Date: Tuesday October 29, 2024

# Subject: TN Council on Autism Spectrum Disorder

Dear Members,

Please find attached a summary of the TN Council on Autism Spectrum Disorder meeting held on October 29, 2024, at the PEARL Room, 220 French Landing Drive, Nashville, TN 37243. The next meeting will be at 10:00 a.m. on January 28, 2025. An Outlook calendar invitation will be sent to your e-mail for the meeting, which is planned to be held in-person in Nashville. If you have any questions, please call me at 615-626-1579.

Sincerely,

Jenna Martin

DDA Director of Developmental Disability Services

Statewide Family Support Coordinator

Cc: TN Council of Autism Spectrum Disorder Council Members

 Brad Turner, DDA Commissioner

 Theresa Sloan, DDA Assistant Commissioner and General Counsel

 Seth Wilson, DDA Senior Associate Counsel

**CHAIRPERSON**

Sarah Harvey

**TYPE OF MEETING**

TN Council on Autism Spectrum Disorder

**MEMBERS PRESENT**

Cynthia Johnson, Tara Mohundro, Lana Woodward, Sarah Harvey, Elizabeth Ratliff, Lia Nichol, Robert Stoffle, Jennifer Holder, Kimberly Black, Tracy Verdun, Shiri Anderson *for Dept. of Commerce and Insurance*,Elizabeth Setty Reeve, Dr. Cooper Lloyd*,* Dirk Strider

**MEMBERS ABSENT**

Rick Fought, Jacqueline Johnson, Alison Gauld, Teresa Sipes

**QUORUM**

There was a quorum of members present for the TN Council on Autism Spectrum Disorder.

**STATE DEPARTMENT PARTICIPANT DESIGNEES PRESENT**
Dr. Timothy Cooper, Catherine Pippin

**DDA STAFF PRESENT**

Kimberlee Cantrell, Seth Wilson, Trey King, Babs Tierno, and Cooper McCormick

**GUESTS FROM PUBLIC**

Kyla Langford, Shannon Nehus, Carl Frizell, Janet Shouse, Michelle Bagby, Sam Long, Joey Ellis, Patricia Powell

**WELCOME/OPENING REMARKS/INTRODUCTIONS, Sarah Harvey**

TN Council on Autism Spectrum Disorder Chair, Sarah Harvey, called the meeting to order at 10:00 a.m. Central Time.

**PUBLIC INTRODUCTIONS/ROLL CALL, Sarah Harvey**

Sarah Harvey did a roll call of the Council Members and DDA Staff.

**APPROVAL OF MINUTES**

A motion was made to approve the minutes as written from the July 30, 2024, meeting. The motion was approved. There was no discussion and the motion passed, and the minutes were approved.

**CHAIR OF ADVOCACY & COMMUNICATION NOMINATION/ELECTION**

* Lana Woodward expressed interest in the Advocacy and Communications Chair position.
* Tara made a motion. The motion passed. Lana Woodward is now the Chair of the Advocacy and Communications Committee.
* There is a vacancy for the Council Vice Chair. Lana Woodward and Cynthia Johnson are both interested in the position.
* Elizabeth Setty Reeve stated that she would like to have representation from across the state.
* Tara asked Lana if it would be too much for her since she oversees the Advocacy and Community position.
* Elizabeth Setty Reeve made a motion to vote for Cynthia. Lia Nichol seconded. All in favor.

Additionally, Sarah Harvey noted that the Disability Coalition reached out to her about having a partnership for the Pat Edmiston award, which was previously passed by the Council at its last meeting. Those discussions will be ongoing about the proposal for that partnership.

