



## **ADA Live! Episode 91: Protection and Advocacy Systems for People with Disabilities**

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**Speaker:** Curt Decker, Executive Director, National Disability Rights Network

**Host:** Rebecca Williams, Information Specialist Southeast ADA Center

**Curt Decker:** Hi, I'm Curt Decker, and you're listening to ADA Live.

**4 Wheel City:** (rapping) Yo. All right, let's roll. Let's go.

**Barry Whaley:** Hi, everybody. On behalf of the Southeast ADA center, the Burton Blatt Institute at Syracuse University and the ADA National Network, I want to welcome you to this episode of ADA Live. I'm Barry Whaley, Director of the Southeast ADA Center. Listening audience, if you have questions about the ADA, you can use our online form at [ADALive.org](http://ADALive.org). Today, we'll talk about the protection and advocacy systems, which are usually referred to as P&A's in the disability rights community. P&As are federally mandated programs funded by the administration on disabilities, which is part of the administration for community living. In total, there are 57 P&A's in the United States with at least one P&A system for every state and US territory. PNAs work at the state level to protect and advocate for the legal rights of individuals with disabilities. P&A's are dedicated to the ongoing fight to defend the personal and civil rights of people with disabilities. P&A's empower and ensure that people with disabilities have the right to make choices, contribute to society and to live independently.

To discuss the important work of P&A's, we're very fortunate to have as our guest today, Curt Decker, who is the Founder and Executive Director of the National Disability Rights Network. Curt was also the former Executive Director for the National Association of Protection and Advocacy Systems. As a guest host for today's episode, we want to welcome our own Rebecca Williams, who I'm a little biased, is a brilliant Technical Assistance Specialist with the Southeast ADA Center. Curt, welcome to ADA live. Becky, I'm going to turn it over to you.

**Rebecca Williams:** Thank you, Barry and welcome, Curt. Curt, I want to say I'm so excited about having you as our guest today. I've been working in the field of disabilities for 40 years. I'm somewhat familiar with what protection and advocacy organizations do, and have referred to P&A throughout my career, but I really don't know anything about your history. I think that'd be a good place to start. How and why was it the P&A system created?

**Curt Decker:** Well, thank you for having me and thank you for letting me talk about our network throughout the country. It is a system that's now been around for over 40 years. We were created thanks to the expose of Geraldo Rivera of the Willow Brook Institution. This was a 5,000 person institution on Staten Island in New York, with the largest institution for people with intellectual disabilities in the world, and the conditions there were horrific. The result of that expos, and shows you the power of media, Congress created the Protection and Advocacy Program in the mid-70s and it came fully into being in the late 70s with a mandate to investigate abuse and neglect. However, quickly after our creation, people with disabilities, their family members realized that now there was this legally based advocacy system and so they came to us with a variety of problems. We continued to this day, working in institutional settings, trying to close them down and get people into the community, but also work on all the issues affecting people with disabilities.

One other thing I would say is that initial developmental disability P&A created in the late 70s, we have added eight other programs to make sure that we are now a cross disability

program. Anyone with a disability can come to the P&A and if they fit our case criteria, can get assistance from us.

**Rebecca Williams:** I remember that Geraldo segment, or expose or show. I was just appalled at the horrendous, horrific conditions. That's interesting that that's how you guys came about. I think Barry mentioned that the protection and advocacy systems work closely with other disability related groups, particularly the state developmental disability councils, sometimes known as DD councils, and the National Network of University Centers for Excellence in Developmental Disabilities Education Research, and Service, which is a big mouthful. Can you tell us a little bit about these collaborations and why they are important in the P&A work?

**Curt Decker:** Absolutely. As I said, the Protection and Advocacy Program is really kind of the legal part of the disability framework of services and programs. It's very critical that the P&A in each state and territory work with a variety of other disability organizations, both consumers groups as well as family groups, and our partners created by the Developmental Disabilities Act, as you said, councils and [inaudible 00:05:26], but also we work with a variety of other disabilities, our friends in the independent living center movement. We need to have that coalition and that collaboration to make sure the full range of needs of people with disabilities are met. We can't do everything. We have limited resources. We have case priorities. Often, that means we have to turn down people who are very deserving of our services, people we could help if we had the resources. We have to have this network of support in the community to make sure that somebody can pick up the issue and hopefully have a positive impact on that person with a disability.

