NDRN
History of the P&A Network

Welcome everyone to a discussion about the history of the Disability Legal Advocacy Network. I'm Curt Decker, the executive director of NDRN. And we are here to talk about a twofold history, the creation of the protection and advocacy system in this country and also the development of the National Disability Rights Network, the voluntary membership association of the P&A Network.

The NDRN, which was created in 1982, is the voluntary membership association, with a vision of a society where people with disabilities have equal quality of opportunity and are able to participate fully in community life by exercising choice and self-determination. And from that vision comes our mission to promote the integrity and capacity of the protection advocacy in client assistance program national network and to advocate for the enactment and vigorous enforcement of laws protecting the civil human rights of people with disabilities.

NDRN itself, based in Washington, has grown along with the development of the P&A system, and I want to take a few seconds to talk about that. We were originally created back in the early '80's as a traditional Washington-based trade association to be able to represent the P&A program here in Washington, with the administration and with the congress, to ensure that the program was continued to be funded and its authorities and powers were intact.

But over the course of these last 30 years, we've also added other functions to enhance the network. One of the first was to become the training and technical assistance provider for the network. It was seen by the membership itself that having the training and technical assistance that is available through federal funding to be centralized and coordinated through its national association, not only to make it more efficient and more relevant but to allow the membership itself to have input in the direction of that training and technical assistance.

Over time the NDRN has also gotten involved in the quality assurance. This is a shared responsibility. The responsibility of making sure programs are following federal oversight, federal financial rules is the role of federal government. But as an association, we learned a long time ago that we are only as strong as our weakest link. So over time, with the support of the membership, NDRN has engaged in a variety of quality assurance mechanisms, such as the development of standards, and also intervention policies that allow us to work with our program that may, in fact, be having some difficulties admitting the responsibilities and obligations of a P&A.

We've also been able to use our buying power as a national network to provide some membership services at a reduced price, and hopefully in a more relevant way, to our members. So, for example, we have created the advocacy data collection system, which allows the P&A programs to lease from NDRN a fairly efficient and inexpensive data collection process to help them respond to their responsibilities of reporting to the federal government. We've also been able to achieve some savings in malpractice insurance and access to services like Westlaw and the LRP publications.

And, as a result of being so intricately involved with our members on a daily basis through the training and technical assistance, and the other activities, we have learned about the needs of people with disabilities throughout the country and are able to take that information to national forums, such as the administration and congress, and, as a result, NDRN has I think developed into a respected national disability rights leadership organization because we are able to speak with such authority about the real issues affecting people with disabilities.

And then, most recently, we have been able to convince certain federal agencies to utilize this network for the needs of enforcement and monitoring and other things that they have responsibility. And through that exercise we have developed a contract relationship with federal agencies, such as Social Security Administration, which allows us then to go out to our members and provide them with some additional funding for certain specialized projects. We're also involved from time to time in various demonstration programs where we are able to show federal agencies the value of working with this very robust comprehensive nationwide organization.

So I want to turn now to the development of the P&A Network itself. And you'll see here a slide of the various pieces of our program. And we use the analogy of a puzzle where we are trying to put together the various programs with their various authorities and responsibilities and jurisdictions in order to provide a comprehensive legally-based advocacy service to the full range of people with disabilities. Now the P&A system was created back in the mid-70's as a result of exposés about the conditions – horrible conditions in the Willowbrook institution on Staten Island where, 7,000 people with disabilities, intellectual disabilities, were being housed and brutally treated in absolutely unacceptable conditions. And so the concept of a protection and advocacy system came to being in that time. And it is interesting, that in our history that initial structure has maintained itself, even though we've added, as you'll see shortly, a variety of programs to make sure that we can become a truly cross-disability program and obtain the resources necessary to do this kind of work.

And so some of those basic principles is that the P&A system is client-directed and legally-based. And so we operate as a legal model, where our clients should have the ability to come to our P&A and receive the kind of advice and representation based on what they believe is best for themselves. That advocacy has to be independent, and therefore there are strong messages in the legislation that require that the advocacy be independent, and it's also a consumer-managed program. And so consumers, people with disabilities, are involved in all of the levels of governance of the organization to make sure that the P&A system is responding to the needs of its clients.

