

Association of University Centers on Disabilities
Coffee and TA Series: Core Functions Basics – Model Services
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>> Luis Valdez: Hello, and welcome to the fifth installment of our Coffee and TA series focusing on model services. My name is Luis Valdez, and I'm a program specialist here at AUCD. We would like to thank all of you for joining us today. Before we begin, I would like to address a few logistical details. Before each individual program presentation, we will provide brief introductions of our speakers, following the culmination of all of our presentations, there will be time for questions. Because of the number of participants, your telephone lines will be muted throughout the call. However, we will unmute your phones one at a time during the Q&A time at the end. You will need to press star and pound sign on your phone to request to be unmuted to ask your questions. If you are using the microphone on your computer, you can raise your hand by clicking the little icon at the very top of the screen that looks like a person raising their hand. You can also submit questions at any point during the presentations via the chat box on your webinar console. You may send a chat to the whole audience or to the presenters only. We will compile your questions throughout the webinar and will address them at the end. Please note that we may not be able to address every question and may combine some questions.

This webinar is being recorded and will be available on AUCD's webinar library. There will also be a short five-question evaluation survey at the close of this webinar. We invite you to provide feedback on this webinar and to also provide suggestions for future topics.

As mentioned, we are hosting a multi-part series on the UCEDD core functions, as categorized. We will start out with a quick overview of how the DD Act mandates core function. We will then have presenters from two different UCEDDs expand on how their program addresses this core function through their program activities. We will then conclude with a period for questions and answers.

Previously, we held our first four installments on interdisciplinary preservice preparation, continuing education, community training, and technical assistance. The archive of those webinars are available on AUCD's library, and we have a tips sheet that will be developed for each. This particular installment will focus on the next core function model services. Here is a list as a heads-up of all of our upcoming webinars planned in this series.

Section 153 of the DD Act covers the purpose and scope of activities to be undertaken by the national network of UCEDDs, outlining a series of core functions. This act includes the specific text, provision of community services that may provide services, supports, and

assistance for the persons described in clause I through demonstration and model services. That text will subsequently split into two UCEDD core functions, model services and demonstration services.

Further, OIDD issued a final rule in 2015 providing guidance on implementing the DD Act. In this guidance, OIDD specifically mentions the need for each UCEDD to have a written plan for how their program will implement the core function. This will also be a topic for a future installment in this series.

This is also echoed in the UCEDD funding opportunity in which each applicant must provide a five-year plan for carrying out the core function, as outlined in the DD Act.

Finally, based on OIDD's logic model in which they provide clarifying definitions for each core function, the definition provided for model services is as follows. Specialized services delivered with the intention to enhance the well-being and the status of the recipient, and not for testing new practices, and may be integrated with training, research, and/or dissemination functions. First, we have Beth Mineo and Brian Freedman. Beth Mineo became the Center for Disabilities Studies third direction in 2008. She is also a associate professor in UD's school of education, where she has a master's, and she is the codirector of the LEND program. Brian Freedman is the associate director of the Center for Disabilities Studies and leads training initiatives and systems change projects and designs innovative service models. He is the codirector of the LEND program. Please join me in welcoming Beth Mineo and Brian Freedman.

>> Hello, everybody. It's nice to be with you today. Just to give you a little bit of context for how our UCEDD is structured within the context of our university, you can see the org chart. We are within our college of education and human development and are one of several centers under that umbrella.

And within our own program, we are organized into a series of programmatic units -- excuse me -- focusing on assistive technology, health and wellness, interdisciplinary preservice training, school aged services, and transition, education, and -- or transition, education, and employment model, which is also known as TEEM. We also have a core of new autism-related initiatives, as well as a communications and advocacy unit.

What we are going to be talking about today, though, focus on two of the units, one in assistive technology that I'll be addressing, and the other from our TEEM unit that Brian will be addressing.

Brian and I wanted to start this by sharing with you that we have some considerations that guide our decision making when we are considering getting into the services business, and we will each talk about these more in depth when we talk about the specific service, but, in general, first, we think about is the service that we are contemplating meeting an unmet need in our state. If we launch a service, will it put our UCEDD in competition with other providers? And we actually try to avoid that. We are very invested in working collaboratively with a multitude of community stakeholders and really don't want ever to be perceived as being in competition with our partners.

