**TN Council on Autism Spectrum Disorder**

**Conference Call notes: April 3rd, 2018**

**Note:** Dr. Quentin Humberd, Developmental Pediatrician, Family Member, and Council Chair, facilitated all four conference calls. In addition, Pat Edmiston, DIDD Director of Developmental Disability Services and the DIDD Liaison to the Council, and Solita Morris, DIDD Policy Coordinator and WebEx conference call host, were on all four calls participating and taking notes for distribution to the council.

**Information for Families/Service Coordination: 9:00 a.m. – 10:00 a.m.**

**Present on the call:**

Jeanine Miller (DIDD Director of Policy), Iseashia Thomas (Family Member, West TN)

This committee is looking at how valuable information is communicated to families. Dr. Humberd stated that developing a unique website and/or aligning with Disability Pathfinder and/or “kidcentraltn” is certainly something that needs to be explored. Also, there are 95 counties in the state. 75 counties are represented by ECF Choices. Tapping into that same information stream, as well as through local Health Department Care Coordinators, with proper training, could be very helpful.

**Top 5 Issues/Action Items (previously identified by this committee):**

1. Ask administrative agencies on the council to provide a map of how people and families enter their services and what services their department provides for individuals on the autism spectrum. Perceived gaps?

This has been done and will be reported at the 4/24 Council meeting.

1. KidCentralTN and Disability Pathfinder. What agency would be the lead in creating such an aligning system for lifespan approach to lifespan info about ASD? We would like “One Door for Autism.”

This is an area where the Autism Summit Team could be useful. Dr. Carolina Clark is on the steering committee for KidCentralTN, so this is being pursued as a way to connect families to services. Dr. Jeanine Miller suggested that involving someone from STS (Strategic Technology Solutions, the State of TN IT Company) would probably be valuable to speak to what would be involved from a technological perspective. Someone from the Governor’s Children’s Cabinet (where KidCentralTN lives) will be invited to the July Council meeting to try to collaborate on a unified approach. It is possible that the Governor’s Children’s Cabinet may not be continued beyond the current administration. Dr. Miller suggested that one of the actions of the council may be to recommend promulgation of that initiative in legislation to ensure its continuation, regardless of administration. We would also like to invite an ABLE TN representative to present at the Council.

1. Connecting families to legal supports. Legal Aid Society would be the first resource, but that would be limited to very low-income people/families. Elise McMillan (at Vanderbilt) may have some suggestions.

Cindy Gardner, a private attorney that focuses on disabilities and special needs, will be invited to the July meeting to discuss a framework for what an appropriate legal system of care looks like. She may be able to help the council develop a “legal toolkit.” Case managers should refrain from offering any legal advice. She may also be able to explain the Supported Decision Making legislation. We will also collaborate with the legal representatives from the Vanderbilt Kennedy Center. Iseashia stated that having all of this information in advance of actual need is critical.

1. TN Promise transition training is not ASD specific. Who could develop customized training as a two year program at a community college? Jenness stated that the issue is not just communicating information. There is also a capacity issue to not direct people to a resource that is at full capacity and cannot help them. TN Promise prepares and pays for college, which is different from employment.

There are not currently enough caregivers with skills and knowledge about DD. Idea for training individuals with autism to access TN Promise for vocational education. Need more clarity around this issue to move forward.

1. Consistent information sharing across agencies.

Dr. Humberd stated that having “Family Navigators” would be interesting to pursue. What would the barriers be to equipping the disability specialists at the local Health Departments with additional autism specific resources?

With regard to the bullet point regarding a standing agenda item to address a current individual issue, it will be important for the council to look consider these with open minds to make sure that the overarching work and solutions put forth by the council address those individual scenarios.

**Early Identification/Education: 10:30 a.m. – 11:30**

**Present on the call:**

Jenness Roth (Family Member, West TN), Roddey Coe (Family Member, East TN), Will Edwards (Family Member East), Rose Naccarato (TN Commission on Children & Youth, Family Member), Lorrie Brouse (TN Dept. of Commerce and Insurance), Alex Heart (DIDD Assistant Commissioner for Policy and Innovation, Community Member), Kim Black (DIDD Director of Residential Services/Community Member/Family Member)

Dr. Humberd stated that Autism Summit Team has offered to provide technical assistance and subject matter expertise to the council’s work. This will be discussed further at the Autism Summit Team meeting at Vanderbilt Kennedy Center on April 6th.