It also has enjoyed some very unique authorities as a result of congressional authorization, and yet the authority itself is relatively simple. It's a sentence that says that the P&A system has the authority to pursue legal, administrative, and other appropriate remedies. That simple sentence really opens up to a very broad role for these programs, and, as a result, the P&A can work on the range of issues affecting people with disabilities. We can use a range of remedies. We have the ability to respond to where the client is in the process and where they have a need for some kind of intervention by a legally-based advocacy program. And we also have access to those people, and we have access to their records and to the facilities in which they live, which allows us, then, to get access to those folks when even maybe providers, professionals, facility directors would prefer that we not have the ability to talk to those clients. So these are very important authorities that only the P&A system enjoys.

There are a couple of limitations on our work, but they're very minor and don't, in fact, I think have much in the way of impact on our work. But they are similar to some of the historical attempts in the past to limit the federal funded legal services programs. So in our CAP program we can operate class action litigation, but there really isn't very much in the way of class action litigation available there, so that has very little impact. Many years ago they attempted to stop us from doing physician suicide cases when that was a very hot national issue; that also doesn't have much impact on our work. We did accept a no-litigation prohibition in our Help America Vote Act, HAVA program for voting access, but we also know that any client that is having an issue with voting that would rise to the level of litigation could actually be represented by one of our other programs.

One limit to our access, which does, I think, hurt our ability to fully represent the needs of people with disabilities throughout the country, is not having the same open access to federal facilities. And we believe that there are many people with disabilities in veterans facilities, INS facilities, federal jails and prisons, possibly DOD facilities, such as Walter Reed Hospital, that could benefit from our representation if we had the same kind of access to those facilities as we enjoy with state facilities. We can represent people in those facilities if they reach out to us, but we don't have the same type of access that other folks with disabilities in other facilities enjoy.

We do have to set up priorities for our client representation. Those resources that are provided to us by congress have never been adequate, have never allowed us to really meet the needs of the population in its entirety. And so we have to go through, often, a very painful priority setting process, but we do that by making sure that there's consumer involvement and try to maintain some flexibility so that if an emerging issue comes up and it was something that was not anticipated, that P&A has the ability to respond quickly, even if it is in the priority. What we often say is that priority setting, while it sounds nice, is often just a way of saying no to our clients. So one of the roles of NDRN has been, consistently over the years, to try to increase the resources of the P&A system in order to make sure that the priority setting can be as broad as possible to represent the largest number of people in the largest number of areas.

And so what it really lends itself to, and, I think, one of the great strengths of the P&A system, which is this continuum of remedies. And, as you see in this slide, it allows us to engage in a range of activities that allow us to pinpoint where the client is in the process and tailor our response in the most efficient way to what we need to do to try to help them. And so this list is, I think, an important statement about all of the ways the P&A system gets involved with its clientele. And none of these are more or less important than any other. They really need all to be available in the particular agency within the state to make sure that we are using our resources as efficiently as possible.

And so through the information and referral and training and self-advocacy, we can accomplish great things for clients at a very low cost. But we also are the only agency in the state that has the ability to engage in more formal representation, such as legal counsel advice, negotiation and mediation, administrative proceedings, and individual litigation. The monitoring that we do in a variety of facilities and the systemic litigation and advocacy, and then it allows us to be involved at the public policy level, which often is the best way to achieve systems change for those very intransient problems affecting clients.

I now want to turn to sort of the chronology of how our system developed over these last 30 years. And, as I said, the first program was the protection and advocacy for people with developmental disabilities, which set up this structure that came into being in 1975, and it was actually fully operational throughout the country in every state and territory by 1978. But it wasn’t, in fact, limited to that relatively small population of people with intellectual disabilities, and meant that so many other folks with disabilities who could benefit from our services weren’t eligible for those services. But as a result of having this program in place, I think our system learned that, in fact, it was no reason not to make this program and this concept available to the full range of people with disabilities.

