people don't have income at all, they're totally relying on benefits, they're not in a position to think about being on a path to economic self-sufficiency.

Another trend that's emphasized over the past years has been a greater acceptance of people with disabilities as individuals. I think for a long time they were seen as a stereotype of their disability. And now we are really understanding by having more people with disabilities, when they're first starting schools in their communities, and employment. They there are individuals that are very different and not just, you know, the stereotype that maybe the people have had about them in the past. A lot of people don't come in contact with people with disabilities unless they have someone in their lives with a disability.

Finally another trend has been, and this is really what's driving employment for people with disabilities now, the recognition that hiring people with disabilities, that they are a great work force makes an advantage for businesses. In the past, they were seen as just, you know, people that were to be pitied or that a charity would take care of. And that's really changing now. People with disabilities, businesses are understanding what they have skills and mobilities and add tremendous value to a business's bottom line and also to its culture.

**BARRY WHALEY:** These are encouraging and welcoming trends, certainly what we have been working for in the last 35 years or so. It's an exciting time to be in the field. Putting on the crystal ball, do you see the trends to continue, Allison?

**ALLISON WOHL:** You can't put the tooth paste back in the tube, but people with disabilities are not going to accept where they were, being institutionalized, being in congregate settings. So I definitely expect the trend to continue. As we recognize the value of diverse groups in our communities and our workplaces, more and more people realize that workers with disabilities are actually an untapped resource. Historically people with disabilities have been confined to poverty and life on the margin. But it's such a waste of human potential. And you know, aside from just a social aspect of looking at this, we have demographic trends that are making it impossible to ignore contributions and potential of workers with disabilities. As baby boomers age out of the work force, we are looking at by 2020, 15% of jobs going unfilled. That means that we'll have 15% more jobs than there are workers available, because 10,000 people per day turn 65. As we continue to shift more towards a service economy, that means the businesses are going to have to find people to keep their businesses going. And they realize more and more that people with disabilities are really an untapped resource with enormous potential.

**BARRY WHALEY:** That 15% is a staggering percentage when you think about it. I'm wondering what concerns you have for the future of disability employment policy?

**ALLISON WOHL:** There are a number of concerns that I have. A number of them are urgent and they're happening right now. The timely recording because right now, we have been working really hard to slash Medicaid. And Medicaid is the vehicle where people with disabilities are supportive. Supportive in living, independent lives. And the affordable care act has gotten us a long ways towards supporting independence for people with disabilities by expanding Medicaid. And also by making it easier to obtain services for people in the community. The American Health Care Act, which is a different proposal has an \$881 in cuts to Medicaid. It would have a devastating impact on the disability service system, which in large part is funded through Medicaid. It's a topic that doesn't get a lot of media attention because politically, services to people with disabilities are not just a headline grabber. But in addition to those proposed cuts, if the American Health Care Act is enacted, it would turn what has been an entitlement system into per capita caps. Each person who receives Medicaid would only get set amounts and it would not keep pace with inflation. So states would have to make tough decisions, whether to make it more difficult to qualify for services or they would have to cap the number of people who receive services. In short, the pot is shrinking and you have more people to serve.

What we have come to know as home and community based services is that with less money from the federal government to serve the same amount of people, we expect the states would take much of the money that they have historically used for community based services like employment and some of the funds towards mandatory Medicaid services that are mandated by law. So that's a really big concern, and I think looking into the future, you need to think about different ways to fund supportive employment or employment supports for people with disabilities because Medicaid is a target for cuts. It has been for a long time, and will continue to be as the number of people on Medicaid continues to grow.

Another area that I'm really concerned about is that as we see more and more people receiving community services and working in their communities, there's been a trend towards segregation for congregate settings. They're called farmsteads or totally segregated settings that really feel to a lot of people, it certainly depends on the person, but feels like institutionalization. People before me, certainly, but to close down institutions and to allow their adult children with disabilities to live in the communities. But this pro segregation movement is well funded. So segregated services and settings, and they also are working really hard to maintain the status quo. Talked about term workshops, they are congregate services where people with disabilities go, usually for the day. And those who contract from the outside like packing and shredding, and they are they are paid often people with disabilities are often paid less than minimum wage. Sometimes they're not. But they're not evaluated on what their skills and abilities would be and what the best job fit would be. They just have a limited sight. And people see them as not actually jobs. Most of the time, but that's not always the case. In most cases they're not jobs. And we know that social and medical outcomes for people who are isolated from the broader society are not as good as those who are supported to live and work in their communities like everybody else. As a parent, I want my son to be supported in his community and to use the skills and abilities to work in a job of his choosing like everybody else.