**Rebecca Williams:** Your here, Curt, representing the National Disability Rights Network and we're also focusing this show on the state protection and advocacy systems. My next question is, does the National Disability Rights Network have priorities that each of the 57 P&A systems focus on at individual state levels, or does each P&A get to decide for themselves what their priorities are and what they may address?

**Curt Decker:** Well, hopefully both. NDRN is the voluntary membership association of the P&As, so I don't have any control over them. That oversight comes from the federal agencies that fund them, and our statutes do require that every P&A set their own priorities within their state. They must go through a process hearing, listening to people with disabilities, hopefully throughout the state, regardless of where they're located, regardless of their income levels, hopefully reaching out to underserved and hard to serve people to really get a sense of what are the issues in that state? I like to also identify issues on a national level, and send out things for them to think about and to consider.

A good example, a recent one was we decided that Amtrak had not fulfilled their 20-year obligation under the ADA to make their services accessible. We filed a complaint with Department of Justice. Department of Justice basically sued Amtrak and just the last couple of months, settled the case. We've created a victim's compensation fund where people who could not access Amtrak stations because of an accessibility can now get some kind of reimbursement. That was an issue where I asked my people to go out and survey those stations, which was the basis of our claim. Hopefully, it's a partnership where they have their local priorities that they must establish according to the statute, but then I can hopefully direct them on issues. When I discover that a lot of P&As are working on the same issue, that's what I try to aggregate that information and try to make a policy argument here in Washington, but then across the country, that this is a real serious issue facing people with disabilities.

**Rebecca Williams:** It sounds like there is some collaboration there, and I actually was just reading my, I don't know, weekly, or however often it comes out, my newsletter from NDRN. I didn't realize you guys were so involved with this Amtrak settlement. That's great to know. You guys at NDRN provide training to the state P&A's, but then the state P&As also provide training. How's that training geared? What sort of training initiatives do state P&As have, or does the NDRN have?

**Curt Decker:** Well, again, it is hopefully a very robust training effort. We, at NDRN, enjoy a fair amount of federal resources to provide training and technical assistance to the agencies, and we then do a variety of things from meetings, now mostly virtual, but also

webinars, direct one-on-one technical assistance answering questions, and provide a variety of training. Everything from how to help our litigators become more astute, but also board of directors training. Most of the P&As, as you know, are private nonprofits. We also do a lot of financial training to make sure that the P&As are spending this very precious federal money accurately. Then at the local level, P&As, again, work collaboratively to provide training themselves, possibly provide some legal rights training when other disability organizations are doing a conference or a statewide conference. Again, it's a combination of a lot of hopefully good training coming from the national level, that they then also participate at the local level and make sure that that information is getting out to a full range of the committee.

**Rebecca Williams:** Thank you for that explanation, Curt. ADA Live listening audience, if you have questions about this topic or any other ADA Live episode, you can submit your questions online at [www.ADALive](http://www.ADALive), L-I-V-E, .org, or you can call the Southeast ADA center at 1-404-541-9001. Now, a word from our sponsor.

**Commerical:** The National Disability Rights Network, NDRN is a non-profit membership organization for the federally mandated protection and advocacy systems and the client assistance programs for individuals with disabilities. As the National Membership Association, NDRN has aggressively sought federal support for advocacy on behalf of people with disabilities and expanded P&A programs from a narrow initial focus on the institutional care provided to people with intellectual disabilities and facilities to include advocacy services for all people with disabilities, no matter the type or nature of the disability. To learn more about the important work of NDRN, visit their website at [www.NDRN.org](http://www.NDRN.org).

**Rebecca Williams:** Welcome back, ADA Live listening audience. Curt, I've got a lot of great information from you so far, but I feel like there's still a lot of questions I have. The first one for the second part of our show is do protection and advocacy systems tend to focus only on one area of the ADA, such as focusing on title two complaints, which would be state and local government entities? Or would a PNA look at individual rights, such as

one person has a complaint against a grocery store, or because they would not allow them to enter with their service animal?

