

**CEDC Quarterly Webinar**

*February 16, 2024, 3:00 – 4:00 pm ET*

**SPEAKER:**  
Hi Beth!

**BETH BOONE:**  
Hi!

**SPEAKER:**  
How are you?

**BETH BOONE:**  
I'm doing very well for Friday meeting, how are you?

**SPEAKER:**  
I am OK, I will keep myself off camera, I am actually fighting COVID unfortunately.

**BETH BOONE:**  
Bless your heart. If this had been any earlier, I had oral surgery the week before last and I was just...

**SPEAKER:**  
Oh no!

**BETH BOONE:**  
My lips wrists-- were swollen. I was off camera a couple of weeks, so I send you some healing powers.

**SPEAKER:**  
Thanks, I am just trying to keep my kids were getting it. I have not really left my basement in the last three days.

**ANNA COSTALAS:**  
She is like a hobbit...

**SPEAKER:**  
I am. I do not know if it is a good thing that my desk and the washer and dryer in the basement with me. That is a curse, I am still keeping up with the laundry. And my Peloton is also staring at me. I will see you in two weeks.

**BETH BOONE:**  
Absolutely, Reno. Looks like people are coming in... Hello hello everybody! Looks like a good crowd today...

**BETH BOONE:**  
Good afternoon everybody, we will wait just a few more minutes for people to come in. And get connected. And then we will get started.

BETH BOONE:

As you are coming in, please put your name, your role, your center and state in the chat for us.

BETH BOONE:

OK, we will wait one more minute to let people come in, and also respect your time, those of you that are already here, please go ahead and type your name and your details (Laughs) In the chat, for our benefit, and we will get started.

BETH BOONE:

OK, unless there are objections, I will get us started. Hi John! Good to see you. Anna has hit the button, so our meeting is now being recorded. Thanks for coming, welcome to the CEDC February meeting. I would like to welcome you all, I am Beth Boone. I am at the Florida Center for inclusive communities and I am the chair for the next few years. I would also like to welcome John Tschida, he is here, he is our big boss at AUCD. And also Anna Costalas is our staff liaison from AUCD.

We also have present our vice chair, Kristine Nellenbach, and our new Secretary Maranda Hooper. I will let Kristine do some more staff stuff and a little bit. But go ahead and put your details into the chat, if you do not mind. So that we have that record. And we can go ahead and get started.

The first thing I want to do is take the approval of the meeting minutes from November. I sent those out in advance. I hope that everybody has had an opportunity to take a look at them. I am going to ask at this point that the minutes have been distributed, are there any corrections to the minutes? Feel free to speak those out.

Any corrections to the minutes? OK, there being no corrections to the minutes, the minutes stand approved as distributed. Thank you. Alright what's next...

So I am going to talk a little bit about our listserv, our Council membership roster, historically we have been working off of two documents, and bless Susanna's sweetheart for trying to keep us all on an updated list, and expect people to go in there and update things. As things change. It just became super unwieldy and so Anna and I have been working together to make sure that everybody on the Google doc is now a part of the listserv for CEDC. And so we will be doing all of our communications through the list, so if you want to respond individually to someone who is sending out a message onto the list, just remember instead of replying all, you have to grab their email from their message and respond to them individually.

But I think that will keep us from having to do multiple mailings for every piece of information, and make sure that our information gets out there in a timely manner, and it will make it easy for you guys as well, if you want to correspond with a whole list, then you just reply to the CEDC listserv. Any questions about that?

We are trying to be efficient, all of us have lots of things grabbing on our time. I did want to talk about... Excuse me. (Reads) Does this mean that the listserv is replacing the Facebook group? No, well... I did not know there was a Facebook group (Laughs) So I am going to say no.

ANNA COSTALAS:

Facebook was a way, if you had events from your centers that you wanted to promote, that

were open to the community, open to everyone, you could post them on Facebook. But yes the listserv is how we can communicate with each other, share resources, and if you need to... If you would like to... I'm sorry for hijacking you.

BETH BOONE:

No, it's good.

ANNA COSTALAS:

If you would like to further share resources outside of CEDC, rather than putting them in the Google drive, a better way of sharing resources is actually filling out a public promotion request form which I will put in the chat box, and that is how it will get distributed to say... Weekly goes to all directors and councils. Or you have a cool project that you got an award, there are different ways we can do it rather than putting them all in the Google drive.

BETH BOONE:

Right.

ANNA COSTALAS:

We are trying to shift away from Google drive, and if we want to promote events, there are a couple other different ways to do that.

BETH BOONE:

Right. And that goes along with... I do not even know how many of you have drill down into the Google doc, but we normally send out by link with our meeting agenda, but it had the front page of everybody, what is your name and email and your role. And then there are other tabs, that were like... What are your social media and webpages for your center? And the third one was what other councils are you on? And they had... There were people on there that retired five or six years ago.

So those other lists were not being updated. And so we sort of made a command decision to pull back from those other pieces on the Google Doc. We have also found out there are a number of universities and workplaces that will not allow Google documents to open within their firewalls. And so... And then again, the Facebook page will be useful for people to chitchat and whatnot, and put things up. But understand that not everybody has those pieces either.