I guess the third point that I would make that is really an immediate threat and certainly have a direct impact on the ADA, the Department of Justice in the last administration worked hard to enforce the [ INDISCERNIBLE ]... people with disabilities must be in an integrated setting and it's based on Title II of the ADA, nondiscrimination clause. So without a strong civil rights enforcement section, it's very difficult to enforce ADA regulations within the state. The last administration had gone a long way towards forcing states to legal measures to either go to consent decree. It forced the states to put people in community settings. A lot of different instances of this. But it was effective as a carrot and DOJ was the stick. Without enforcement, laws and regulations don't mean a lot. So that's a real big concern.

And another concern is we're seeing bills in congress which will weaken the ADA. One is called the ADA education act. There's another bill that will make it very difficult for groups to bring class action suits. These have historically been the vehicle by which people have forced states to provide employment and serve people with disabilities in their communities. Those are really some things to keep in mind.

**BARRY WHALEY:** Thank you for sharing those concerns. ADA live listening audience, if you have a question about disability employment policy, please submit it at any time at our online forum at ADAlive.org. Now a word from our sponsor.

**VOICE-OVER ANNOUNCER:** APSE the Association of People Supporting Employment First advances employment and self-sufficiency for all people with disabilities. Its vision is that people with all types of disabilities are employed, pursuing careers and building assets just like people without disabilities. To change expectations and achieve outcomes, APSE champions the Employment First principle that employment and careers be the expected and preferred outcomes of all publicly funded services for those with disabilities. Policies, practices and funding to advance employment, career development and economic advancement for all. For more information about APSE, please go to our site at [www.apse.org](http://www.apse.org).

**BARRY WHALEY:** Welcome back to our show. We are talking with Allison Wohl, Executive Director of APSE about what's happening at the state and federal level on disability employment policy. Allison, are there specific laws or regulations that have helped to push disability employment into the public eye?

**ALLISON WOHL:** Absolutely. There are really two mechanisms for disability service providers that enable those providers to find to explore job opportunities for finding the right fit for people with disabilities in jobs. And then for actually providing job support to employers.

The vocational rehab system is funded by federal grants, we have service administration and the bill that authorizes the funding is the work force innovation and opportunity act. It was originally called the work force investment act. And it was originally enacted in 1973. But every ten years there's supposed to be reauthorization. There was one in 2013. This bill really went a long way towards supporting youth who are transitioning into the adults to support. And it really, it was kind of revolutionary in a quiet way for those who actually follow this kind of legislation closely. It turned historical assumptions on their heads. And so, the one opportunity for people with disabilities. It would assume that people with disabilities who are being served by the vocational rehab system could work. In the past, it was assumed that they would just go into institutions. But this assumes that they will work and gives them the opportunity to find employment, to try employment. Before they are before they are referred out

to a more restricted option. So everyone who comes into employment through the public system of supports and services comes in through a voc rehab system and WILA was an enormous boost and has been a challenge to implement because it requires a lot of different thinking and requires agencies to have different processes. But it would fit from a public perspective, people with disabilities are supported to find employment before they decide that their employment is not the right path for them. And then along those lines, I talked a little earlier, home and community based services are agencies and individuals who access them directly. And they are Medicaid funding services that do fund employment. And there was a rule in 2014 which explores its planning phase for all states who are having they had to come up with a plan there. They would talk about how they would come into compliance with the rule. What the recommendation basically says is that people with disabilities must be served in a setting where they are not isolated from the broader community. This has been a big change for state and service providers. It is the same for WILA. Laws really focus on serving individuals in the community, enabling them and supporting them to work, and providing different incentives for support for people with disabilities who work.