The third question we ask is does the service have the potential to influence the way that things are done in our state, either through policy or through practice.

Another, of course, getting something new off the ground, there usually needs to be an initial investment and resources to launch a new service available, and oftentimes that's from external funding.

And then finally, how likely is it that the service can become self-sustaining once that initial

seed funding has concluded? And we'll both talk about the ways that the two services we'll focus on today continue to be supported.

So, the thing I'm going to talk about falls within the auspices of our assistive technology unit, and that is the Delaware Accessible Instructional Materials Center or the AIM Center. And we are going to step through our discussion of the services in the context of those considerations that I -- Individuals with Disabilities Education Act very specifically mandated that students with print disabilities must have access to their instructional materials in a format that is consistent with their needs and preferences. What we knew is that even though that was the law, Delaware school districts weren't in compliance, either because they truly didn't understand the law or they found compliance too burdensome, and we recognize that there were other states that had launched centralized services -- among those are Virginia, Indiana, and Wyoming. There really was no competition for this kind of a service, because the only accessible instructional material serviced in the state was run by our Division for the Visually Impaired for the exclusive benefit of students who were blind and low vision, and that division was not in the position to expand its services to serve students state-wide with a variety of additional disabilities.

One of the things that was very attractive to us, and initially we weren't contemplating offering a service, we were in advocacy mode. We wanted to raise the expectation that all school districts would be providing AIM to students who needed them. In order to kind of move that forward and make it a very prominent expectation, we actually succeeded in adding a new special factor to the IEP form, requiring consideration of AIM for students with print disabilities. We also expanded the definition of print disability beyond the kind of typical copyright exemption definition so that more students in Delaware could qualify. We promoted the use of evidence-based assessments to determine if students had qualifying needs for AIM, and happily, all of those initiatives intended to drive policy and practice really did end up impacting thousands of students.

We were among, as far as our seed funding, we were among 15 states that got some initial funding through the Office of Special Ed Programs and cast to kind of start this AIM ball rolling in our state. That work culminated in a retreat for stakeholders state-wide, and ultimately the State Department of Education contracted with our UCEDD to operate a centralized Delaware AIM Center, so that all students with print disabilities could get access to the materials that they needed at no cost to the district, and that was really key in this model. Districts were balking at having to pick up the expense, both in terms of personnel time and purchase of materials, and so making it a centralized service eliminated that barrier.

I am sure this is difficult to see, but it represents a timeline from, you know, really IDEA through advocacy and finally the awareness that we probably need to roll up our sleeves and be part of the solution if we wanted to get that access to AIM, so we proposed to create a centralized service and kind of the rest is history.

As far as sustainability, I think if we were to convert to sort of a fee for service offering for districts, we may see much more uneven utilization of the AIM Center. The fact that we have a centralized service, which is supported by our State Department of Education, makes sure that all students statewide have the access that they need to free and very high-quality accessible materials. You know, someday, and I state this in every training that we do, we would love to be put out of business because publishers are making accessible content available just the way that they make print available, but we are certainly not there yet, and until we get to that point, there is certainly a need for AIM services in our state. So, I think that wraps up the piece

that I was going to start with. I'm going to turn things over to Brian now.

>> Brian Freedman: Thanks so much, Beth. I'm going to share with you a little bit about our career and life studies certificate program, which is UD's two-year certificate program for students with intellectual disabilities.

Following along with the guiding questions that Beth shared earlier, we considered evidence for need, and as many of you are probably aware, the employment rate of people with intellectual disabilities was and still is quite low, and we began to examine post-school options, and there really was a call for more creative options for young adults with intellectual disabilities transitioning out of school. There also was a growing recognition of a lack of equity of opportunity for students with intellectual disabilities to benefit from postsecondary education settings and all of the various types of things that students in those settings are learning.

At the time that we were considering this, CDS actually had existing programs where we were supporting young adults with intellectual disabilities, including an employment services unit that was founded through a foundation grant and then through contracts with state agencies, as well as a campus-based secondary program that was funded through school districts. And as Beth mentioned earlier, we closely examine those model services as they are being conducted, and, in fact, for these programs, we did see some and were able to show to stakeholders a sort of proof of concept for key elements of those programs, and we saw growth among external programs in offering similar sorts of services, and so, ultimately, these programs were phased out as we phased in an inclusive higher education program.