Roddey has provided information regarding the Autism Conference in Chattanooga on 4/20/18.

Jenness is concerned that the various committees are creating a diffusion of focus. At this point, we may need to identify big impact issues and move solely on those things. She feels that our task as council members is to start advising.

Dr. Humberd stated that the Information for Families committee (that just met earlier) has done just that. Each of the departments will report on their view of autism supports at the 4/24/18 meeting. In order to offer recommendations, we need to have all of the information around the issue. He sees the April council meeting as being a time to identify recommendations.

Jenness stated that children at age 3 and under are going unserved across the state, and there are definitely ways that that can be impacted. TEIS does not offer speech therapy services. We need to contract with speech therapy techs to work with this group of children. How can the council push for that? The early identification piece has made a big difference, but we must figure out how to serve these children once they have been identified.

Dr. Humberd stated that reimbursable services is another part of the issue. Where does this workforce come from? Possible reimbursement through TennCare for developmental therapy (not ABA) services is being discussed. There has to be a licensed person supervising the techs to be a reimbursable service.

What would be the potential barrier to implementing “extenders”? Jenness stating that therapists are being produced every year, but they do not go into early intervention services because of the lower pay, burden of paperwork, strenuous turnaround timeframes. There are many barriers to becoming a TEIS provider. Perhaps that is an area where the council can make a difference.

Dr. Humberd stated that early identification does not do us any good without a workforce to serve those individuals. We cannot bypass TEIS. We have to help them work through barriers. Can there be a waiver for the Boling Service to allow them to become an EIRA (Early Intervention Resource Agency)? Will stated that looking at the way that the Knoxville campus contract with TEIS is handled may be helpful.

Dr. Humberd mentioned the “legal toolkit” idea that was discussed during the info for families’ conference call. Will stated that the clarifying point from the Supported Decision Making legislation was ensuring that rights of the person served are not taken away entirely and that the judge now will assure the least restrictive alternative to conservatorship when possible.

Dr. Humberd asked about strategies to educate families about IDEA. This is another potential low-hanging fruit where the council can really make a difference. Roddey stated that, rather than putting the burden on families to educate themselves, perhaps providing the schools with the training, at least at the administration level, would be a more impactful approach. As a parent, Kimberly stated that she agrees that the schools should have this training. Because her son is on the mild/almost invisible end of the autism spectrum, he is dismissed from the implementation from intervention techniques. There also are not enough paraprofessionals to assist teachers with implementing these.

Alex asked about mentorship for families. Jenness stated that there is a mentoring piece to the Tennessee Family Voices program. We need to put the pressure on to legally oblige schools to teach families.

Pat asked if the STEP Program could assist with this effort. Jenness stated that they do collaborate, but that capacity is thinly spread across the state. When she was STEP’s Executive Director, there were nine trainers across the state. Will stated that STEP has hardbound and video trainings that could be helpful.

Dr. Humberd stated that uninformed families turn oppositional very quickly because they don’t know what they don’t know. Informed parents are going to be a huge part of this solution.

Lorrie stated that there have not been any insurance legislative changes in this arena from the Department of Commerce and Insurance perspective.

Rose stated that it appears that paraprofessionals are funded at a 1:60 ratio. This is not reflective of realistic needs. Schools are actually providing much more paraprofessional school support based upon parent input and student needs.

* **Action Item:** **TEIS leadership to provide thumbnail sketch of services/White Paper, as well as have their data person to put a face on the present workforce gap. We want ALL kids birth to 3 years identified and served with the goal of moving off of the spectrum with appropriate services and therapies. Issue is that many of the services recommended on the IFSP (Individual Family Support Plan) are not being provided and/or recommended services are not being written down on the IFSP because it is known that services are not available.**
* **Action Item:** Alison, our Dept. of Education member, needs to be informed of our discussion around educational needs so she can incorporate that into her upcoming report and clarify any barriers or resources required.
* **Action Item:** Work force development and training, due to the shortage of therapists and direct support professionals.