**Curt Decker:** Well, as I said earlier, we were created initially around looking at an institutional abuse, but very quickly that expanded to all of the issues facing people with disabilities, wherever they live, reside, work, go to school. As a result of the additional resources that we received from different funding programs, there really isn't any issue affecting people with disabilities that we aren't involved in, again, within our certain priorities. Yes, we do a lot of government oversight and try to make sure that the ADA is fully compliant. We have learned that the ADA is not self-enforcing. There has to be constant vigilance to make sure that it really is benefiting people with disabilities 30 years after its original passage, but we are involved in many individual cases.

We provide a lot of non-legal advocacy as well, monitoring and investigation in a range of facilities, nursing homes, group homes. We enjoy a very strong access authority. Congress gave that to us back in our initial forming and then it has only grown over the years, which allows the P&A to go into any facility, school or workplace to make sure that the person is receiving the services that they're entitled to and are not suffering from abuse and neglect. An incredibly powerful tool. That makes us very unique, I think overall to most other federal-funded agencies.

**Rebecca Williams:** Now I have to say I have no legal background or training, but my understanding is that class action lawsuits are lawsuits that are filed on behalf of a class or a group of people who all say a particular civil right was violated. Do the protection and advocacy councils participate in or file class action lawsuits? If so, can you give us a couple ideas of some of those examples?

**Curt Decker:** Absolutely. Again, the P&A system, to this day, still enjoys the right to provide full range of legal services on any issue, including class actions. That is a very powerful tool. We represent thousands of people with disabilities every year, but after a while, when you realize the same case is coming up over and over again, an agency's program services are not changing. It's very critical to be able to aggregate those situations and bring a class action which allows us to challenge policies and the services

of the state, or of a private agency to really make significant change, so we're not constantly repeating the same case over and over again.

We are very fortunate that authority has not been taken away and removed from other federal legal agencies, and the P&A system to this day still enjoys that very powerful tool. We have broad class actions in just about every kind of setting, certainly against school systems, in jails and prisons, against states that refuse to downsize large institutions, and just about any kind of entity that consistently violates the rights of people with disabilities. When we can show that pattern, we can then develop hopefully a very powerful class case that would change that dynamic for the better of our clients.

**Rebecca Williams:** I know when I've been doing some of my technical assistance through the Southeast ADA center, I've seen some of these class action lawsuits that some of our states have done. Florida comes to mind, as you mentioned with Department of Corrections and so I'm a little bit familiar with those.

**Curt Decker:** Well, because we do so much work with now with people with mental illness, and unfortunately in this country, we tend to put a lot of people with mental illness in our criminal justice system. The P&As have to be very active in those setting to try to provide, not only mental health services in those settings, but hopefully convince corrections departments that these people do not belong in that kind of a setting.

**Rebecca Williams:** You're right, Curt, that is extremely important work. I'm glad that the P&As are working on that. Curt, I have another question that's sort of legally based. I understand that many P&A councils may participate as a friend in the court brief, also known as a... I might not pronounce this right, *amicus curiae*. Can you explain how that works?

**Curt Decker:** Well, unfortunately we don't have the resources to bring all of the legal work that I think is necessary in the community and so we do rely on other partners, other legal entities who will get involved in disability cases. Sometimes it's private lawyers, sometimes an entity like the [Baslan 00:17:23] Center or the Center for Public Representation, or sometimes our friends at the ACLU. If that case is moving through the

courts, it's very important that we come in with this friends of the court brief that really emphasize the disability aspect of the case, if it's not directly a disability case.

If it is a case on disability, often there is limits on what you can say in a brief, and so an amicus brief allows other groups, including and NDRN to come in and expand the information so that the judges, when they're reading the briefs and making their decisions, get a fuller picture of the impact that this case is going to have on people with disabilities. Judges can be difficult and unfortunately, I think some judges share the stigma that exists in our country on people with disabilities. Anything that we can do to educate a judge who is coming to a disability issue for the first time is really critical.

**Rebecca Williams:** Thank you very much for that explanation. That certainly increases my knowledge. Curt, as you are probably aware, there's 10 ADA National Network centers and we work to provide information about the ADA. We often refer to protection and advocacy system, so one of my questions to you is do you see a way that the ADA National Network could help support the work of the protection and advocacy systems?