And so we began a journey where we looked at opportunities in congress, and whether they were reauthorizations of laws or new programs being presented or possible scandals that identified serious abuses of people with disabilities, to increase the role and the function and the funding of the P&A. And our first success was in 1984 when we were able to convince congress that the vocational rehabilitation program needed to have a comprehensive advocacy monitoring program to represent people who were clients of the vocational rehabilitation system. And so we were able to get the client assistance program authorized as a formula grant program, similar to the DD program, and establish at every state and territory, and that began the broadening of P&A function from beyond just people with intellectual disabilities, but it also included all clients in both rehab, which was the full range of people with disabilities. This is an important program not only because vocational rehabilitation is critical to people with disabilities, but it began to move the P&A system into a broader range of disability advocacy and make ourselves available to many other people with disabilities besides just the intellectual disability community.

In 1986, we were able to build on an investigation that Senator Lowell Weicker, a republican from Connecticut, had conducted with his staff on the conditions in hospitals for people with mental illness. So similar to the exposés in the '70’s, that led to the development of the Developmental Disability P&A Program, Senator Weicker was the architect of the PAIMI program, Protection & Advocacy for Mentally Ill Individuals. And that added funding and authority to the existing P&A system throughout the country to begin to represent people with mental illness. Now, initially, this program was limited to people in institutional settings based on the abuses that were documented in those institutions, but we were able to take advantage, in 2001, to expand the program to people with mental illness in the community. We were able to show congress that while our work needed to continue in those facilities, there was still a demand for services for those people with mental illness who lived in the community and who were coming out of institutions and needed to receive quality service in the community. So this enabled us by 2000 to represent the full range of people with mental illness, regardless of where they resided.

That program also had some interesting aspects of it, because it really brought into a relief some of the disagreements in the disability community and some of the concerns about, you know, who would receive our services. And so in order to get this bill passed, we had to convince a new group of people that the role of the P&A could be very helpful in protecting their rights. We also had to assure our old clients, people in the intellectual disability community, that we weren't going to neglect them or forget about them. And so there were various structures that were established in that statute in 1986 to sort of reassure both communities that this program would meet the full breadth of needs of these two communities. So, for example, a PAIMI advisory council was created, which brought people with mental illness into the P&A system to give them advice and to work with them on developing this program and to make sure we were addressing the real needs of people with mental illness. And so that was an attempt to make sure that we maintained our consumer management role, as I laid out earlier in the discussion.

Then in the late '80's, again, we took advantage of a reauthorization of the Rehabilitation Act. And having demonstrated in several P&As the ability of the P&A to represent those people who were not eligible for the DD or MI program, or were not clients of a rehab, but were people with disabilities that did not fit in that category, we were able, again, to convince congress to develop the PAIR program. And the PAIR program definition of eligibility is quite simple, it's everybody else in the disability community who is not eligible for the other three programs.

And so by 1993 we were able to get sufficient funding to make sure that every protection and advocacy program in the country had money to represent this population as well. This population would include people with physical disabilities, people with HIV, people with sensory disabilities, such as blindness or deafness, the full range of disabilities. And so in 1993, with the advent of this funding, the P&A system became truly a cross-disability program, where every person with a disability would have the access to our services. Now, of course, that didn't address the resource problem, which meant that even though everyone was technically eligible for our program, it didn't mean that we had the resources to actually assist them, even though they may have needed our help.

And so we then began, in the next two decades, to not only strengthen and build on these four main programs that gave us this cross-disability position but also to try to find innovative ways of adding additional resources to the program. You'll see now several programs that have been added, many of them small, with some very specific targeted audiences or targeted issues. And our concept here was that we wanted to make certain types of issues and certain types of disabilities an absolute priority for the P&A system.

Remember, I said that we had to do this priority setting process, which meant that we had to eliminate some folks from our services, and we were able to convince congress in these next iteration of bills that certain issues were so critical to the disability population that there ought to be dedicated funding for that issue, for that population. That meant that every P&A had that as a priority in their agency. So the very first on was the Protection & Advocacy for Assistive Technology, recognizing the great advances in technology and how important it was to people with disabilities to have access to technology. We now have a program that every P&A has to look at assistive technology issues in their state on behalf of their population.