Simultaneously, there were organizations like Think College out of the Institute for Community Inclusion that began describing in detail the benefits of college for people with disabilities.

At the time that we started the Career Life Studies Certificate program, which I'll refer to as CLSC, there were no other state programs in Delaware, and in fact, there were very few other programs across the country and in particular in states surrounding Delaware at the time.

We saw a true opportunity here to influence the community in multiple ways. We knew that there was a lack of understanding of the benefits of college for students with intellectual disabilities, and thinking even beyond the college environment, there was an opportunity to develop a model, evidence-based and best practice transition programs for schools, providers, and employers and families, as well as students in the community.

We also had and continue to have a tremendous need for more self-advocate leaders, and we saw the CLSC program as an opportunity to cultivate some new leaders.

The Higher Education Opportunity Act of 2008 created a couple of mechanisms that offered some potential seed support. There was a funding mechanism called the Transition and Postsecondary Programs for Students with Intellectual Disabilities, or TPSID, that was created through this act, and UD was in fact one of the 27 programs that received a grant for this program in 2010 that provided us with the initial funding to create the CLSC program. The Act also created an opportunity for students for financial aid called the Comprehensive Transition and Postsecondary Program, or CTP, which allowed us to consider from the get-go some options for sustainability. As Beth mentioned earlier, sustainability of our programs is something that we think about quite deeply from the outset, and, in fact, as we were developing opportunities for some initial seed support, we were also thinking about future sustainability, and we recognized that we were already a provider for VR and DD services, which we felt might be helpful as we planned for sustainability, and we knew that we had some potential ambassadors for inclusive higher education within those agencies.

So, I thought I would tell you a little bit about the CLSC program itself. It's a two-year certificate program that promotes involvement in all aspects of UD student life. Students participate in credit-bearing courses, internships and other career development opportunities. They utilize campus resources and join student organizations and also have the option to live in residential facilities on campus. All of our students receive one-on-one coaching and group-based instruction and support, and they receive assistance in finding employment during their time at the university, so that they are well set up as they graduate from CLSC.

And, in fact, we have seen a lot of growth over time in the program as well, as we maintained a strong connection with the community, understanding the types of opportunities that students and families are looking for and thinking about how to create a program that is as inclusive as possible.

Our students have taken a growing number of academic credit-bearing courses, participated in first-year seminar. Residential options, we were thrilled when we had the opportunity to finally develop residential options, and our students participated in many, many programs across campus, including things like an alternative spring break, where over the spring break week, UD students traveled to other communities and conduct an intensive community service project. But this growth over time really required collaboration and patience and advocacy, both our own advocacy within the university, as well as advocacy from students and families.

As I mentioned, we have thought about sustainability, certainly from the beginning, and as we neared the end of the grant, we realized that we had actually developed a fairly expensive program and worried that the program, if we didn't have a strong sustainability plan, would not be affordable to students in our communities, and so we made a point early on to develop a relationship with state agencies. In addition to helping them understand the benefits of college for students with intellectual disabilities, we also took the time to understand those agency philosophies and what they saw as needs among the community. We also made sure to understand the kind of terminology that they use and the kinds of systems of support that they operate and fund. We also spent time networking with others in the inclusive higher ed movement, which includes many people who are connected to AUCD. We have lots of UCEDD partners who had similar sorts of programs, and those connections were quite important as we thought through creative options.

And, in fact, we feel very fortunate that we were able to achieve some sustainability. We did receive Comprehensive Transition and Postsecondary Program CTP status. We also developed an understanding with our state vocational rehabilitation and developmental disability services, so that there could be multiple types of funding mechanisms.

We also worked as part of a group to help establish a state scholarship for college students with intellectual disabilities in our state, while other students had an opportunity for college scholarship, while students with intellectual disabilities didn't yet have that opportunity, and taken together, each of these areas covers about 90% of university tuition and fees, including fees associated with our program, although that doesn't include residential.

We also considered out-of-state students and some of their needs and had been working over the past couple of years to develop creative options with those students and families as well.