**Healthcare: 1:00 p.m. – 2:00 p.m.**

**Present on the call:**

Iseashia Thomas (Family Member, West TN), Dr. Beth Malow (Family Member, Middle TN), Will Edwards (Family Member, East TN), Alex Heart (DIDD Assistant Commissioner for Policy and Innovation, Community Member)

The goal is to have providers in every county of Tennessee engaged in a monthly telehealth conference focused on taking care of individuals with ASD throughout their lifespan. The concern is that there are not enough providers across the State.

Dr. Malow spoke about the “ECHO Autism” initiative to empower families and providers. Inconsistencies with codes has bogged things down. There still needs to be an integrated, comprehensive, patient-first approach. Providers and clinicians need to feel like it is a valuable and effective use of their time. We have to look to a team-based care concept. Dialogue between TennCare and the council to strategize around this would be helpful. Dr. Humberd stated that TennCare is looking at other team-based initiatives across the state. Providers that feel they do not have the skills are not going to engage without sustainability incentives. Dr. Malow stated that an example of incentivizing would be series of videos that were presented to prescribers of psychotropic meds whereby, if the prescribers agreed to watch the videos, they were granted a less cumbersome process for prescribing.

Dr. Humberd asked if any of the committee members were aware of what the ABA processes were among the 3 MCOs. Dr. Malow stated that it may be more impactful to focus on the telehealth bullet and make an ask of TennCare and other partners to set up a brainstorming session to come up with incentives, and then tackle the ABA issue a little further down the road.

Iseashia stated that doctors who really want to see patients thrive do not care about incentives. As a parent, she would rather have a list of doctors who do not have incentives than the ones that do have them. Dr. Humberd stated that what we want to do is take that “willing” group of providers and reward them and help them to make sure that they are not losing money and resources to continue to provide the level and quality of care that people on the spectrum need.

Dr. Malow stated that “incentive” could be something like an easy to navigate website. It isn’t necessarily about money. Telehealth speaks to both exchange of information from provider to patient, but also to provider to provider regarding the healthcare of the patient.

Autism Speaks and ECHO network – Legal toolkit? Will spoke about the Designation of Surrogate Act that allows the physician to designate someone to make healthcare decisions for individuals that do not have a conservator.

* **Action Item:** **Ask TennCare to participate in a feasibility discussion regarding telehealth incentives. Dr. Humberd will email Dr. Frigon directly about this, as well as the MCO ABA policy question. Dr. Malow suggested including with this ask a description of what the ECHO model looks like for the benefit of the entire council be provided at the next meeting. We don’t have to figure out the incentives at the meeting. We just need the buy-in that this is a great idea. Dr. Malow will develop a brief presentation. (This ECHO presentation will be on the council’s July meeting agenda.)**
* **Action Item:**  Ask Commerce and Insurance Commissioner what can be done to level the playing field so that people do not have to be poor to qualify for services. Do they even have a way to track how un-level the playing field is? The first ask will be for data and information. The second ask will be what can be done to improve that.
* **Action Item:** Healthcare providers will be trained to serve our sons and daughters throughout their lifespan. Perhaps Title V coordinators (CSS Program) through the DOH could also be utilized in this effort as recommended by the Information for Families committee.

**Aging and Adulthood: 2:30 p.m. – 3:30 p.m.**

**Present on the call:**

Michael Collins (Family Member, East TN), Ginger Day (ASD Coordinator, Tennessee Rehabilitation Center, Dept. of Human Services) Dr. Beth Malow (Family Member, Middle TN), Mary Ellen Chase (Family Member, West TN), Dr. TA McDonald (Community Member/Vanderbilt Kennedy Center, Family Member)

The goal is for adults diagnosed with an ASD have access to person-centered services that support the person to independence.

Ginger shared that there now is ASD training for all the VR Counselors and it has been developed on-line. She is in the process of taking the training and will share it with us.

Perhaps a low-hanging fruit action for the council would be to take all of the available resources and make them easy to navigate. Navigating resources for both the ASD person and the caregiver is difficult. Michael stated that there is a challenge for making the Disability Pathfinder easier to navigate, but another challenge is just getting information out that this resource even exists.