**TN START ASSESSMENT & STABILIZATION TEAMS, PRESENTATION BY ASHTON HOOPER**

**TN START**

* 7 Teams across 7 regions Statewide
	+ Memphis, Jackson, Chattanooga, Nashville, Knoxville, Murfreesboro, Putnam (in development)
* 24/7 Crisis Response and Consultation
* Comprehensive assessment & stabilization planning
* Clinical education, consultation and training
* Formalized network building
* Systemic analysis, consultation and support
* Training and certification provided by <https://www.centerforstartservices.org/>
* For more info visit: <https://tn.gov/didd/ast>

**PHASES**

* Phase 1
	+ Accepting Referrals
	+ Building small caseloads (3-5)
	+ Eligible: Individuals 6 years of age or older currently enrolled in the following Medicaid waivers:
		- 1915c
		- ECF Choices
		- On call crisis response ONLY for individuals on TN START AST caseload
* Phase 2
	+ Accepting Referrals
	+ Gradual increase in caseloads (10-15)
	+ Eligible: Individuals 6 years of age or older currently enrolled in the **ALL** Medicaid waiver service
		- 1915c
		- ECF Choices
		- Katie Beckett
		- ICF
		- On call crisis response ONLY for individuals on TN START AST caseload
		- **Community training, including TN START AST Partners who are crisis responders**
* Phase 3
	+ Accepting Referrals
	+ Gradual increase in caseloads (20-30)
	+ Eligible: Individuals 6 years of age or older **currently enrolled** **or eligible for enrollment** in ALL Medicaid waiver service
		- 1915c
		- ECF Choices
		- Katie Beckett
		- ICF
		- On call crisis response ONLY for individuals on TN START AST caseload
		- **On call crisis consultation w/ TN START AST Partners for individuals with IDD**
* Phase 4
	+ Accepting Referrals
	+ Full caseloads
	+ Eligible: Individuals 6 years of age or older currently enrolled or eligible for enrollment in **ALL** Medicaid waiver service
		- 1915c
		- ECF Choices
		- Katie Beckett
		- ICF
		- On call crisis response for individuals on TN START AST caseload
		- On call crisis consultation w/ **ALL** emergency or crisis service providers for individuals with IDD
* Phase 5
	+ Accepting Referrals
	+ Full caseloads
	+ Eligible: Individuals 6 years of age or older **with a suspected or confirmed IDD diagnosis**
	+ On call crisis response for individuals on TN START AST caseload
	+ On call crisis consultation for ALL emergency or crisis service providers for individuals with IDD
* Most Common Crisis Contact Dispositions
	+ 76% Maintain Setting
	+ 7% ED (held over 24 hours)
	+ 5% ED (released)
	+ 3% Psychiatric Hospital Admission
	+ 9% All Other
* TN START Overview
	+ Statewide Coverage
	+ Crisis Stabilization
	+ 24/7 Crisis response/Consultation
	+ Comprehensive assessment
	+ Cross-System stabilization planning
	+ Clinical consultation, training, education
* Biopsychosocial Factors
	+ Biological
		- Medical problems
		- Pain
		- May be impaired mobility
		- Medical treatments, health care needs
		- Physically dependent on others
		- Common Biological Factors:
			* GERD/GI, Constipation, Diabetes, Seizures, Dental, Sleep, Infections, Sinus problems, Pain, Medication Side effects
	+ Psychological
		- Mental Health conditions
		- Communication
		- Cognitive & processing delays
		- Increase risk of exposure to trauma and increase risk of PTSD
		- Common Risk Factors:
			* Lack of coping
			* Skills/resiliency
			* Impaired communication abilities
			* Executive Function impairments
			* Anxiety, Depression, Trauma
	+ Social
		- Dependent on others
		- Decreased ability to protect self
		- Lack of control/choices of own life
		- Lack of sexual education
		- Common Risk Factors:
			* Loneliness/isolation
			* Lack of meaningful relationships
			* Traumatic experiences
			* History of rejection
			* Cultural/linguistic factors
			* Noise, temperature, space, changes in routines, lack of control/choice
* Current stats:
	+ 52 people activated over the last quarter
	+ 188 total people served actively at this time
	+ 90% diversion rate across the state of the past quarter
	+ 80% in person response to crisis calls
	+ Focus on building partnerships
	+ Very active in training CIT across the state
	+ Completing program certification through the National Center for Start Services
* TN START Community Events
	+ Who: Partners and Providers
	+ When: 4th Thursday at noon
	+ Where: In-Person
	+ Join the listserv via a TN START Training Request
* Navigating the IDD System
	+ Connecting to services and supports:
		- Employment and Community First CHOICES (ECF) waiver:
			* Intake Hotlines (\*Business Hours):
				+ East Region 1-888-531-9876
				+ Middle Region 1-800-654-4839
				+ West Region 1-866-372-5709
			* Self Referral Form also available online:

<https://tcreq.tn.gov/tmtrack/ecf/index.html>

* + - Behavioral Health Services
			* Contact insurance provider (back of card)
			* Ask for behavioral health team or nurse case manager to identify benefits available
* Contact Information:

Ashton Hooper, EdS, BCBA,

TN START Clinical Director

629-239-1282

Ashton.Hooper@tn.gov

Google TN START DDA to find us!!

<https://www.tn.gov/disability-and-aging/about-us/divisions/clinical-services/tn-start.html>

**Questions:**

* Cynthia asked how are the people trained? Ashton answered that they have a bachelor’s or master’s degree in the field. A lot of training is offered upon hiring. Mental health in the IDD population. They go through 19 weeks of training. There are team leads for each region. Looking to hire a team lead in Knoxville. Majority of the team leads are former coordinators.
* How do you train the police? Ashton answered a MHIDD partner with Nami and the mental health cooperative. Give a lot of diagnostic understanding. A lot of time coaching on how to respond in the moment. Police have been receptive and eager for the training.
* Ashton stated that MCOs do submit a number of referrals.
* Lia asked how long can they be in the program? Ashton stated that it is indefinite.

**COMMITTEE UPDATES**

**ADVOCACY & COMMUNICATION, SETH WILSON *IN ABSENSE OF COMMITTEE CHAIR***

* A number of goals were completed at the last Committee meeting and full Council meeting over the Summer, which was also the last meeting where Jolene Sharp was the Chair of the Committee. The Committee reached its goals of enacting bylaws and the Pat Edmiston award.
* At the moment, there is no Chair for this Committee and the focus of the Committee is open.
* Lana Woodward was voted in as the new Chair of this Committee earlier during this meeting.

**EDUCATION & EARLY INTERVENTION, ELIZABETH RATLIFF, COMMITTEE CHAIR**

* Elizabeth reported that the Committee spent most of the time talking about things going through the legislature. One is assault against employee act. The staff can file a felony charge against the child.
* Parental rights for retention from K-2nd grade. Cannot be retained in 3rd grade. Not an IEP it goes through the school.
* Paraprofessionals and how they are supervised and the things that they are working on and how to better train them. Especially behavioral models.
* Tara stated that she was at the Policy retreat. Does not have the percentages yet.
* Elizabeth Setty Reeve stated that we do not know the breakdown of disability vs no disability. It is a felony charge.
* Joey Ellis from TN STEPS stated that in the upcoming Session there may be amendments to the bill.

**HEALTHCARE COMMITTEE, TARA MOHUNDRO, COMMITTEE CHAIR**

* Tara stated that young adults who are in care facilities who are being discharged or sent away due to anger issues. The providers are no longer working with adults. Looking to see what can be done and recommendations we can make. In a fact-finding mission. Going to meet with Rick Fought soon since the Aging and Adulthood is looking into housing.
* Intent to discharge data-. Shannon at TennCare is a contact. Looking for trends for providers where they have not been able to support due to behavioral concerns. Need to better understand the scope of care. Request coming from the Council. Shannon-may want to reach out to Robert Marioni. Agency can discharge someone and can stay enrolled. May need to come from the MCO.