Through our program and through many of our model service programs, we also give thought to some of the other core functions we have at UCEDD and try to consider areas of overlap or areas where we might be able to utilize a program under one core function to support other core functions, and, in fact, that's been the case with CLSC, where we have

created opportunities for pre-service preparation as well as for research.

We have also leveraged the kind of success we have realized through the CLSC program to think about how we want to grow additional transition-related services through our UCEDD, and, in fact, through the relationships that we have developed in the practices and lessons learned through CLSC, we have been able to develop additional services under pre-employment transition services, which includes bridge programs for high school students with disabilities, and we now have a new program called Spectrum Scholars, which is for students on the autism spectrum and funded by JPMorgan Chase and conducted in collaboration with them.

So, I'll pause there, and this is Beth's and my contact information. I think we are going to end up taking some questions at the end of this session, but I will pass it along to our moderators.

>> Thank you so much Brian and Beth. And, yes, as a reminder to everyone, if you have questions, please feel free to type them into the chat box, and we will address them at the very end.

Up next, we have Danielle Haener and Kathleen Angkustsiri. Danielle Haener is a licensed psychologist at UC Davis MIND Institute. Her clinical work focuses on diagnosing and assessing neurodevelopmental disabilities, such as developmental delays, intellectual disabilities, autism spectrum disorders, and ADHD.

Kathleen Angkustsiri is a developmental behavior pediatrician with interests in neurodevelopmental disorders, including autism spectrum disorders, chromosome 22q deletion syndrome and fragile X syndrome. Please join me in welcoming Danielle and Kathleen.

>> Danielle Haener: [Off mic] -- about our MIND Social Skills Clinic, which I am currently the director of. So, this program actually began back as a postdoctoral fellowship grant, funded by the MIND Institute. At the time, within the community, we were noticing as people came in for research that the children had participated in ABA, but we had school-aged children and adolescents who were no longer participating in any type of intervention, and through various research studies, we were really noticing a deficit, specifically in social skills, emotional recognition, isolation and they wanted to create a program to target these needs. So, the program had a grant for the first year, and they wrote kind of a manual, and since then, they have been utilizing it for the past 18 years, and we think we have served roughly over 650 children, their parents, and siblings since the program's inception.

Oops, nope. I don't know what I just pushed. [Laughter]

Share my screen. Sorry. I pushed the spacebar. [Laughter]

Okay. Sorry. And, again, with our goal to increase social motivation, improve self-esteem, decrease isolation, teach TEEM skills, both for school-aged children, and I'll talk about we are working with adolescents as well, so we are always hoping to target some of those transitional development skills in preparing them for the next aspect, which includes the enhancement capacity for independent living.

So, our program is a 20-week program for children and adolescents. Over the years, we have kind of refined what our requirements are, and, again, looking at the services that are available within this greater Sacramento area, we have decided to target children and adolescents who have an official diagnosis of autism. Currently, we serve individuals between the ages of eight and 17. Our program is a pretty verbal program. We utilize a lot of language as we teach the various skills. Over time, we have decided that the range that we are able to

serve are children and adolescents with an average verbal IQ, so somewhere around the 85-115 range or above, and one of the things that we now say is that they can't have significant behavioral or mood symptoms that impair their ability to participate in group. Many of our children and adolescents have co-occurring disorders with anxiety and ADHD, and, on occasion, mood. We just want to make sure that this is not their primary difficulty at the time.

We currently have -- we usually have about three to four groups per year. This year, we will have three groups. We serve the following age groups. We have a group for eight to ten-year-olds. We have a group for 11 to 13-year-olds, and we have an adolescent group for 14 to 17-year-olds. At the same time as the child and adolescent group, we have a fee-based parent psychoeducational workshop and a free sibling support workshop. So the parent workshop is both doing training for the parents over what the lessons are each week, and we often have community speakers to come in and talk about IEPs, how to advocate for your child in school. They talk about difficulties with executive functioning, talk about sensory processing and integration and some of the resources within the community. They talk about preparation for college transition, all kind of depending on the age of the children within the group and the parents, and that is, like I said, a fee-based parent psychoeducation workshop as there is not a direct insurance code that is billable at this time. That is still something that we are working on.