So we will move our main communications into the (Name) group that makes it easy for everyone to get it, and we will make sure that everyone that connects with us gets added to that group. Good questions, other questions and thoughts? OK. I would like to take a few minutes to give some updates.

John is here, so if there are exciting things that need to be updated on our update (Laughs) Then he can certainly pop in. We met recently as a board, in January, some of the things that we talked about included the policy committee talked about the appropriations for fiscal year 2024 and 25. There is a continuing resolution signed into effect until early March, while they continue to look at appropriation bills and pieces. Certainly one of the ones we are keeping our eyes on are the-- is the Austism CARES Act.

But currently the budget that is submitted within the CR (?) would keep these programs at level funding, which is not the best of news, because we do a lot with a little, and we would always

like to have a little more. At this point, continuing our funding, even at a level stage is better than the alternative. So we will keep an eye on those things. And if you are not signed up for the legislative newsletter, that comes every week, and has really great information, then definitely grab that from the AUCD homepage.

Some of the other things we talked about in our most recent meeting, our February board retreat is in Reno Nevada at the end of this month. We are also planning the summer board retreat, which is I think probably going to be in Wisconsin, in Madison. We had also talked about another site or two, but that is what we are looking at. I cannot read my own handwriting... DTA Institute and directors meeting for the LAND and (Name) directors, which is normally in DC in April, but conflicts some with the disability policy seminar, has been moved this year to August. In Minneapolis? Is that right? OK. So that is exciting, what your emails, all of those things are coming up.

The AUCD conference will be held November 3-6 in DC, originally it was scheduled for early December, that would put it on thanks giving holiday, so it has been moved back. To November 3-6. A little problematic, because our election day is within that time period, so make sure to get your ballots in, or make your travel plans. And we will keep you posted if that changes, there has been some discussion about that.

The board is reviewing committee assignments. And we are working on Council discussions, making sure that each council has a training liaison, and Kristine can talk about hours in just a few minutes. Updates regarding the processes, the roles, and the relationships of counsel, one to another.-- One to another. That is a big emphasis in Derrick's role as chair of the board. We will also look at revising AUCD strategic map and equity framework. In looking at our international partnerships.

We have reaffirmed the need for disability representation as a seat on the board. The representational seat on the board can actually fill... As far as I understand, it can fill in the end--any representation lacking on the board. We look at demographics, where people are from, the presence of different demographics, including disability. Or race, ethnicity, gender. Or in some way that there is something missing from a critical piece of the board, there is a representational piece that can be assigned, or voted in in a way that others get voted in. Just to make sure that our seat is truly representational of AUCD.

That is enough of a report from the board. John, do you have any big things that I missed there?

JOHN TSCHIDA:

I think you did a good job, I just want to stress the importance of engagement in the councils, that our current president Derrick Williams has. He has a big focus is welcome you heard this at the conference for those of you in attendance, on emerging leaders. Those that are earlier in their careers, and what paths of leadership are re-created, what leadership opportunities are we creating for all people in our network, but especially those who are new to the network. And we want to make sure that they are viewing this is potentially a lifelong relationship, even if they choose to have employment outside of an AUCD center.

But seeing this is a place to engage in peer conversations, potential collaborations, and just places to continue to learn, no matter where they are. So part of that is understanding what is happening now, within all of the councils. What you see is valuable? What needs to be

changed?

So I would invite all of you to reach out to me, reach out to Beth, what do you like about these meetings? If this is your first meeting, what were you expecting? What did you experience? And how can we better meet your expectations given the roles that each of you has within your centers, so we wanted to be relevant. We wanted to be valuable, we want this to be a place where questions and challenges you are experiencing in your work can be shared and addressed. With your peers across the country. So help us make this time worth the blocking time on your calendars to dissipate.

**BETH BOONE:**

Yes, and thank you for your patience with me as the new chair and the new vice chair. We have a new slate of folks here. I want to thank Susan who is both on the Council of leadership and advocacy and the CEDC and does cross reporting. I am going to give a little update from Susan who is here with us from the most recent February 12 meeting. They also have a new counsel trainee representative, Lindsay Crane, at the Southern California (Name). There was a recap of the November annual meeting because a lot of councilmembers were not at the AUCD conference.

They also talked about the leadership conference about marriage penalties with people with intellectual and developmental disabilities. There is going to be a tip sheet on marriage penalty and marriage penalty legislation, and once that project is complete they will be sharing that information with the CEDC. We will make sure that you guys have that.

And then they have been doing a survey to ask what the priorities would be for (Name) right now. Some of the priorities are marriage equality, healthcare access, employment and subminimum rate. We will keep going and giving you information as we get that from our sister project. They will have their next meeting in May. OK, that is about enough for me, right? Any questions or thoughts about these pieces so far? Seeing no hands, I will pass the torch to Kristine Nellenbach who is our vice chair.