One other piece of legislation that really helps to push disabilities to the public eye and the system of supports and services for people with disabilities that keeps them in poverty is the ABLE act. Achieving a better life experience act, which passed in 2014. The able act allows people to save tax free up to \$100,000 a year. If you live on SSI, there are \$2,000 asset limitation and also state by state income limitations. This allows people to save money and gets around the limitations which hadn't been waived before. It's very difficult for anyone to try and live on what people lived on 30 years ago. And so the ABLE act helped people and families plan and save, and in that way, it is an incentive to work because people don't have to artificially deflate their wages or hours.

**BARRY WHALEY:** That's great. I want to turn to APSE, and mention that I'm a proud member of APSE myself. It is an organization that promotes the full inclusion of people with disabilities in the workplace and community. And the marquee term and the name of the organization is employment first. What I would like for you to do is explain what employment first means and why it's important for disability employment policy.

**ALLISON WOHL:** Sure. It just means that we believe that employment should be the primary service outcome for any individual with a disability who comes into the long term services and support system in this country. So what does that mean? When someone ages out or graduates from high school or ages out of secondary education, parents often, families often face the disabilities cliff. And there aren't a lot of choices or there historically haven't been a lot of choices about what comes next. And employment first just says that when people are considering their next step, from a

perspective of public policy, we ought to be encouraging and supporting people with disabilities to work real jobs with real wages just like anybody else. We do get a lot of people who can't work for whatever reason or don't want to work. And the answer is employment first doesn't mean employment only. It does mean that when we're using public dollars to support people, we really ought to be focusing on employment as a primary option. And then people try employment and they're supported appropriately in employment and they fail, then they should be able to try again. And fail as we all do, and try again until it's determined that that person, this really isn't the right direction for them. It's really taken off across the country. There are 32 states that have some sort of policy action, whether it's an agency directive or legislation around employment first. It is a very popular phrase, and certainly has been adopted in many places.

What we need to work on is shifting the funding. It often goes to segregate people with disabilities, and shift it over to additional funding away from those services in supporting people to work and live in their communities.

**BARRY WHALEY:** Obviously there is still work to be done. What can we do, Allison, to influence state or national policies around employment first?

**ALLISON WOHL:** I think the best thing that people can do is to get to know the legislators in their state, get to know, you know, invite them to come and see somebody with a disability who is actually working in a real job and getting them to see first hand how this can work. A lot of times they just don't know. This is a topic that is not it's not really front and center for a lot of people. As people get to know their members of congress, kind of come into their district all the time. And you can always schedule a visit. So they can see how supported employment works. Some districts do a take a legislator to workday and they invite representatives to come and shadow people with disabilities and see what their days are like and see what's possible in employment. A lot of people just don't know.

Other things people can do are get to know their governors. They have big staff, and their job is to understand constituents and their issues. And you know, I think a lot of people are intimidated by legislators or, you know, people at the governmental level, and we forget that they are public servants and that it's our job to advocate as citizens. And again, a lot of people just don't know have much about it. APSE can certainly help you if you want to schedule a meeting with a policymaker. We have lots of talking points and leave behind information packets that people can read if they want to do some more education past the meeting.

I think the most important thing that people can do is tell their story. If you're an individual with a disability, talk about your job and the supports that you receive and why that's important to you and your family and to your community and what other

people have learned from you. If you're a disability service provider, educate people in policymaking and in political roles, again, what you're doing in your agency. How that is impacting your community. And certainly, for families, having someone who, you know, is empowered, is enabled to work, and who is fulfilled and living a life that they wanted to live. If you want to do that through social media, through e mail, send pictures, send cards. It's their job to collect them, and often we feel our legislators are out of our region and they don't care about us and it's our job to understand the constituents and what's going on in the communities. So we're overseeing a lot of people who have been involved before. There is nothing more important than telling your story and doing your advocacy on your local level because it does matter. That's what gets bills passed.

**BARRY WHALEY:** It's a grass roots effort. What legislative or regulatory milestones do you consider the result of grassroots advocacy?