Dr. Malow shared the “objectives” from the chapter on Adulthood from the following document:

 ***IACC 2016-2017 “Interagency Autism Coordinating Committee” Strategic Plan for Autism Spectrum Disorder, October 2017. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: https://iacc.hhs.gov/publications/strategic-plan/2017/***

Much of the information in this report is applicable to the council’s work.

Michael stated that, being a parent and working for a DIDD and ECF Choices (Employment and Community First) provider agency, his greatest concerns and struggles is the development of the ECF CHOICES Program. He is really excited about the employment opportunities and possibilities for employment for people with ASD and DD. There are now two programs. There is DIDD, and then there is ECF Choices through TennCare and the three MCOs. It seems like administrative waste of dollars to fund the positions and programs at two separate agencies and that ECF Choices being administered by DIDD would have made more sense. ECF Choices’ willingness to accept provider feedback regarding the “level of need” of individuals. It seemed that DIDD is more understanding of the population and receptive to provider feedback. Provider voices do not seem to be as heard by the MCOs. Dr. Humberd stated that there needs to be mechanism to incorporate both positive and negative feedback into the ECF Choices learning curve.

Dr. Malow suggested taking an incentive approach with employers who are already employing people with disabilities to grow that workforce. It would be good to have them present their current programs, state what they might consider incentive, and allow time for council feedback. Dr. Humberd stated that we need to first look into what TNWorks Community Conversations has already done around this, but this is definitely something that we will want to look at in the future.

Solita shared that the DIDD – DDPPC (Developmental Disability Planning and Policy Council) has supporting this council as one their focus areas. We need to tap into their resources.

* **Action Items:**
* Training for VR providers around ASD
* More ASD adults being able to self-advocate
* Getting information about changing landscape of services with ECF Choices and how that program will work alongside DIDD services.
* Transition from education to adulthood and employment

\*Email from Ginger dated 4/4/18

In regard to the VR Counselor Training on ASD, I obtained the following information:

Almost all VR Counselors and Supervisors have recently completed on-line Training for ASD through the VR Development contract on-line training module.  The ASD course included the following:

Autism Spectrum Disorder and Employment

* Define and understand the range of Autism Spectrum Disorders (ASD)
* Demonstrate knowledge of common characteristics of ASD
* Establish accommodations to alleviate barriers to employment
* Develop plans to assess and assist those with ASD in obtaining and maintaining meaningful employment

The link to the training can be located in the following website:

<https://vrdevelopmentgroup.com/>

Since the website does not provide much information unless the training is purchased, I have provided a list of the Autism training topics (since I am currently in process of taking this training myself):

* Introduction – Autism Spectrum Disorder

  Definition

  Autistic Disorder

  Asperger’s Syndrome

  PDD-NOS

  Comorbidity

* What Causes ASD

  What Causes ASD?

  Occurrence

* Core Characteristics of ASD

  Core Characteristics of ASD

  Difficulties with Social Skills

  Communication

  Unusual Sensory Experiences

  Other Common ASD Experiences

* Top 10 Things Every Rehab Professional Should Know About Autism

  Top 10 Things Every Rehab Professional Should Know about Autism

1.       Autism and Neurotypicals, the Basic Differences

2.       Basic Supports

3.       Theory of Mind

4.       The Career Portfolio

5.       Possible Work Problems

6.       “Natural” Supports

7.       Social Coaching

8.       Courtesy Rules

9.       Sins of the System

10.   Social Stories

* Assessment

  Assessment

  Important information to gather during VR planning

  Choosing an Assessment

* Job Match

  Job Match

  Accommodations

  Technology

  Support

* Case Studies

  Case Studies

  Mark

  Peter

* Conclusion
* Quiz

Please let me know if you have any additional questions.

I also wanted to clarify my answer to your question during yesterday’s conference call regarding students with an IEP qualifying to receive VR services.  Students who receive Pre-Employment Transition Services (Pre-ETS) do not have to be VR Clients.  The Pre-ETS Students need to be age 14-22, have a documented disability, and be enrolled in school.  Students who meet these age and disability requirements and who have an acceptance letter to a college or university also meet Pre-ETS program criteria.

I will be working to obtain more information about the different Pre-ETS services offered through VR, in addition to the ones we provide at TRC Smyrna.