**Curt Decker:** Oh, absolutely. I was very happy back after the passage of ADA and I was lucky enough to be one of the lobbyists on that program. Didn't know I'd still be around 30 years later, but it was very good to see the funding of the ADA centers around the country to provide that information. As I said earlier, no law and especially the ADA, is not self-enforcing. There has to be a combination of information out to, not only the disability community, but to the business community as well about what the ADA requires. Make sure that they understand it's a balanced act, it is something that was compromised and is a reasonable law. Then you need the P&A system to actually be the group that comes in and really pushes a business to change if they're being resistant to the requirements of the ADA. There really needs to be that synergism, I think, between the information and support that you provide and the legal advocacy that we can come from behind when people realize that things just aren't changing the way they should.

I would hope that, first of all, thanks to this type of podcast that all the centers are aware of who the P&A is in their state. Sometimes we make that difficult. We have a branding problem. I've tried to get our folks to be disability rights X state. There's about 35 that do

that, but then there's a few that have some interesting names, which might make it a little harder to find them. Number one, figure out who all the P&As are, and then be very ready to refer folks who are calling you for information and are indicating that they're having a problem to the P&A.

Being aware that we do have priorities that we set and also resource issues, and so I would let people know that we exist, that we're available, but just be clear that it may not necessarily mean that their case will be taken. We have to always make a judgment as to whether there's really merit. You could be a very strong referral source for the P&As. Also, I think, again, be available to let people know just the limits of our work, work with a P&A to find maybe additional resources in the community that could pick up when we can't necessarily serve that individual.

**Rebecca Williams:** Great. Great. That's good to know. Of course, as with you guys too I think, the ADA National Network does a lot of referrals out. This agency might be able to help you, that agency might be able to help you. I guess my question is what might be an appropriate referral to a P&A and what might be something that we shouldn't refer to? Should we just refer to when it seems to be a systemic, a title two possible discrimination, or should we go ahead even if it's say individual discrimination? Typically, I'm thinking of when there's not a center for independent living that may be able to help somebody and we may think, "Oh, well, maybe the state P&A can assist." Are there types of referrals you might want to stay away from?

**Curt Decker:** I think I would err on the side of referring any of your cases if you think the person really needs help. I know we have focused a lot on our legal resources. As I said, we are very fortunate to still to have the full range of legal remedies available to us, but we also encourage our P&As to have a variety of other lower level interventions. We pride ourselves on being able to get involved with the person with the disability, wherever they are in the system. Maybe it's not going to end up as a legal case, but we might be able to negotiate. We may be able to give them information about what their rights are so that we can help them become their own self advocate. This happens a lot with parents in the education system. We do, as I said, a lot of monitoring and investigation. It's a really a

continuum of services and we encourage the P&As to make sure that they can do all of those things, not just a group of lawyers, but a group of advocates and lawyers.

I will say this, it's very nice to have the power of litigation hovering over one of our advocates who can often say, as you said, to a school or a business, "You really need to resolve this situation because if you don't, we have lawyers that we can call and bring into the situation. You might want to settle this situation right now, easily and quickly, rather than get involved in a much more formal and possibly expensive operation." Having that continuum with the legal resources at the end of that continuum, really allows us to be able to make many, many positive changes well before it gets into some kind of adversarial situation. I would just encourage you to refer any of your cases to the P&A. On our end, our information and referral staff decide whether it's something that really can't become a full blown case in our network.

**Rebecca Williams:** Well, that's good to know that the P&As could look at as a small individual case depending on the situation, or at least then perhaps they could refer to an attorney or somebody that maybe ought to assist that individual. It's really good to know that, so I appreciate that. You mentioned that the state P&As are private non-profits, and I think there's maybe board of directors involved. If someone is interested in getting involved or supporting the work of their state P&A, is there a way they can get involved? Is there something they can do?

**Curt Decker:** Absolutely. As I said earlier, first of all, there's the priority setting process where P&As do a very public, either every three years with maybe intervening years, where they will publish or put out newsletters and requests for comments. People in the community ought to be looking for that opportunity to come in and actually talk about what issues they're seeing and what they would like the P&A to prioritize as an important case.