**KRISTINE NELLENBACH:**

Thank you, Beth. Before I start I saw the question pop in and I wanted to make sure we address that. Audrey asks: what virtual attendance at the November CEDC meeting be available this year? Do we know that?

**BETH BOONE:**

I do not know that. It was not available this past year.

**ANNA COSTALAS:**

No, sorry. Go ahead, John.

**JOHN TSCHIDA:**

This is going to be a topic of conversation with our conference committee. I think a part of what we saw in the surveys was people are looking for additional opportunities to engage, and certainly the Council is one place to do that. There has also been talk about moving the councils from Sunday to later in the week for those who come to the conference, a lot of people show up. They show up late on Sunday, are not able to make those Council meetings. Recognizing that virtual participation and AV at hotels is very expensive, we are going to do what we can. No

guarantees, but know that this is an agenda item for our conference committee that we have already started to talk with Elka from Cincinnati, the director there, about conference theme and that conference committee will be meeting in early March, I believe. So, stay tuned. We know there is a demand.

KRISTINE NELLENBACH:  
Alright, thank you so much.

I am Kristine Nellenbach. I am the new vice chair of CEDC. And I am with the Maryland center and will talk a little bit more later on about my center in particular. As for my updates, Amanda Clinton, I have been trying to monitor, I do not think she has made it on yet. She was trying to make it on. She might happen later. I will go ahead and introduce her. Amanda is the CEDC emerging leader representative. And she is coming to us from South Carolina. She did send me a little blurb so I could share it in case she was not able to make it in time.

She is with the South Carolina LEND program. She worked during the day at the Charleston's reach program. The College of Charleston. That program is a four-year college certificate program that educates students with mild intellectual and developmental disabilities. As part of her work with CEDC, she is to come up with some sort of project that she would like to create that we could use and disseminate widely across the nation. So we had a discussion, we are in the early stages of her starting her project. What she is really passionate about since she works in post secondary education, is she wants to create some sort of PowerPoint presentation or a short video that can be shared statewide and then nationally that early interventionists, schools and families can just be aware of what the options are for their children as they age.

So we think that those early years, it may be too soon to think, what is going to come after high school? From her experience and what she has seen in her work, that is an area she is really passionate about. Helping families start thinking about those things early on. What do they see for their children post high school? What are the options that are available to them in their states and then across the nation? So that is as far as we have gotten for her project, she will be working on that throughout the next several months. And then when she completes it at our next quarterly meeting, she will be able to give a little presentation and sort of share it with us and show us what you came up with. So that is what Amanda will be working on.

And then I also wanted to give a moment to congratulate and welcome Maranda Huber, who is here with us today -- Maranda Huber. Who stepped up and accepted the secretary position. Miranda, if you want to say hi and introduce where you are from, that would be great.

MIRANDA HOOPER:

Hi, my name is Maranda Hooper. I am up coordinator out of the Oklahoma's, at the center for learning and leadership. I am excited to be here. I was ready to offer up my secretarial skills, and then I saw the email that somebody had already come in for it. When a spot opened up, we were talking about it in the professional development meeting. I had already looked at my time availability. It was a very easy opportunity for me to volunteer. I am happy to be here.

KRISTINE NELLENBACH:

Thank you so much, we are really happy to have Miranda. Thank you. Next on our agenda " if there are no questions about that " if Amy is here from the professional development committee, we just had a couple of updates to share --

**SPEAKER:**

My name is Amy, I am from the UST center for disabilities, I am part of our committee and if you all do not know that we have a professional development committee, we do and we are always looking for more people would like to join us. We are a small but mighty little group, and we are always looking for different opportunities to really do some fun, innovative ways of connecting all of us together as well as providing some really nice professional development opportunities.

Many of you took advantage of completing the survey that we sent out in November, that was just asking about ways that you want to receive information, maybe topics that you want to learn more about. As well as maybe knowledge and topics that you possess that you might be willing to share with the rest of the group. We have met as a committee trying to find different ways that we can maybe work around and think about how we want to do some of these different things.

We have a new opportunity that we are going to launch starting in March, and we are calling it Coffee Chat. Coffee Chat is an opportunity to come together and gather and really spend some time talking about different topics. Maybe you are coming to that coffee chat because you are doing some really unique things with the identified topic for that month and you want to share about it. Maybe you are coming to the coffee chat because you heard about that topic and you are thinking about how you might want to implement it in your respective setting. It is just kind of an informal way to get together, to join together, have great conversation, and just have a robust kind of environment that we can do maybe some fun things.

You will be getting some correspondence about this. Just kind of be on the lookout. We are looking at doing the third Thursday of each month at 3 o'clock Eastern. We wanted to make that catchy so maybe you will remember it. Just for an hour. Again, we will have an identify topic each month that we will be covering. Our first topic will be storytelling. If you are interested in that, maybe you are doing some cool things with that in your work, please join us. Again, be on a lookout for a zoom link, and having a standing slot in your schedule for the third Thursday of every month, with the exclusion of the month we do our orderly meeting. We will not be doing them those months. But other than that we will have in the third Thursday of every month at 3 PM.

