



## **ADA Live! Episode 127: What Are Developmental Disabilities Councils?**

**Broadcast Date:** March 6, 2024

**Guest:** Johnny Callebs, Executive Director, Kentucky Commonwealth Council on Developmental Disabilities

**Moderator & Host:** Barry Whaley, Project Director at the Southeast ADA Center

**Recording:** [adalive.org/episodes/episode-127](https://adalive.org/episodes/episode-127)

---

Aarti Sahgal: Hi, I'm Aarti Sahgal and you're listening to ADA life.

**Johnny Callebs:**

Hi, I'm Johnny and you're listening to ADA live.

Music

**Barry Whaley:**

Hi everybody on behalf of the SE ADA Center, the Burton Blatt Institute at Syracuse University, and the ADA National Network, I want to welcome you to ADA live. I'm Barry Whaley. I'm the director here at the SE ADA Center. listening audience. If you have questions about the Americans with Disabilities Act, you can use our online forum anytime at [adalive.org](https://adalive.org). Or you can call the SE ADA Center at 404-541-9001. And as always, those calls are free and they're confidential. March is Developmental Disabilities Awareness month a month where we raise awareness about the barriers that people with developmental disabilities face in their daily lives. And it's also a time to promote

acceptance of people with developmental disabilities to live their best lives. In thinking about the barriers that people with developmental disabilities face and their families, we know it can be hard to find accurate information about quality services and programs to get what you need to live independently in our community. One important resource to find that information are the State Developmental Disability planning councils. In the disability community, the name is often shortened to DD councils. I'm pleased today to have as our guest Johnny Callebs. He is the executive director of the Kentucky Commonwealth council on developmental disability. So Johnny, thank you for joining us and being on the show.

**Johnny Callebs:**

Thank you for having me. I appreciate it.

**Barry Whaley:**

Johnny I want to start with what are the developmental disability planning councils? What do they do?

**Johnny Callebs:**

DD Councils are self governing councils, they are charged with identifying the most pressing needs of people with developmental disabilities in their particular state or territory. They then conduct advocacy systems change and capacity building efforts. And every state and the District of Columbia and the five US territories have a DD Council. Interesting. Yes, and they are again, self governing. So they're intended to reflect the makeup of the disability communities in that state or territory and be directed by those council members.

**Barry Whaley:**

So the council is a group of how many people

**Johnny Callebs:**

It varies from state to state. In Kentucky, there are 26 members 16 of those are supposed to be individuals with developmental disabilities or their family members and are appointed by the governor. The remaining 10 seats, are representatives from state agencies, that chairs department for vocational rehabilitation, Medicaid services, public health and the like.

**Barry Whaley:**

But how are these councils funded? Are they a government agency? You said they're self governing but where's the money come from?

**Johnny Callebs:**

Councils are funded by an award from Congress to Health and Human Services and the federal government and within the Health and Human Services. Our is the Administration for Community Living ACL then funds, individual state councils. So we get that Congressional Award. And then also some councils get additional funding from their state governments and potentially other sources.

**Barry Whaley:**

So Johnny, you mentioned this council and that some people are appointed by the governor. Others are your partners. How does somebody become a member of the Council?

**Johnny Callebs:**

You first have to have a developmental disability or be a family member and then complete an application, governor's website from the boards and commissions that gets vetted by the governor's office and you may or may not be appointed by the governor, but it's solely at his or her discretion. And then you serve a three year term and can also serve a subsequent three year term. And then the state agency representatives are appointed to the council just by their governing commissioners. They can send whoever they would like Whoever has an interest or knowledge.

**Barry Whaley:**

So the council's they fund various initiatives across the state, is that correct?

**Johnny Callebs:**

That's correct.

**Barry Whaley:**

So how do you decide what you want to fund? What how do you decide the priorities for funding?

**Johnny Callebs:**

The council receives money from Congress based on the federal formula, and then the monies are used to initiate programs and projects that fulfill the mission of the DD Act. These projects are, first you have to apply for them. How do you know how to apply? Well, the council will issue a notice of funds available, basically describes the goal that we're seeking to accomplish, and gives the parameters on which you can apply for your particular project. Projects should be innovative, replicable and sustainable. They're typically funded anywhere from two to five years. So it's not intended to be a long term funding mechanism. The council has worked teams, and each work team addresses a particular goal in the council's five year plan. applications that come in once funds are available, get reviewed, discussed and scored by work teams. Those projects that are selected get notified those that are not, and there are many good applicants. But everyone can't be funded, we send out the notifications and then get contracts in place and let the projects begin their work.