**ALLISON WOHL:** Two of them stick out as grass roots advocacy and first is obviously the Americans With Disabilities Act. At that time, people who had a very difficult time accessing the world around them came out from all over the country in a very organized grass roots way and said, Hey, it's our right to be able to access public places and be able to ride the bus and get around town in our wheelchairs. Businesses should comply and open up the way to be more accessible to people with disabilities. So I would say that would be the first. And more recently is the ABLE act passed in 2014. And the ABLE act was passed by a lot of grass roots groups, often family groups who had people come out from all over the country, meet with their legislators and tell their stories and why it was that they were not able to save for their children with disabilities and people saying hey, I rely on public funds to when that bill passed there were 417 out of 445 members of congress who voted for that bill. It was important. It made legislators feel like they came together to accomplish something that was really important and to support people with disabilities, which is a really important function of government. The ABLE act is the first grass roots movement that I was a part of. I was told that I had to write my son out of our will because he couldn't inherit assets and that was two months after he was born. And that was so deeply wrong that you would have to disinherit a child. I got involved in a society and a hill day where you go to capitol hill and you talk about various legislative efforts, and that is where the ABLE act started.

**BARRY WHALEY:** Our voices matter, right?

**ALLISON WOHL:** Your voices matter, your story matters.

**BARRY WHALEY:** What are areas of challenge for APSE chapters and the work that APSE is doing on a national level?

**ALLISON WOHL:** Our chapters are all volunteers including our board. We want to have members join and also having those members become board members and leaders within APSE on state and national boards. We don't want people to burn out. You can be involved in large ways or small by becoming part of your state chapter. You can also get involved just by joining and being a member in your state. And if you want to try out APSE and see what we're all about, I invite you to register for the 2017 APSE conference in Portland, Oregon, on June 20, 21, 22. It is the only conference of this kind where 1,000 people will come together, experts and likeminded people from all over the country to focus on employment for people with disabilities. So I hope you will join us in Portland in June.

**BARRY WHALEY:** Our time is almost up. Before we end this episode of WADA ADA Live!, what are the one or two most important things you'd like our listeners to remember about advocacy on the state and federal level?

**ALLISON WOHL:** So I think the two most important things that I would like people to remember, there are a lot of different ways to be an advocate. You don't have to have a degree or dress in a certain way or think in a certain way to have your voice heard. Public servants work for you, and you as constituents, it's our job to advocate with people with disabilities, with our families, with our communities, but I would like people to not be afraid to get to know their legislators, keep in touch with them and build relationships with them because, as I said earlier, your voices matter, your stories matter, and ultimately, this is such a cliché, but think local. And members of congress run every two years in the house, every six years in the Senate. There are so many different ways to organize now whether it's Facebook or Twitter, whether, you know, you prefer writing letters or sending letters or sending e mails or having face to face meetings, there are a lot of different ways to do it.

The second thing is, for a long time people with disabilities were closed off from our society, put away where no one had to interact with them, and that's really it changed so drastically so much so that, you know, having a child who's 7, he has a very, very bright future. That is important A lot of people don't know or understand the issues. They're complex. But it's really important to be advocating and to be educating. You don't have to be a political person or, you know, be a Republican or a Democrat. These are human issues. These are bipartisan issues. It's important for people who are making policy and what policy means is who makes the rule. And they're the funding. It's really important to spend the public funds supporting people with disabilities to use their abilities to achieve full and rich lives just like anybody else in the community. So don't be afraid to tell your story.

**BARRY WHALEY:** I would like to thank Allison Wohl, Executive Director of APSE, the Association of People Supporting Employment First, for being our guest today. The

show will be archived on our website, ADALive.org. I also want to thank you, our ADA live listening audience. The Southeast ADA Center is grateful for your support and participation in this series of WADA ADA Live broadcasts. You may submit questions about any of our ADA Live topics by going to ADALive.org. Please join us again on Wednesday, June 7th for another episode of WADA ADA Live. Our topic will be Think College, Inclusive Education for People with Disabilities.

If you have questions about the Americans with Disabilities Act, please contact your regional ADA Center at 1 800 949 4232. Once again, that's 1 800 949 4232. All calls are free and confidential.

**VOICE-OVER ANNOUNCER:** Thank you for listening to ADA Live! Talk radio. Brought to you by the Southeast ADA Center. Remember to join us the first Wednesday of each month for another ADA topic, and you can call 1-800-949-4232 for answers to your ADA.

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