And then we have a free sibling support workshop for the brothers and sisters of the individuals participating. This is ran by our child life specialist and is really a curriculum based upon enhancing self-esteem and identity within the siblings so that they can feel supported, as they may have had a sibling who they feel gets a lot of attention, and this is really a time for us to come and help develop and facilitate their learning.

For the staffing logistics, we offer a one to three to a one to two student to staff ratio. So, for each of the groups, we have a license provider. This is often a clinical psychologist but has also been a physician, or recently we had a BCBA that led one of the groups. We also have a licensed provider that leads the parent workshop, and then we have one non-licensed provider who is a child life specialist. So, how do we make up the rest of this? It's volunteers. We are lucky. Here within the MIND Institute, we have a lot of research students, and so we send out emails recruiting. We also use LEND trainees, medical school students, and on occasion we will put out information into the community, so we have had people from the fields of counseling, school psychology, MFTs, social workers, and speech and language pathologists who are really looking for some additional training and experience working with children and adolescents with neurodevelopmental disorders.

So, the group structure, just to kind of give you guys an idea, depending on the age range, this is modified, but there is usually an initial snack and game time, something that's a little bit more structured to help reduce some of the anxiety and give them something that they are doing that's an activity, an opening circle where we are really introducing the lesson for the day and usually asking a question. The lesson is broken into both large group and small group outside time, weather varying, and we have a social experiment which is really a way for us to phrase homework that's really having them do a practice and then reflect on how that practice went. We have joke time, so that we can kind of discuss sarcasm and inferences and continue to develop that skill. And at the end, the leaders and coleaders check out with the child and their family, as I said, with the 1:2 and 1:3 ratio. Each child is assigned a co-leader, who usually has one to two or one to three children. They each have three goals that they make during their individualized intake, and over the course of the program, their progress on the

goals are monitored. They are modified as needed, and we discuss new things to implement. The goals are both things that are observable in group and also things that they can come back and report, such as inviting a peer to hang out outside of school.

This is probably very hard to see, but I kind of just wanted to put an overview of the curriculum on there. We discuss a lot of varying things, with conversation skills, identifying friendships, where to even kind of start conversation, navigating group conversations, emotional recognition, regulation skills for emotions. We, you know, do perspective taking, problem-solving, discussing bullying, teasing, hygiene, nutrition, professional development for the older adolescents, of course, the actual inviting individuals over, hosting parties; rescue phrases for group work; planning projects; and then at the end, we have some small group goals that they work on over the course of several weeks, and eventually, we have a graduation.

So, strengths and challenges. The strengths, it is an in-depth 25-week program with developed curriculum that's been kind of modified as research comes out. It is now I think in its 18th year. We are able to meet the needs of children and adolescents aged 8-17, and within our area, there are very few social skills classes outside of the early ABA.

We are able to bill insurance authorization, and we are also partnered with Regional Center, so we are not only able to accept patients who have insurance but also that may have Medicare and Medi-Cal, or for families that aren't able to pay, we refer them to Regional Center so that they are able to get the parent workshop paid for.

We have some difficulty recruiting families who meet inclusion in the group. There can be years where we have hundreds of families and years where we don't have as many. We really work on word of mouth and partnering with the local school districts to refer families that they think would be appropriate. We know that there is a fee for the parent workshop, and that's out of pocket. We try to break those payments down so that it's more accessible for families, but we do understand that that may limit other families who are able to, and we have been working very diligently with the Regional Center to help address that concern. And, of course, recruiting volunteers, this is a very volunteer-heavy program, and we work really hard within the MIND Institute and also within the community to try to, you know, instigate this kind of want for learning, because it is volunteer, and our volunteers do end up using about four to five hours a week during that 25 weeks, in addition to some initial training before the group begins.

All right. I'm going to go ahead and hand this over to Kathy.

>> Kathleen Angkustsiri: Okay. Hi. Good morning and afternoon, everyone, depending on what time zone you're in. Thank you so much. Thanks, Danielle, for your presentation. I can tell you that, you know, as a clinician, leaving at the end of the day, the place just comes alive with our social skills group, you know, that's run after-hours to accommodate school schedules and everything like that. It's really a big part of what we do here at the MIND Institute.