**Barry Whaley:**

You mentioned that you've just done a couple of nofas. Recently, what what were those areas of interest.

**Johnny Callebs:**

One was for housing. One was for employment. And another one was for community access.

**Barry Whaley:**

You mentioned housing employment. So we would find that in your five year plan,

**Johnny Callebs:**

yeah, there are current projects addressing those. And then, as I mentioned earlier, the projects are not meant to be long term. But if we have to let them run long enough to have a chance to succeed and develop alternative funding sources, so they're sustainable, and hopefully can be replicated in other parts of the state if it's not already a statewide effort.

**Barry Whaley:**

You mentioned areas like housing and employment. We're looking at the aspirational goals of the ADA. Those areas fall in line with the you know, the full inclusion of people with developmental disabilities in their community. Can you maybe talk about some ways that DD Councils promote full inclusion for people?

**Johnny Callebs:**

One way is to fund projects with targeted goals in those areas. They're important activity that we did was advocacy. Areas of advocacy we're involved in is advocating for employment for folks with disabilities. We have a seat on Kentucky's Employment First Council. Kentucky is important first state meaning that competitive integrated employment is the first choice for folks of working age of developmental disability. We also advocate for home and community based services so that folks can live in the communities of their choice and not in institutional care. We provide training for self advocates in that people with lived experience, people who have developmental disabilities receive training on how to effectively advocate for services, access, inclusion, all the things that matter. We also provide education to lawmakers in the legislative branch, government officials and the executive branch. Higher education is also an area many folks might not think about people's developmental disabilities attending higher education at university, but we have

a fantastic program at the University of Kentucky. I don't know what the acronym stands for. I just know that it's SHEP. And I can't think of the

**Barry Whaley:**

I can help you with that supported higher education project.

**Johnny Callebs:**

Thank you very much, Barry, appreciate it. So we support not directly but just through collaboration, and we're all sort of stumbled there. But we've sucked that's a fantastic project. For the University of Kentucky to give folks with developmental disabilities an opportunity to be on campus in classes with their peers, hopefully leaving with a degree. We also work to ensure that folks with developmental disabilities are represented on boards, task forces, work teams, Commission's councils, any place that helps shape public policy, and could possibly affect folks with disabilities, which is pretty much about anything in life, whether you're talking about employment, transportation, health care, education, whatever it may be.

**Barry Whaley:**

So you've mentioned a few minutes ago, and I did want to touch on this Johnny, that you provide training for self advocates, and often hear a term Partners in Policymaking? I didn't know is that what you're referring to when you're talking about training? And can you tell us a little bit about that program?

**Johnny Callebs:**

It is sure. It's called K Pip, KPIP, and that's Kentucky Partners in Policymaking. It's kind of in house project. For us. It is a eight or nine month training program for folks with developmental disabilities, or their close family members. And so folks gather and get training on the legislative process, how to contact their legislators how to tell their own personal story of their lived experience, what services are available, we bring in outside speakers from around the country, sometimes in person, sometimes virtually, they're self advocates return to deliver their experience, work experience advocacy experience, after

having gone through the program. So a rich, diverse learning model in which the participants get to take a look at advocacy from a lot of different perspectives and what it means to advocate. There's a graduation ceremony in May, afterwards, there's kind of a post graduation assignment, they are asked to take on a project, some type of advocacy project shortly after, to kind of use some of the skills that they've learned over the past few months. So I think it's fantastic program. It's one of the best things that we do, and the ideas that we're over time creating a larger and larger network of self advocates and their family members.

**Barry Whaley:**

I believe this is a program that is replicated in each of the states. I'm sure somebody listening today in California could go to their DD Council and find a similar program to participate in.

**Johnny Callebs:**

I think so whether it's called Partners in Policymaking or something else, I believe every state DD Council has a self advocacy training program or project.

**Barry Whaley:**

So you know, here at the SE ADA Center, one of the things we do is we provide technical guidance on disability rights law, specifically the ADEA. And we often refer people who call us if their area of concern or their question has to do with Developmental Disability Services. We refer them to state DD Councils for help with disability rights advocacy, policy issues. What are some of the projects and programs you believe have been most successful? And why do you think that?