**AGING AND ADULTHOOD, SETH WILSON *IN ABSENSE OF COMMITTEE CHAIR***

* Lana and Rick will be attending the DDA housing workgroup moving forward as Michael Collins is no longer on this Council. Janet Shouse was also at the meeting. Overall, the group was looking at affordable housing. Jordan Allen and other members of DDA looking at partnerships for housing. DDA is implementing a Down Payment Assistance Program. Some funds have been allotted for persons supported in1915c waiver services. Put money down for down payment of the home where at least one person supported is on the lease. The maximum allowed to be charged for rent is the amount set by the federal government under HUD. Once DDA has more data from the implementation of the program, DDA can go back to general assembly with that data and seek an expansion of the program.
* Cynthia stated that Gloriana has a family model and working on getting it passed through the community.
* Janet Shouse discussed the Best Buddies program.

**EAST TN EMERGENCY EFFORTS IN RESPONSE TO HELENE**

* Joey Ellis with TN STEP on behalf of Karen Harris. Stephanie Willis was able to raise $7,000 within the first week of the devastation. Lifeline Inc. raised nearly $5,000 in partnership with TN STEP and delivering medical supplies.
* Catherine stated that TEIS outreach and services with telehealth and eligibility. Provide services through telehealth. Meeting the resources for the support.
* Dr. Lloyd stated that TennCare contributed funds from shared savings. Using for no interest loans for water and wastewater damage and help cleaning up debris from the area. TennCare is providing a lot of flexibility for those affected. Prior authorizations, fill limits for medications. Intake processes are being virtual or telehealth. Providers for the other side detailed in a memo.
* Elizabeth Reeve stated that counseling assistance grants. Immediate needs for up to 18 months.
* Kim Black-DDA worked with TEMA to make sure the need for drinking water was distributed. Providers put flexibility in place to expand the homebound service. Katie Beckett and Self Determination waiver and everyone to check on their status and their needs were covered. List kept of needs for people that need supplies outside of water, food, etc.
* Tim Cooper stated that there is a TN Strong home in the area and housing three people and DDA did a great job maintaining their safety. DCS checked on the youth and receiving education services. Provided support to employees who were affected.
* Dirk attended Coalition-In touch vulnerable population subgroup. Receiving updates. AEC-sent those to the shelters with experts. Shared community resources.
* Shiri stated that Governor Lee Executive Order 105. Emergency management community board provides training year around and like to bring the information forward. Consumer Protection standpoint-there will be a lot of cleanup. It is important that they check the status of their license to prevent fraud. Can verify at verify@tn.gov

**COUNCIL DISCUSSION OF STATUS OF PROJECT FOR RECOMMENDATIONS ON TRAININGS FOR EMERGENCY PERSONNEL BY SARAH HARVEY, COUNCIL CHAIR**

**What Was Learned**

* TDOH has oversight of EMT, AEMT and Paramedics
* Existing onboarding training related to persons with disabilities.
* Emergency personnel rely heavily on natural supports in the community to understand how best to support a PWD (Person with Disabilities).
* TDOH personnel can support the submission of training content for review and approval for CEUs.
* Tennessee is divided into eight regions, six of which include Director’s Associations and regional conferences.
* Professional associations that hold annual state and regional conferences in TN:
	+ [**TASA Member Services – Tennessee Ambulance Service Association**](https://tennesseeambulance.com/current-members/tasa-member-services/)
	+ [**Tennessee EMS Education Association (tnemsea.com)**](https://www.tnemsea.com/)

**Potential Opportunities**

* TDOH has identified gap between onboarding trainings related to PWD and ongoing trainings throughout employment.
* TDOH suggested resources that cover supporting PWD across the lifespan and specific to health emergencies (i.e. cardiac event).
* TDOH identified gap between trainings offered in metro versus rural areas.
* Recently passed legislation allocates funding for training stipends for those who successfully complete 40+ hours elective training.
* Offer CEUs to encourage participation due to obligations to fulfill annual professional licensing requirements.
* Connect TDOH with TNSTART and other resources in disability community.