So, I'm going to shift gears a little bit in terms of telling you more about our 22q Healthy Minds clinic. This is kind of a direct service, as well as meeting some of our teaching and research goals here, and it's quite a bit of a different type of program, more individualized and niche-y, in terms of meeting the needs of families who have children with a very particular genetic disorder. But, really, this came about based on existing research programs that we had going on here and hearing from families that they needed more support in terms of clinical service for their children who were coming through.

So, let me just get started by giving a little bit of background, since many of you probably may not have heard of this rare condition. It's the most common microdeletion system in man.

The prevalence is about one in 2000 to 4,000 live births, and it goes by a lot of different names, such as DiGeorge syndrome, velocardiofacial syndrome, and a lot of others, which is part of the reason why it's not as well recognized, and that's part of the contributing factor as to why families have difficulty accessing providers thankful familiar with or comfortable with this condition, because they don't all necessarily recognize that it's caused by the same common deletion.

So, the syndrome itself is really characterized by medical issues. So, early in life, a lot of kids are identified because of congenital heart disease, many of which need surgeries, and they are in and out of hospital in those first couple of years. In addition, there can be cleft palate, speech issues. The immune system can be affected, and they can be sick a lot, and then in addition, some of those children have problems with the endocrine system, hormones, and can have growth delay. That's really what characterizes the first few years of life for these individuals. And then, as they kind of grow into early-middle childhood, there are more developmental and behavioral mental health concerns, so IQ tends to be in the borderline range, and then a lot of them come to see us in developmental behavioral pediatrics because of problems with anxiety, ADHD and social deficits, and then later in life, there's a 20-30% risk of psychosis and schizophrenia. So, as you can see, even on just this one slide, there are so many issues that affect these individuals and their families, and families really feel like they need more support to help all of these different aspects of this disorder.

So, I can give you a history about how we got our clinic started, and, as I mentioned, this really stemmed out of expertise from our research program here that was started by Dr. Tony Simon when he came here in 2005. And so he had a robust NIH-funded program that's still going, and when I was a fellow here, we actually started incorporating visits with a developmental behavioral pediatrics fellow in the research visits kind of alongside there, to again help support some of these families who were coming in for research focused on neurocognitive deficits and not particularly necessarily health difficulties or anything like that, but, of course, as families were coming to a specialty center, they were expressing interest in wanting to be able to meet with someone who could help them along those issues.

In 2008, in addition to developmental behavioral pediatrics, our clinical neuropsychologist became part of the kind of what we were calling translational clinic at the time, so these were really still research visits, kind of added on supports to the research visit when people were coming in to participate in the studies. And so that was really funded by separate funding sources so that these families could have that time with the developmental behavioral pediatric fellow and the clinical nurse psychologist.

After we got great feedback from families that this was really a useful visit, but that, you know, it was too bad that these were opportunities that were only available to families participating in the research study, we got together with some of the MIND's leadership to talk about how we could talk about or start or create kind of a very similar model of an interdisciplinary team evaluation, but open that up to not be limited by those individuals who were participating in research. So, in 2009, we started our 22q Healthy Minds clinic, which is staffed by myself and Dr. Ingrid Leklitter, the neuropsychologist, as team evaluations that we commonly did in clinic for, you know, other evaluations, whether for autism, learning disabilities, et cetera, this would be specifically for individuals with a 22q11.2 deletion syndrome. So in 2009, we started doing that through insurance, so that required a bit of planning and reorganization involving our billing system downstairs, et cetera. And, as I mentioned before, this really started because families were reporting to us and others that their

local providers were unfamiliar with, you know, not only the medical management of 22q but finding individuals, providers who could help them with the learning and behavior issues that are common, that there are a lot of providers in their local areas that were uncomfortable with medications to use, because -- and medications for, you know, psychiatric reasons, particularly because of all of the medical complications these children had. And, you know, I think for these families, a lot of times parents go to providers, and they were the ones that had to give background to doctors about what 22q was, and feedback that we received was that it was really a breath of fresh air for families to be able to come somewhere and be able to have providers who could help tell them about their experiences, seeing many individuals with this genetic disorder, as opposed to the other way around, where they would come in and have to tell the specialists about their child's condition. And this has been a pretty successful model for us, in terms of, you know, initially getting started, from research kind of filling in into clinic, and then later on, as word kind of spread about the kind of services that we could provide, we had families coming from other parts of the United States, as well as other countries, and then that would feed into research as well, so we could coordinate with doing two visits, both clinical and research.