**BETH BOONE:**

This is very exciting. This is very exciting news and I love that you are starting with storytelling. I have a college student, my kid is a college student and he is a journalist although he would call himself a storyteller. Rather than a journal writer. Having people talk about their lives and experiences for them is more moving than sometimes having a bunch of us "professionals" talking statistics and things, which are always important. It is moving, perhaps.

New business. And then I will open the floor to anyone who has things to discuss or ask. You can either get on your mic or you can put things in the chat which I can see now. I just want to make sure everybody has a chance to share things out. Also, as you come up on things in between our quarterly meetings that are important, you can either share them out to the listserv, or you can contact me and you can be added to the agenda for the next meeting. I am going to put my email in the chat.

It is not at AUCD, that is not where I work. Taking one other minute of quiet. OK, well, understand that you do not have to wait until the quarterly meeting to interact with one another.

More with me. -- Or with me. We have ways of staying in touch, so please do so.

What we are trying to do, one of the reasons the PD committee decided to go to coffee chat was because when they did their survey, they said people were still interested in webinars and people sharing out information. But we had decided we would have at least one or two people try to speak on certain topics that they are doing at our quarterly meeting. We decided to use a little more casual, interactive forum for the PD meeting would give us an opportunity to share information in various different ways.

Today, our network spotlight speaker is Christine. -- Kristine. We had heard in the other meeting that the Vanderbilts were doing some cool things around video research briefs. I reached out to them this week. None of them were going to be able to come. But they will be sharing with us at a future meeting. And Kristine is going to talk to us about their program at the Maryland center, the research finders. -- Resource finders.

KRISTINE NELLENBACH:

Thank you so much, Beth, I don't know if you are the host, could you enable screen sharing for me?

BETH BOONE:

That would be Anna.

KRISTINE NELLENBACH:

Anna...

BETH BOONE:

You should be good now.

KRISTINE NELLENBACH:

Perfect, thank you. Alright. OK... So as I mentioned before, my name is Kristine, and my title is program coordinator. I am going to share about the program that I manage called resource finder. And I am with the Maryland Center for Development of Disabilities, this is our main avenue for information dissemination.

To quickly go back here for a second, our center is actually housed within Kennedy Krieger Institute, it is pretty well known in Maryland, it is a hospital in school, they do research, it is an established facility, so we are really lucky that we can be a part of it. Some of the things I will talk about later, that will come into play.

So the MCDD, which is our acronym, is the only UCEDD in Maryland, and the program resource finder was developed over 20 years ago, it was initially called resource network, and it was managed by one person, so the name was a little bit of a misnomer, which is why they changed it to resource finder. Network sort of implied it was this team of people, gathering resources, when it was just one person. So resource finder sort of reflects that this is a person who is finding resources for people.

And I have been in this position for about a year and 1/2 now, I took over from the person who basically started it, she was in the position for 17 years (Laughs) So since I have come in, I



have sort of revamped a little bit, and trying to spend some more awareness of the program. Also we are in the process of writing a peer-reviewed research article, just to sort of dive really deeply into how the program works, that we are hoping to be able to share widely with other UCEDDs in case anyone is interested in adopting a similar model.

So the overarching goal of resource finder, our official description, is to inform individuals, families, trainees and professionals about community services, service providers, trainings and other information on intellectual, developmental and other disabilities across the lifespan. Very long wordy sentence, but overall basically, again finding resources. For anyone on any topic.

Our program motto is "the more you know, the more you can do." So this program differs from AIDS case management model,-- a case management model, we are not walking through scheduling appointments, or talking about how to schedule services, we are handing over the information empowering people to know what is available. And people get in touch with me in a variety of ways.

I may throw to the word we and us occasionally, but resource finder is just me, it is party of one (Laughs) So people can call me, they can leave a voicemail, I work remotely three days a week, and I have an office in the outpatient building two days a week. But I do have a phone at home, so I'm really available from phone. We really try to... This is something I implemented because we know it is so important for people to get a hold of a real person. It can be really frustrating when you are trying to get answers, and no one answers phones, and you leave messages, and it takes a long time for people to call back. So I do try very hard for to be available by phone.

People can also email, we have a dedicated email for that, and there is a online web form where people can go through and fill in the blanks, located on our website. Did you have an office, so we have a physical resource Center in the Kennedy Krieger outpatient building, this is a room that I manage. It has brochures, pamphlets, booklets, basically anything that I can get people to send me. And I try to keep it stocked with resources, printed resources, on a variety of topics, so people can calm, our families can stop by and take what they need, but they can also leave questions for me. I have a dropbox in there. A QR code that goes to the web form. And if I am on site, they contact me and ask me questions in person.

So I get asked all kinds of things. I will tell you, I will never say no. So any inquiry, any request that comes in, I make my best attempt to answer it and provide resources. This is just a very small sampling (Laughs) Of some of the topics that tend to come in over and over again. These are the things that people are asking for. So a big one is financial assistance, I get that all the time. And for a variety of things, right? People looking for help may be paying rent, but maybe even financial assistance to pay for medical bills, or to purchase a wheelchair.