**Johnny Callebs:**

I just explained KeepCup. Another one is a transportation initiative that the council funds that is operated by the Human Development Institute at the University of Kentucky. This project is really all things transportation gathers information about transportation options around the state. One of the important wins recently is that through advocacy with

department for Medicaid Services, the project was able to convince Medicaid to change one of their long standing rules on a licensed vehicle being at the place of residence for a Medicaid recipient. So that used to disqualify you from non emergency medical transportation, which a lot of people depend on. So they're going to relax or eliminate that rule. And that's just going to make assessing transportation services through Medicaid much smoother, and will that renew it for some people who had been excluded because of it, that was a big win. Another one also at the Human Development Institute is supported decision making Council funds that project whose goal it is to make available alternatives to guardianship. If you are a person with disability, frequently you find yourself under guardianship, whether it's private guardian, or state guardianship. And it's a big deal because if you're under full guardianship, you essentially have many or most of your civil rights taken away your rights to make basic life decisions for yourself, in many instances, and so forth. And decision making is just a model, a concept, which assists the person in getting people around them that they know and trust, to help them make important decisions by providing all the information pros and cons and supporting them through the decision making process. We also do a lot of public policy work in house public policy coordination, tracking, bills, laws, regulations that impact or may impact people with disabilities. One of the efforts that we've honed in on here recently is the long wait list that Kentucky has Medicaid waiver services. We've talked during over the interim, since the last legislative session. We've I don't know how many legislators that we've met with and explain the importance of Medicaid waiver services, community based services, and how the alternative, which is institutional care is just not the right thing to do not the way we should be spending our money. It's much more expensive and has far worse outcomes for people. And it's just not the right thing to do. So far, the Kentucky house's budget bill has significant funding increases for waiver services. And we hope that some of our advocacy work has made a difference in that and we're not taking all the credit, many others have advocated for it as well. And we're happy to see that in there. And we hope it stays in there. So we'll be continuing to advocate for that.

**Barry Whaley:**

That's great news.



**Johnny Callebs:**

It is great news. thrilled about it.

**Barry Whaley:**

Johnny, thank you for this great information and ADA live listening audience. If you have questions about this topic or any other ADA live topic, you can submit your questions online at [Ada live.org](http://Ada.live.org). Or you can call the SE ADA Center at 404-541-9001. And now we'll pause for a word from this episode sponsor the Commonwealth Council on Developmental Disabilities.

**Voice Over**

The National Association of councils on Developmental Disabilities, otherwise known as N A C D D. Works with state councils on developmental disabilities to create inclusive and welcoming communities. They work with people with intellectual and developmental disabilities, their families and allies to advocate for policy change. And a CDD ensures that people with intellectual and developmental disabilities can live the life they want in the community. To learn more, visit their website at [nacdd.org](http://nacdd.org)

**Barry Whaley:**

Hi everybody, welcome back. I'm Barry Whaley and I'm talking with Johnny Callebs the Executive Director of the Commonwealth Council on Developmental Disabilities in Kentucky. We've been talking about how the Commonwealth councils projects and programs, advocacy help people with disabilities live better and participate more fully in their communities. The Kentucky Commonwealth Council is part of the larger or national organization called the National Association of councils on developmental disability or NACDD. Can you tell us more about NACDD and why it was created the

**Johnny Callebs:**

National Association of councils on Developmental Disabilities NACDD is a national membership organization specifically designed to support DD Councils all across the

country and the US territories and some of the activities that in a CDD engages in our leadership, education and attention on national issues and policy affecting folks with developmental disabilities. They advocate to Congress and federal government agency's on public policy agenda that supports folks with IDD. We are not allowed to lobby, but they can. So they talk with members of Congress about continued funding for state DD councils, maintaining and hopefully increasing funding so that DD councils can do more projects in their states. Lastly, they also provide technical assistance to DD Councils to make sure that we are conducting all of our activities, you know, in line with the DD Act, and in line with federal award that we get from Congress. There's a lot to keep up with. So we really rely on that technical assistance effort. And so we really appreciate that effort to keep us all councils educated, and in compliance with what we're supposed to be doing.