Sorry. Okay. So, this is our team here. As I mentioned, I'm the developmental behavioral pediatrician. Dr. Leklitter there in the middle is our neuropsychologist, and that's Tony Simon on the bottom, who is the researcher that got us all started. Depending on who we have rotating through with us, this is a great teaching and learning opportunity, and we have at different points of time a child and adolescent psychiatrist joining us. We have our LEND trainees that involve, you know, physical therapists, occupational therapists, speech therapists and other disciplines, medical students and pediatric residents, which, you know, given particularly the feedback that we have from families about medical providers not being very aware of this condition, it's nice to be able to provide some education early on in their training. This is not a high-volume clinic. We actually spend all day with the family. We see two -- we started out just once a month, but as demand kind of increased, we hold clinic two times per month. And then, as I mentioned before, on our administrative side, we really had to create that or get that organized in order to get the clinic successful. So that involves having individuals who help us with insurance authorization for the neuropsych testing and the medical visit. There's quite a bit that goes into triage and record review, and then providing information before the visit for intake and questionnaires, because what we don't want is to, you know, have a child come in from out of town for this all-day visit and then not have the information that we need, like his IEP or other things like that. We want everything to go as smoothly as possible. And then, obviously, also scheduling is a big deal, given that many of these people are coming from out of town and we have to help them with travel, as well as housing, if needed.

Here's just a snapshot of our website, which is trying to get the insurance authorization to go as smoothly as possible, actually providing individual codes that we want the referring provider to request so that we can go ahead and do all of the testing that we'd like to do on the day of the visit.

So, as I mentioned, this is a full day visit. So the neuropsychological assessment happens in the morning from about 8:00-12:00, and then in the afternoon we have a medical visit with a developmental behavioral pediatrician, and then, after that, there's a small break for the family, and the part that's been so useful is really having this team discussion and staffing together, so with both of the clinicians that are seeing the individual as well as any of the other trainees,

other disciplines that we have involved, kind of putting -- brainstorming together, discuss what they are seeing, and really talking about what resources can be helpful for this individual.

And then after that's determined, we meet as a team. So all of the providers together with the family, to give feedback and really, I think, help the family understand the child's current level of functioning and prioritizing realistic and reasonable goals for the immediate and mid and long-term future for this family.

So, common topics that we usually go over with families or the families come in wanting is really discussing or understanding developmental delay, and for those that are older and intellectual disability, if that child is in that range of functioning. Not all of them are.

Dealing with a diagnosis and the comorbidities, both medical and mental health are usually what we end up talking quite a bit about, as well as disclosing the diagnosis to the child, is something parents have a really hard time with or want help and figure out support around.

We provide individualized recommendations for the child, that we have the families tell us has been very useful in terms of helping guiding the school to support this individual, as best we can, helping to find local resources, in terms of if there's, you know, a social skills group we'd like for them to be able to participate in or mental health providers or cognitive behavioral therapy et cetera.

We give recommendations in terms of medical treatments, medications. And then, of course, evidence-based interventions when possible, so, sometimes we have people coming from rural areas where they don't necessarily have access to various particular types of therapy, and then we help give at least kind of general principles about what they should be looking for in an intervention or providers that they are seeking care from.

And then we do have a written report that is to be shared with local providers to help guide future treatment.

Strengths and challenges, so, I think something that obviously families really appreciate is this is a full day in-depth assessment. By the end of the day, they really feel like they have a good idea of what was done and where their child is in terms of different levels of functioning and where they want to go in terms of prioritizing treatment or changes. One of the difficulties that we do have and struggle with is insurance authorization, particularly for the neuropsychological assessment. Sometimes this just isn't a covered benefit. We tend to have a bit more success, given that we are billing under a medical diagnosis that has associated cognitive deficits with it, but sometimes that's just something that's really difficult.

Travel and recruiting families has been both a strength and a challenge, so, when we have an ongoing research study that, you know, the participants will be, you know, in clinic the first day, and then the next two days, they might be in research. It's helpful in terms of, you know, they are coming in for research so that we can coordinate with those coordinators for their travel, but also we need to be very careful in terms of how we are scheduling time and that we have good communication between the two teams.