I get a lot of questions about therapy, so people are looking for providers who can provide some kind of therapy, whether it is a mental health therapist, speech therapy, feeding therapy, therapy overall, that is very popular. A lot of people are looking for that. On the screen you can see lots of other ones, the other one I will point out that I have noticed a big trend is people seeking an evaluation, so they can be diagnosed.

We get a lot across the age span, but particularly what has stood out is many adults calling to be evaluated for autism or ADHD, or dyslexia, or learning disabilities. In adulthood. So those resources have been a little bit trickier for me to find, but over this last year and 1/2, I have a

pretty chunky list, and later I will explain how I get my resources and how I store them.

So to give you an idea of some of the inquiries and requests that I receive, I just copied and pasted a couple of quotes. One person said, "I am trying to find funds to help with the portion of which are not covered by insurance. You know organizations that help with that type of thing?" And of course there are plenty that we have here in Maryland, and some nationally. So that was a pretty easy one to answer.

This next one said, "our son was diagnosed with ADHD last year. We are looking for options to help them with issues related to his ADHD, specifically executive functioning." Another thing I will mention is when I receive inquiries, whether it is an email or a phone call, a voicemail. Or an online form. Sometimes it is a conversation, I may have to call people back, I may have to email them back to get a little bit more information so I can find exactly what they are looking for.

For this one, I would want to know how old is the son, is this a child, teen, adult? And then I would ask them of course where they live, because I'm finding resources where people live. So for this I may have searched for a therapist who specifically helps people DH-- ADHD. Or an executive functioning coach. Or if it is a child, some group therapy where they are working on some of those skills. And sending that list to the family.

The next example says, "I am seeking resources from a six-year-old son. I would like to explore recreational activities and workshops for advocating is apparent." So for this one, they told me that her son is six, so that is helpful, because a lot of recreational activities, there is a wide range of who can participate in some of them. For this one, I would want to know, of course, where they live, as well as if the child has a disability. Or is diagnosed with something that they would like me to keep in consideration.

I try to be very sensitive with asking that question, we do not require people to disclose that information. But if they think it is going to affect the types of resources that they want, then that is something I would want to know. If this child uses a wheelchair, that is going to affect the type of activities I might find. I might have to search for adaptive basketball, versus a child who may be within the general population, and there could be basketball leagues that would make more sense for that child.

I have come across so many different programs, some that are just for children with autism, some for children with any disability. Physical disability, intellectual disability, so again, getting that information would help me tailor those resources better to me that families needs.

In this last one says, "my son is 16 years old, and we are starting to plan next steps in terms of applying for disability benefits, workforce development, etc. It is overwhelming trying to figure out which programs you may be eligible for or may be helpful. Are the disability navigators or agencies who help families of this process?" And again, I would want to know where they live for this one. In Maryland, I have come across a lot of different organizations. We have some state-funded ones, but then we have some private companies as well. That can help families through the process that they are describing.

This kind of gives an idea of the types of questions that I get. Some are simple, some are people saying, I have a five-year-old, and I need speech therapy in this neighborhood. Great, that is easy. Sometimes I get questions that are a little trickier, or may be very specific. I

recently had one where it was a family looking for a pediatrician who can speak Spanish who can accept Medicaid who know something about developmental disabilities and to was only located within a certain county in our state. Sometimes I can be very specific, and can take me a while to find that, but other times it can be pretty simple.

So anytime people are getting in touch with me, I just need a couple pieces of information. Like I said, I may have to call people back, I may have to respond to an email, if they did not provide everything I needed on the first contact. Most people are very happy to get an email, I would say 95% of people want an email, so they can click on links and have it that way. But some people they do not have access to the internet, or they are not familiar with email, so I have been asked if I can send resources in the physical mail.

In those cases, I would print out the resources that I find and then send it that way as well. Usually the age of the person who needs the resources is really helpful. Because again there is a big difference between a pediatric neurologist and an adult neurologist. So knowing the age can help me find the resources that would make sense for that family. ZIP Code is my favorite way of figuring out where they live, that can give me a very small space. And then I usually start searching in that area, and I will kind of move out, depending on how many resources are available.

So if it was something like speech therapy, there may be 10 speech therapists pretty close to them, within that county. But if they are looking for something very specific, I may have to look an hour away, two hours away, and in those cases, I would make a note when I respond saying these are the closest I could find, but just be aware they are a couple hours away.

Sometimes if I'm on the phone with people, and I know that what they are asking me for is going to be hard to find, I recently received an inquiry from someone who wants a primary care physician for their adult son who is diagnosed with Engelman syndrome. I already know, that I have searched for something like that before, it is going to be really hard to find. So I would ask them, how far are you willing to travel for this? Are you willing to go out of state? Are you willing to go a couple hours?

Because I might have a feeling already, that I will have to search pretty far for that. I might ask if they are open to virtual services, depending on what they are asking for. Because that could give me some more options. We have some very remote areas in Maryland where there are not a lot of resources nearby, so some people are OK with virtual. And of course the more specific people are with their request, the better it can be to an extent...