**Barry Whaley:**

Johnny, we've been talking about that you're one of many councils on Developmental Disabilities. Do these state and federal organizations all have the same goals? I'm curious what are some of the shared disability policy and this initiatives of NACDD and the Kentucky Commonwealth Council,

**Johnny Callebs:**

they actually line up pretty well, as far as the goals and initiatives. One area is civil rights and voting rights. So work is done at the national level, to protect against forms of discrimination based on disability, also, to protect, enhance and ensure adequate funding for federal protection and advocacy programs for people with disabilities and to fully implement laws that protect the voting rights and access to people with disabilities. Just a Kentucky fact 72% of people with intellectual and developmental disabilities in Kentucky are under some form of guardianship, removing the freedom of choice in many aspects of their lives. Talk about civil rights and voting rights, guardianship, just a lot of attention given to that because of what it means for folks with disabilities to have your rights taken away. So whatever we can do nationally and at the state level to protect against that and provide alternatives, also to ensure access to the polls for folks with disabilities. Another

area where our goals line up is access to home and community based services. I mentioned earlier in the podcast, Kentucky has over 12,000 people waiting for waiver services just in the two IDD waivers. So at the current rate of adding funding for waiver services, it would take almost 83 years to eliminate the waiting list. Wow. So that's why we have advocated so vigorously before the session started to educate lawmakers policymakers about the waitlist, for what it means the feeling of desperation the families have, and it's not just in Kentucky, it's nationally, many states have 10s of 1000s. The larger states, you know, door, Kentucky's waiting list. Again, very happy with the current budget bill. And it's a great start. So we just have to keep at it. Right hand in hand with that is direct support professional crisis, ESP direct support professional. Those are the folks the boots on the ground, the hands on people who provide day to day care and support for people with disabilities many times in home services or sometimes in a provider home. But there's not enough of them. They're not paid well enough to stay. So providers and families who self direct and hire their own staff are finding it more and more difficult to recruit, hire and retain DSPs. It's a national crisis. It's certainly Kentucky crisis. We have providers closing up sharp because they can't hire enough people to deliver the services. That's a big deal, because we're, you know, we're going to get increased funding for waiver services, but it's no good if you don't have anybody to provide the services. So again, much work to be done there and that is a nationally recognized problem. Employment is another one that in a CDD works on and along with A DD Council, and we support the work of the Employment First Council. One very dismal fact about Kentucky. Only 33.7% of Kentuckians with disabilities are employed, compared to 76% people without disabilities, that employment gap ranks 48th in the nation. So we need to close that gap health care, the average life expectancy for individuals with intellectual and developmental disabilities and Kentucky is up to 22 years less than the US population as a whole. You know, we need to do a better job of educating healthcare professionals so that we have a competent healthcare workforce. And that folks with disabilities have access to health care, access to insurance, equal access to get the care that they need. And then finally, one thing I'll mention again, is just transportation is a problem all over and that goes in tandem with employment. It's hard to get and keep a job if you can't get to the job. So another bad one is that 70% of people with disabilities are

forced to reduce their daily travel due to a lack of transportation from preventing them from necessary medical appointments, employment opportunities, and the social aspect of it can't just get over to see a friend or maybe go somewhere for recreation. Those things aren't readily available because of lack of transportation, in many cases, also national issue, and particularly acute in some rural areas. So those are some of the ways in areas that Kentucky City Council does work and lines up with in a CDD priorities and issues.

**Barry Whaley:**

It sounds like in talking about these initiatives, that they seem to align very nicely with the overall goal of the ADEA. You know, for equal access, equal opportunity, financial independence, Community Inclusion, for all people with disabilities, there's a real alignment, I think, between the work of the DD Councils in fulfilling the the aspirational goals of the ADA.

**Johnny Callebs:**

I agree. We've mentioned employment several times and the fact that Kentucky's an employment first state, we have an Employment First Council that's doing a lot of good work. The council funds a project through Mattingly edge in Louisville, called Edge employment, one of the things that they do is try to promote employment with disabilities by educating individuals, families, school system, lawyers on disability benefits that you can go to work and not lose your benefits. It's a common belief that I have a disability and obviously this benefit, therefore I can't work or I'll lose it. And it's important to me, many, if not most of the times, that's just not the case. It's not as dismal and hopeless as folks make it out to be sometimes just demystifying disability benefits so that folks can keep those and continue to work. So that's a goal of edge employment. Another one the transportation initiative, providing information and education on transportation options. The housing project seeks to bring together builders housing coalition's housing authorities, potential homeowners to create a pathway and provide housing that would be desirable to people without disabilities. Of course, affordability is a barrier. In many instances, they're doing good work to help try to find some solutions. Just another

housing fact only 1% of Kentuckians with intellectual or developmental disabilities on their own home. Like to see that number go up, obviously, also, our public policy coordination and keeping an eye on housing assistance. There are a couple of bills in the General Assembly right now affecting housing. Two of them would prohibit cities from passing ordinances or laws regarding discrimination on income source. Another area that we've done a lot of advocacy work in is custody rights. There's currently a bill and the house which seeks to protect the parental rights of parents with disability currently in Kentucky parental rights can be taken away based on intellectual disability This bill would prevent that from happening prevent termination of parental rights based solely on disability and would also require reasonable accommodations are afforded the parents, both on services support services that are offered as well as full access to the courts to make sure that any legal proceedings are fully accessible for the parents. Those are some of the projects we've been working on.