Another challenge is that it's great that we are able to see families from all over, but follow up for nonlocal families is also difficult. That's not something that we can just have them come back in three months to see how things are going, and we have different models about how we can maybe use telemedicine or some other modalities to help ensure that maybe things are getting taken care of.

And I think another area that we are trying to improve on is figuring out what to do as these individuals age, particularly given the mental health concerns in adulthood and, you know, as we are currently staffed, we are equipped to kind of see children up to age 14, but after that,

we really need kind of our adult counterparts in helping with that transition to adulthood.

So, those were all of the slides I had to tell you about our 22q clinic, and we are happy to take questions, and I'll hand it over now.

>> Great, thank you so much. So, we now have time for question and answers. If you have questions, please press star and pound sign on your telephone keypad, and the conference call system will unmute you in the order in which you indicated that you have a question. You will hear a prompt when your phone line is unmuted, and then you may ask your question aloud. If you have a question, please press star pound sign now. You can also type in your questions into the chat box next to the slides. I will read the questions aloud for the presenters, and I do see here that we have one question already from Amy Whitehead, and I believe this was during Kathy's slides.

"How many patients do you schedule for the one-day clinic?"

>> Kathleen Angkustsiri: So, this is quite an unusual clinic, so we see one patient for the entire day. That neuropsychological assessment is a half day in the morning, and then in the afternoon, we are meeting the medical visits about an hour and a half, about 30 minutes for discussion, and then another hour feedback for the family. So, this took a lot of discussion and really investment of our clinic leadership in this particular disorder to kind of let us do it as a trial and see if we could get an insurance reimbursement for it so that it will be sustainable.

>> Luis Valdez: Great. Perfect. And I do see another question here. Are the patients also enrolled in the research, or now that you have a clinic, are there families who only come into the clinics?

>> Kathleen Angkustsiri: Yeah, thanks. So we have both now. Again, and this has been really helpful, I think, for sustaining our contact with the 22q population, because, as you know, you know, research funding comes and goes, and the clinic is pretty steady. So we have some individuals that come in and only do research for either they don't want to come to clinic or they can't work it into their schedule, or their insurance doesn't really authorize the visit. Then we have got kids who come in and just do clinic, because maybe they don't -- they are not in the right age range for the ongoing research, or they don't want to, you know, kind of do a two-day research visit, et cetera. They just really want some clinical recommendations. And then we have some that do both. And, again, that's tricky with scheduling, but it's also complementary, because they are coming in here for research as it is already, and we have travel funds for them. Then, really, it's just getting the insurance authorization for the extra day to stay here, that then they can actually participate in both programs.

>> Luis Valdez: Great. Perfect. And I did receive here a private question for our Delaware presenters. Can you expand on some of the more creative sources of funding that you mentioned to sustain your program over time?

>> Brian Freedman: This is Brian. So, I'm wondering -- so I'm assuming this relates to the work presented on the CLSC program. Beth may have an answer to this too. I don't know that there are too many others besides what we have shared, but the creativity really has come in a manner of thinking about how there might be some existing funding mechanisms that aren't typically used for higher ed that we might be able to use. So, for example, vocational rehabilitation does traditionally offer some support for higher ed for some students, although we looked at some of the employment-related supports that they offer and saw that they were similar to some of the supports we were offering within our program. For example, services that resulted in an assessment of job skills. So, that's really something that VR funds under, at least in our state, under a supported employment model, and so we worked with VR to come

up with an agreement where the funding that typically is provided to that assessment for a community provider instead could help to fund a student's time in CLSC, because that work is happening as part of their time in the CLSC program.

>> Luis Valdez: Awesome. Thank you so much, Brian. Any other questions? I think we have time for just one more question, if there is anyone in attendance?

So, seeing no other questions, I want to thank each one of our presenters today, and I want to thank all of you for attending the webinar. This webinar has been recorded and will be archived in the webinar library at AUCD.org, as well as a tip sheet on its core function will be created. If you would like more information about the UCEDD Resource Center, please feel free to contact us. Please take a few moments to complete our survey.