Sometimes only request is very specific and may not be able to find something, but if it is too vague, I may not give them what they were actually looking for, when I use the example earlier about the child who wanted recreational activities, if they did not tell me that they had a disability, and I gave him general population activities, they may be looking at that like that is not really what I had in mind.

So what kind of try to do a nice balance of getting enough information, but not overpromising that I cannot find certain things.

So here is another example of an inquiry I received, on the left, and then on the right is to show you how I might respond. The inquiry said "I'm looking for mental health therapist near the

Annapolis area for 1/4 grade boy with Autism Spectrum Disorders and ADHD." So they give me all the information I needed, I know the age, that it is a child, I know they are diagnosed with autism and ADHD, and I know where they want me to look. So Annapolis and Maryland is located within Anne Arundel County, so I searched that, and on the right you can see the list of resources that I could find. I try to provide a little note with my resources, so you can see for example, Thrive Works Counseling in Psychiatry, I put a website-- note that on the website it says they treat clients with ADHD and autism, which is what they're looking for.

I am clear when I talk to people on the phone that I am looking for these resources online, so if it isn't on the website, it does not mean that they do not do that. But I try not to include those in less they really cannot find anything. And then I may have to include a note saying you may have to call these places, to get more information, I am only getting it from whatever is on their website.

We try our best to meet many diverse needs. We use CyraCom which allows us to call and get a translator for any liquid. I have been able to get any language I have ever needed and then I can do a three-way call to the person who submitted the inquiry and they can translate. We are aware that Google translate is not perfect. Unfortunately, that is the extent of what we can offer at this time. We do, for Spanish, have two Spanish-speaking staff in our department. I am able to have them help with that. If it is language other than Spanish, I have to rely on Google translate.

We can find resources for people of all ages. Because we are attached to Kennedy Krieger Institute, within Maryland Kennedy Krieger is pretty well-known. Many people know it as a Children's Hospital. It is primarily pediatric. There are a few programs that will see adults but for the most part it is pediatric. Sometimes you will see the Kennedy Krieger logo on resource finder and they have this assumption that because their child is an adult, that they cannot use resource finder. That is something we like to clarify, that anyone for any age can ask for resources. Again, it is not just Maryland, it is anyone in the world. It does not matter where they live, I have helped people find resources in Mexico, and India. I do not get a lot of those questions, but they are able to contact us.

Although most people who are contacting resource finder are trying to find resources for an individual with a disability, this, again, is a resource for anyone. People who do not have a disability can also ask for resources. I have received phone calls for people who are living on the street and are looking for a shelter for the night and they are just calling and asking if I can find the nearest shelter for them and giving them the number so they can get help. Again, this services for anyone. Not just Kennedy Krieger patients, really for anyone. I tell people if you are human, you can use resource finder. I get questions like, "well, could a person whoâ€" Yes, anyone.

A few resources we include. The resources are not recommendations or suggestions or referrals. I am very careful with the language. Sometimes if people call or they send an email and the email says, "I am looking for recommendations onâ€" I make sure I reiterate, even though it is in our disclaimer statement, it is included in the email signature. I just make sure people know. We cannot vote for them, I cannot say here is the best one. People want the best for their children. I cannot say they are the best. I am just curating the list and doing the legwork of research for you.

Another disclaimer is that I do not have a medical background. I was an elementary school

teacher for 12 years before this. I am unable to give any kind of medical advice or guidance. This comes into play when sometimes you will contact me and they describe the challenges they are experiencing with their child. And I am very careful not to say, "well, maybe you need to try ABA their AP," or something like that. I do not want anything to come back to me if people are unsatisfied with that type of service.

In those cases I usually will provide articles that say, here are some providers who may be able to address toileting issues with children who are autistic. I will tell them, once you have decided what kind of provider you will like, then let me know and I will search for that type of service. I try not to suggest services, if that makes sense.

I know in this group, the topic of finding resources and organizing has come up a couple of times. The way that I find my resources primarily is Google. Part of my teaching career, half of that I was a school librarian. I taught a lot of lessons on how to be good at using Google. I use a lot of operators. I will share this slide deck with everyone afterwards and I have that resource linked if anyone is interested in exploring that. Basically, using quotation marks, the +, the subtraction sign where it makes sense to refine results you are getting from Google and really trying to unearth the resources that you actually need. An example, if you typed in "speech therapy AAC Baltimore" and then put quotation marks around that, you will get different results. Google is good if you are using Google Chrome with telling you when you are looking at a result in the little description, it will say missing AAC.

It will let you know the word is not included in there. I wanted to make sure for some people who were saying my child is using a communication device, they need a speech therapist who is familiar with using that device and work with them, I need to find a speech therapy that somewhere on their website it lists that they can do that. The quotation marks make sure that all the results that are showing are guaranteed to have that somewhere on the website. That helps me be more efficient, and get more specific.

I also subscribed to every organization, newsletter, that I possibly can. All of our states, every county, the autism Society, all of the organizations I could possibly subscribe to I do so that when they come in my inbox, I look at them and they might have events that are coming up, I have an event board I put up in the resource center, but it is also great for people who are looking for webinars. Maybe share resources that they find, or services they are offering. That is a really great way that I have just come across really helpful resources.