We also worked with congress when they were developing the Ticket to Work and Work Incentives Act, a program that was designed to try to convince and help beneficiaries of social security to come off the rolls and take a chance at finding real work and not rely on benefits. As we know, so many people with disabilities need the support of social security because of the lack of employment and the lack of health insurance. So even if they are able to work and would like to work, they often just don't want to take the chance that the workplace would be available to them and provide them with assistance. And so this program was created by congress in 1999. And we convinced congress that there had to be a protection and advocacy component to this very large nationwide program to assure that people received their benefits, did not get discriminated against in the workforce, and that this would actually enhance the ability of this very ambitious program to work. And so we created the Protection & Advocacy for Beneficiaries of Social Security in 2000.

We also recognized the very critical situation regarding traumatic brain injury and the rapidly growing number of people who were experiencing traumatic brain injury, whether it was from inside the country because of automobile and motorcycle accidents, but also as a result of the wars, which brought back many veterans with the signature injury of traumatic brain injury. And so, again, with the assistance of the Brain Injury Association of America, we were able to convince congress that there had to be dedicated funds for people with traumatic brain injury in the P&A system to make sure that when they came and asked for our help, they would not have to be eliminated by lack of, because of our priorities, but could be assured to get the kind of assistance they needed. And, again, we used a similar process of some competitive awards. Initially when the funding was low, and then, as the funding reached a certain trigger, it allowed every P&A to get some money to be able to focus on this very important and underserved population.

We also were able to take advantage of the work in congress to reform our voting system. If you'll remember in the year 2000 there was quite a scandal about the difficulty in many states of processing an election campaign that fairly represented everyone. We in the disability community had known for many, many years that people with disabilities were disenfranchised and that were not able to vote independently and privately, and had made several attempts in previous legislation to try to address that issue. However, it was not until the passage of the Help America Vote Act that we were able to establish some very strong mandates for making sure that the polling places were accessible at every level, from physical accessibility to voting machines and poll worker training. And we also convinced congress that there had to be a protection and advocacy program that would be in place to make sure that those mandates and those requirements in fact occurred and that people with disabilities could become an integral of this most important civil right, the right to vote.

Then we had the ability to add some interesting new concepts. Again, as I said, we were taking advantage of scandals where there has been documentation of abuse or exploitation of people with disabilities. As I said, we created the program in the mid-70's with DD. It allowed there to be PAIMI program in the mid-80's. And then in the late 2000's, 2009, there was the exposé of what was happening to people with intellectual disabilities on a turkey farm where not only were they being forced to work in sub-minimum wage activities, but were given poor housing and were having their social security checks taken from them and exploited through the representative payees that had been put in place.

We have worked now with social security administration for four years to develop a very innovative program where the social security administration contracts with NDRN. We, in turn, then work with each individual P&A throughout the country, provide them with the names of entities that act as representative payees, the names of beneficiaries who are in their care, and then pay on a per-site visit for the P&A to go out and work to review the entity and make sure that the funding that they receive from social security is being properly spent and properly accounted for. One of the spinoff benefits of this program is that by using the protection and advocacy system, not only do we look at the financial issues, but we were able to observe what's going on in that facility and make sure that other issues of quality are being addressed. And so there is a great value added to this program by virtue of utilizing this system because of its great expertise and understanding of the issues with disabilities. So, at this point, I would say we are, you know, trying to put together our puzzle to make sure that it meets the full needs of people with disabilities.

A couple of other interesting milestones along the way that make our program unique and that I think need to be recognized, in 1994 we had been approached by people on the reservations in the Southwest, and showed us how, despite the good work of P&As in those areas, they were still underserved, given the size of the population and the great distances. And so we went back into congress and created over these last 20 or 30 years a Native American P&A, a 57th P&A, if you will, that addresses the needs of this underserved population in the American Southwest. This is unique and I don't think there's any other national federal program that has recognized this particular need. We changed our name in 2005 to the National Disability Rights Network, and we've been working with P&As to brand the network. And many P&As have joined in that branding effort and have changed their name to reflect their relationship as a large national disability rights network.