As you said, we do have not only boards of directors, which are volunteers, and we also have a PAIMI, Protection Advocacy for Individuals with Mental Illness advisory council. These need to be populated. We want a broad group of people within the state, both geographic, and racial and disability diversity. There's often a good opportunity to actually become a volunteer in the P&A network as a board member or an advisory board

member. It's very important that we get the broadest amount of support from the community to be the governance of the P&A, and make sure that we really are responding to the needs of people with disabilities. We don't always want it to be the well-known disability advocate or director of a program. We really want to get involved, the full state geographic background on our boards and our advisory councils to make sure we're hearing what's really going on, even in the furthest reaches of the state.

**Rebecca Williams:** I have one last question. You mentioned earlier in our talk today that there are now eight programs in the P&As. Originally started as a developmental disability issue, but maybe just for our listening audience who may not be aware of the eight programs, would you mind just telling us what those are?

**Curt Decker:** I would be happy to. What I find interesting is that the structure of the P&A system is the Legally-based Advocacy Program with Access Authority, which was created in the late 70s. It's really not changed over these last 40 years. What has happened is we've been able to take that model and begin to expand it to a variety of other populations and issues. Quickly in the 80s, we were able to add a client assistance program, which represents clients of vocational rehabilitation regardless of their disability. That was the beginning of us broadening beyond people with intellectual disabilities. Then in the mid-80s, we got the mental health program, which brought us to representing that very vulnerable population. In the 90s, we got a program that expanded to the entire disability community, sensory and physical disabilities. Then over the next 20 years, we took the opportunity when Congress was looking at a particular issue, so we added a traumatic brain injury program, a voting access program to make sure that people with disabilities can vote privately and independently.

We saw the need for assistive technology, so every P&A in the country receives funding to look at the assistive technology issues for people with disabilities so they can enjoy the benefits of this incredible burgeoning of all kinds of devices. Then most recently, we added a program, which I think is absolutely critical. It's from the Social Security Administration. It has the P&As going out and looking at the 8 million beneficiaries of social security who have a representative payee, someone who's been appointed to

manage their money and to basically take care of them. We're now about year three of this program. Unfortunately, we are finding many, many cases where representative payees are not performing their duties appropriately, not spending the money properly, sometimes stealing it and worse yet, really not putting people in good situations.

It's really brought us out into parts of the community that we have never seen before. It's critical to make sure that this very vulnerable population has someone coming up, for the first time in decades, to look to see how they're being treated. It's been trying to convince Congress that there is a role for a P&A type model in just about every single issue out there. We're looking at veterans, we're looking at people in juvenile justice facilities. We want to do more with special education. We want to be advocates with Medicaid managed care. We have been lucky to add these programs to our already existing system, but there's a lot more to do.

**Rebecca Williams:** Thanks, Curt, for that explanation of the eight programs of the P&As. I had no idea you guys did such in-depth work. I want to thank you for sharing your time and insights with us, and explaining the wonderful work that the protection and advocacy systems do and National Disability Rights Network.

**Curt Decker:** Thank you for the opportunity to participate.

**Barry Whaley:** That's great. Thank you, Curt, and thank you, Rebecca. Thank you ADA Live listening audience for joining us for this episode. As a reminder, you can submit your questions and comments for this episode online at ADALive.org. Get access to all ADA Live episodes on our website at ADALive.org. All episodes are archived with streamed audio, accessible transcripts and resources. ADA Live can also be found on the SoundCloud channel at SoundCloud.com/ADALive. You can download ADA Live to your mobile device podcast app by searching for ADA Live. If you have questions about the ADA, you can submit them anytime online at ADALive.org, or contact your regional ADA center at 1-800-949-4232. Remember, those calls are always free and they're confidential. ADA Live is a program of the Southeast ADA Center. Our producer is Celestia Ohrazda, with Beth Miller-Harrison, Mary Morder, Emily Rueber, Marsha

Schwanke, and me, I'm Barry Whaley. Our music is from 4 Wheel City, the movement for improvement. See you next episode and be safe everybody..

**4 Wheel City:** (rapping)

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