I also and the representative for my department when going to resource fairs. At resource fairs, at the end of the event, usually I go around to all the people and I tell them what I do. I try to learn about what they can do, so that way I can get more information about what is out there. And then of course, word-of-mouth. Sometimes people within Kennedy Krieger or my department, they hear about something cool, and they forward it along to me to say just so you know this is the thing.

The organizing part. I have been in this position for a year and 1/2. It took me about six months to really figure this out. The woman who was in my position before, very sweet woman. She had been there for 17 years, so technology was not necessarily her forte. There really was not a system in place when I came in. There was not one central place where all resources were. I tried XL, and Excel sheet would be great, I could put columns and categories. I found that to be cumbersome because some organizations may offer more than one service. So how do I sort

that? Or some places may serve more than one age range. How do I indicate that?

It did not do everything I wanted it to do. But I came up with is Microsoft one note. At Kennedy Krieger, we are a Microsoft facility. One Note, I love. I tinkered with it before in other aspects, never found a good use for it. But for this I think it is perfect. It is private, so only I have access to it. I wanted to share it with you all to give you viewing rights, but unfortunately the Institute does not allow us to share outside of the Institute which is such a bummer. I may try to tinker and see if I can make a copy or send it to my personal email just because I would love to be able to share that with you. I'm going to give you a tour in just a second.

It also allows me to write notes to myself that I may be " and they might want to keep in mind because they have been brought up before in other resource inquiries. I do not have to worry because it is not public, I don't have to worry about maintaining it for the public. Websites go out all the time. So before I am sending a list of resources to someone, if I am taking it from my depository, I will check all of the links at that point and that is when I will maybe delete them or if a webpage moved because the website got updated, I will make those changes at that point in time.

But I do not spend my time doing it just randomly. So let me show you what it looks like. If you have never used One Note before, on the left I have my big categories. When I click on one of these big categories I have smaller categories that populate. I can add them very simply down here. Basically, this is one long word document. You just type into it, just like you would a Word document. I have everything organized by the counties. Maryland counties, because most of our inquiries do come for Marilyn. As well as out of adequate. -- Come from Maryland. I have general things could apply to anyone no matter where they live in Maryland, and I try to put notes for myself. This is my accessibility, when people are asking me for how they can afford to buy some assistive technology or durable medical equipment, these are the resources I have for that.

I might have little notes that I can remember, that when I am sending it to people I may keep the notes in. You may delete them depending on what they are asking and who I am sending it to. I have the different counties, and any resources that may be only relevant to that specific county. For this, this is only available to the people who live here. I would not give this resource to someone who does not live in that area.

I tried to think about the big things that people ask me for. And this is a growing collection. It really is as I search for things, as people ask me for things, and if I have to go find it on Google, before I send it I will dump it in here and organize it. This has been growing for the past year. From scratch. Where it is just as I find stuff now, I have been housing it. This is been helping me tremendously because then when I get a question about transition, I can come and cross my fingers and hope, did somebody from that county already asked me for resources. Do I already have resources for that area?

If someone was from Baltimore County, I can go through and think, great they are 15, this would work because it takes ages 14 to 21. This one will not work because it is only 16+. Some may not have ages so I can give that to anyone. I already have some to go with. This is been tremendous. I have care, afterschool care, child care, in-home care, anything that my brain associates with care. I have a whole section for different diagnoses. If they were diagnosed with fragile X syndrome. Some of my sections I have not put there, because maybe no one has

asked me for this since I started putting them in here.

I have found this to be the most efficient way to organize, especially because for my purposes I am emailing these lists. All I would have to do is come here, highlight what I need, copy it, paste it, put it in the email, already formatted in the way that I like to send the email. Like I said, at that point I would check the links, make sure that before I click send, are these all still current? I might search for more if I feel like this is not a lot, let me see if there is more, anything new that has come up and I will do that, that way I can send it to them.

That is a little tour of my One Note. Last thing I want to share, is what we do with all this data. We have a database called Apricot. Every single inquiry that comes in, no matter how it comes in, get entered into the database. If they come from the online form, they automatically go in. If it is someone who calls or emails I have to manually put it in. I periodically look through the data and we use this to help our department and center plan for trainings, presentations, we look at trends. What are people asking for? What has been difficult to find? I also will share with Kennedy Krieger to see if they can offer some services that people are looking for that maybe they are not already offering. Here's to show you idea... We started using apricot for a few years, even though the program has been around for longer, as you can see that service providers is huge. People are calling saying I need a... Blank. I need a neurologist, speech therapist... That is what I'm getting the most.

People are all also getting a lot of calls in for evaluation, I get a lot of questions about benefits. People denied SSDI, or people who may be just received a new diagnosis and they want to know what benefits could even qualify for. I get a lot... Yes?

MIRANDA HOOPER:

I'm sorry, I still just see your one note, I don't know...