**Barry Whaley:**

That's a lot. So the it's been a lot of information, right information Johnny and about the work of the Commonwealth Council in Kentucky. We've we've talked about the National Network, and the important work they do so I'm going to give you the final word do you have any final thoughts that you want to share with us?

**Johnny Callebs:**

I would just encourage everyone who's listening to the podcast today to find your voice tell your story. If you're a DD council member, use your seat on the council to advance the cause that you care about in your state. Meet with your legislators know how laws are made in your state. If you have an opportunity to serve on a task force, a work team, a council, a commission, whatever it is, jump in, get a seat at the table cast your vote, vote on Election Day. Also, if you want to visit our website at [CC dd.ky.gov](http://CCdd.ky.gov). You can sign up for our newsletter. We put out a monthly newsletter with upcoming events, news policy issues, and then you can also follow us on Facebook and LinkedIn.

**Barry Whaley:**

Well, Johnny, thank you again for being with us today sharing a lot of good information about the good work that you in the Commonwealth Council do. Listeners I want to thank you for joining us for this episode highlighting the work of the Commonwealth Council on Developmental Disabilities in Kentucky to improve the lives of people with developmental disabilities and their families. Thank you for joining us for this episode. And as a reminder, you can access all ADA Live episodes with archived audio accessible transcripts and resources at our website. [Ada live.org](http://Ada.live.org). You can listen to ADA live on the SoundCloud channel search [soundcloud.com forward slash ADA live](https://soundcloud.com/ada-live). You can download ADA live to your mobile device, go to your podcast app and search for ADA live. If you have questions about the Americans with Disabilities Act, you can use our online forum anytime at [Ada live.org](http://Ada.live.org). Or you can contact your Regional ADEA Center at 1-800-949-4232. Those calls are free and confidential. Ada live is program of the SE ADA Center the Burton Blatt Institute at Syracuse University, and a collaboration with a disability inclusive employment policy, rehabilitation research and training center. Our producers Celestia Ohrazda was Cheri Hoffman, Mary Morder, Marsha Schwanke, Chase Coleman and me I'm Barry Whaley. Our music is from four wheel city, the movement for improvement. We also invite you to tune in to our companion podcast Disability Rights today for in depth discussions on important court cases that shaped disability rights in the Americans with Disabilities Act. You can learn more and listen at [Disability Rights today.org](http://DisabilityRightsToday.org) We'll see you next episode.

### **Music4 Wheel City**

They watching. They don't want us be part of the city, man. They put all these steps, man. All these curbs we can't get over. All these inaccessible stores. 4 Wheel City. They don't want us here. We'll survive and we're going to make our own place. Our own world. The 4 Wheel City-

[End of Transcript]

**Disclaimer:** The contents of this publication are developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant #90DP0090-01-00). NIDILRR is a Center within the Administration for

Community Living (ACL), Department of Health and Human Services (HHS). The contents of this publication do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

The information, materials, and/or technical assistance provided by the Southeast ADA Center are intended solely as informal guidance and are neither a determination of your legal rights or responsibilities under the Act, nor binding on any agency with enforcement responsibility under the ADA. The Southeast ADA Center does not warrant the accuracy of any information contained herein.

Any links to non-Southeast ADA Center information are provided as a courtesy, and are neither intended to, nor do they constitute, an endorsement of the linked materials. The Southeast ADA Center provides these links as a courtesy and does not endorse, take responsibility, or exercise control of the organization nor vouch for the accuracy or accessibility of the contents of the link destination. The information is intended solely as informal guidance and is neither a determination of legal rights or responsibilities under the ADA, nor binding on any agency with enforcement responsibility under the ADA.

Contact for More Information or Assistance:

Southeast ADA Center

Email: [ADAsoutheast@syr.edu](mailto:ADAsoutheast@syr.edu)

Phone: 404-541-9001