In 2005 I think we, as well as many people in the disability community, were quite shocked and upset about the failure to address the needs of people with disabilities in disasters. As a result of Katrina, the hurricane in Louisiana, it was a wakeup call to the disability community and to the P&A system about the great unmet need of this population in disasters. As a result, we were able to find some money – to receive some money through the Katrina Aid Today project. And similar to our SSA representative payee program, we were able to distribute that money to the states that were most affected, and developed a case management system to be able to work with people with disabilities who had survived and needed assistance in recovering from this disaster.

As a result of our experience, NDRN and the P&As have stayed very involved in the ongoing planning and implementation of disaster relief protocol and programs to assure that people with disabilities are being treated and considered when there is a disaster, regardless of the type of disaster or where it's located. We talked about the SSA Representative Payee Project. And then we also were able to get congress to authorize program – a P&A for the long-term services. Unfortunately, that was repealed as part of some of the political machinations that occur here in Washington, but it is our hope that we can revisit this issue and make sure that we are involved in the very pressing issue of long-term care for people with disabilities.

This slide, I think, sort of represents where we are and where we'd like to go. We clearly don't have the resources necessary to really meet the needs of the disability community and all of its issues. And, as you can see from this slide, while we managed to be able to get nine programs in place, there's still a great need for assistance to veterans in particular, or people with autism. We do a great deal with special education work, but that has never been funded by the Department of Education, and so we want to see if we can receive funding to continue and expand our work with special education. P&As are very involved in the juvenile justice facilities, again, not without any dedicated funding. And so we feel it would be important to receive funding that would assure every P&A being involved in these facilities where young adults with disabilities are often neglected, abused, exploited, and not receiving their full access to education rights. We want to make sure that we stay involved in the emergency preparedness roles. So we have much more to do to fill out this whole puzzle of disability advocacy.

This is an old chart that sort of lays out where P&As provide many of their services, and it should be of no surprise that mental illness tops the chart, with about 35%, because we have dedicated money in the mental health program. And there are other aspects of mental health issues in our other programs, whether it's PABBS, Assistive Technology, traumatic brain injury. And, as you can see, we are truly a cross-disability program, reaching out to just about every type of disability that exists in this country. The appropriations will be available, the history of our appropriations is available in materials that accompany this presentation.

Now one of the issues that has complicated the administration of this program has been the fact that we have gone after these various programs, and they have been delegated to certain federal agencies for administration, and that makes for some interesting opportunities and some interesting administrative barriers. Every program has a requirement for reporting. Every program should be monitored and administered by the federal agency that has been given the program. One of our roles at the NDRN is to try to make that administration as burdenless as possible so that the P&As can devote the majority of their resources to services and not to meeting administrative burdens. So we work very hard with these agencies to make sure that the funding comes out efficiently and quickly. That's been difficult in this last decade or so, given congress's inability to finish the appropriations process in a timely manner, and therefore we live in a world of continued resolutions and government shutdowns, even sequestration, which means that this essential funding can get delayed and held up and can often put a small protection advocacy program in some jeopardy by not receiving the money.

Also, each program, initially, wants to collect data the way they traditionally collect data, and have not been able yet to develop sort of a consistent data collection tool that would address each of these programs, provide the agency with the necessary data, but make it more efficient for the P&As to be able to collect that data and provide it to those agencies. This is a work in progress, and we think we are making some headway in convincing the various federal agencies that it would be a good use of P&A funds to have a consistent reporting tool and that would allow us to compare the work across programs and would also lessen the administrative burden on the P&As when they yearly submit these forms. We have had some success in convincing the agencies to collaborate, coordinate the technical assistance.

NDRN is the major provider of that technical assistance. I think that works very well and allows us to really provide comprehensive, relevant training to the full range of staff that are in the P&A, the full range of disciplines, and are able to track the benefit and the success of that training and technical assistance.

That ends the slide presentation. And we have a variety of materials attached that you can look at. This is a fairly brief overview of how our programs have come together. And I think that we have created a very unique and comprehensive and robust network that is essential to the quality of life for people with disabilities. And this program now, having been around since the mid-70's, I think has proven its efficacy, proven its ability to accomplish important work, and using its vision and its mission to assure that people with disabilities are fully integrated into the mainstream of American society. Thank you for your attention.