KRISTINE NELLENBACH:

Thank you. Let me started over again, because they did switch over. OK, should be good now?

MIRANDA HOOPER:

Yes.

KRISTINE NELLENBACH:

Great. Because we are attached to Kennedy Krieger, I get a lot of calls because people are confused, they see the logo on resource finder, and they think they are getting Kennedy Krieger services, so I do have to be knowledgeable about what services are available there, and I may have to redirect people.

This shows you some of the topics that come in. And then because service providers is such a huge topic, we have a way to see what specific providers people are asking for. Earlier I mentioned therapy is huge. So behavioral therapy is a lot, neuropsychologist, psych and medication management. Counseling, psychology, social work. Those are huge. The other section is so big because the amount of different topics that people ask for is so wide. When I say people ask for all kinds of things, I mean like I have gotten all kinds of questions.

I have gotten questions about how to finance a funeral, all kinds of stuff. How to help your teenager who is addicted to technology. We're up with that?-- Where do I put that? The other

question is large because we get so many questions. Speech therapy is huge as well, inpatient...

Just to show you by state, 80% of the inquiries at the-- that we are receiving are from within Maryland even though anyone can contact. So Virginia is pretty close to Maryland, so we get a lot from there as well. Pennsylvania is on the other side of Maryland. Washington DC is also 45 minutes away. It makes sense that we get a lot of the states that are close by. Florida, we get a lot from Florida. I do not know how our word gets down there, but that is pretty cool. And New Jersey and so on...

The non-US states would be people from other countries, we do get some people from there.

Finally, with every email I sent, with resources, we include a satisfaction survey. So people are welcome to respond, there is a text box to read any comments. And people seem to be thankful to be able to have somebody else searching the internet for them. I am getting paid to Google for hours (Laughs) And sometimes people, it just helps them so they do not have to sit down for an hour and try to dig some of the stuff up.

If you have any questions about the program, please reach out. This is my professional email, if you ever have an inquiry, you are looking for resources, I just ask that you use the resource finder email, so I can keep my two inboxes organized. I will leave this slide up for another minute if you want to take a picture or screenshot. But again, I will send this out with the meeting notes as well. Happy to answer any questions...

I will take a look at the chat...

**BETH BOONE:**

In the chat, I see that Austin had to leave but was impressed with your efforts. And Aimee says you are doing absolutely amazing work, and I agree, this is a very cool service. What occurs to me is one of the reasons... One of the things that I do at our center is a run for the Center for autism and related disabilities, and we do individualized resource and referral information, and people often ask us, why don't you just have a list on your website? And it is always what you said, as soon as you put it up there, the link goes out, or the link changes or something happens and that person is not doing that anymore. And it takes 10 weeks to get your IT department to put things up on your website.

So we have gone to people calling in and we customize their resource and referral information from every single call and email, for the same reason. Just to make sure that everything they get is timely and individualized, and immediately consumable for them. And it is a ton of work! And we have two people to do that. So I can just say kudos to you, that is a lot. And I imagine it is very comforting to families that really need something to hold onto sometimes, just to have that person behind it, saying I got you, I am going to find you something, even if it is not exactly what you're looking for, I will get you somewhere down the road. Very cool.

**KRISTINE NELLENBACH:**

Yeah.

**BETH BOONE:**

Any other questions for Kristine? Maranda, if you can make sure to grab Christine's email



address and we will put that in the notes for everybody, that would be super.

OK, that is our agenda for today. I had put the remaining meetings for this year would be May 17 and August 16, and the AUCD meeting. But I think... The doodle poll was split almost 50-50 between Thursday at 3 PM and Friday at 3 PM, and I know 3 o'clock is late for those, especially for Friday, but we are trying to accommodate all of our time zones.

So I think I'm going to try to push back into the third Thursday at 3 PM Eastern time, sort of alongside our professional development group. So unless there is a huge upward to having our meetings on Thursdays instead of Fridays, we will have the May meeting on 16 May. In the August meeting on 15 August. And then we will have our in person meeting at AUCD. And we will not say when that is yet, because our conference committee is still grappling with how to make those in-person meetings possibly within the framework of our actual meeting, both for the fact that people do not come in two days early to go to meetings. It also because the Council, a lot of councils overlap. And people may be involved in several councils, or several special interest groups, and we want to figure out how to stagger those, so people can get to more than one.

That's right John. That is some of the things we are grappling with. Alright, well for Friday afternoon, we sure did have a nice crowd, thank you everybody! Thank you for your patience, and support, as we have a new slate of people. And also as we work with the home office to try to streamline some of the things that we are doing. To try to make sure that things we are doing are aligned with the way that other councils are doing things. So there is not... So there is some certainty about things. Thanks for your flexibility.

If you are interested in the professional development committee, and having a say in how we put in information and support each other with information dissemination, make sure to reach out to Amy, or you can reach out to Kristine and I and we can connect you to anyone. So thank you very much everybody. Have a great weekend! Be healthy! Those of you that... Seems like a whole new crop of people getting COVID these days. Be healthy, be well, and if we don't talk to you before then, see you in May!

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