**Police Education & Awareness Efforts**

**What Was Learned**

* 11 Police academies, extensive comprehensive training required that includes 24 hours of crisis intervention completed over 12 weeks.
* One academy, TLEA, has a course facilitated by a parent or individual with ASD.
* Non-mandated training is at discretion of each individual agency.
* Workforce capacity constraints make additional training requirements and participation in non-mandated opportunities challenging.

**Potential Opportunities**

* TDOH has identified gap between onboarding trainings related to PWD and ongoing trainings throughout employment.
* TDOH suggested resources that cover supporting PWD across the lifespan and specific to health emergencies (i.e. cardiac event).
* TDOH identified gap between trainings offered in metro versus rural areas.
* Recently passed legislation allocates funding for training stipends for those who successfully complete 40+ hours elective training.
* Offer CEUs to encourage participation due to obligations to fulfill annual professional licensing requirements.
* Connect TDOH with TNSTART and other resources in disability community.

**911 Education & Awareness Efforts**

**What Was Learned**

* 911 provides elective Autism specific trainings.
* 33% of all 911 communicators statewide have elected to take the course “Autism Awareness for 911 Telecommunicators.” This training is conducted via virtual academy.

**Potential Opportunities**

* Training materials are available to review and provide feedback on.

**Fire Education & Awareness Efforts**

**What was Learned**

* Fire Departments have two avenues of training.
* Skill based trainings to execute firefighting and prevention.
* Medical support to fill gaps & provide capacity relief to area medical emergency resources.
* Emergency Medical Responder, Emergency Medical Technician and Paramedic trainings are conducted through EMS which falls under TDOH.

**Potential Opportunities**

* See EMS slide as the representative at the meeting felt these trainings (the medical support ones) were more suited for ASD awareness and education.

First Responder Education & Awareness Efforts SFY2024-2025

Next Steps

* Identify interested members and committee to lead efforts to include:
	+ Coordinate training/resource research
	+ Lead communication with contacts
		- Perform additional outreach with other first responder organizations (i.e. TN Sheriff Association)
	+ Develop timeline for recommendations and potential rollout.
	+ Ensure necessary steps are taken to formalize recommendations and support rollout
	+ Quantify & provide updates on ongoing efforts
		- Callout barriers, risks, opportunities

**Discussion**

* State Park offices are participating in CIT training.
* Cynthia stated that this project may need to be its own committee. Would like to also get into the court systems such as the bailiffs.
* Tara 1/3 of the state doesn’t have to follow them because they are exempt because of their size.
* Robert stated to be careful about overloading firemen, police, bailiffs, etc. AMR are building an online training program. Been working with the state park rangers. Get a working group across the state.
* Sarah asked if there any reason to have a separate working group that would bring in members of the community?
* Seth stated no reason why that could not happen as many committees having public participation.
* Sarah asked if it is okay to have it in a separate work group or add to an existing workgroup?
* Seth stated that it would be up to the Council members on how it comes together.
* Sarah asked if the group would you like a separate work group?
* Kim Black stated that the Advocacy and Community workgroup would be good because they don’t have any tasks to complete.
* Sarah mentioned that it could consume a workgroup.
* Motion made by Elizabeth. Jennifer Seconded. Motion passed to add this project to the Advocacy and Community Committee.
* Janet asked where and who will be doing the training? Under DDA, Commerce and Insurance, etc.?
* Sarah was not sure as training doesn’t exist. Finding out what works best for them.
* Robert stated three different jobs and it is one size fits all. The problem is of all the different ambulance services.
* Tara stated that we need to be careful on what type of training we recommend. If we can make a list of what we recommend and put a government stamp on it? Then they will follow it.

**2025 COUNCIL REPORT DECISION**

* Seth began by stated that the report is not required by law or any other authority. However, under the bylaws a vote needs to be taken by the Council whether or not it wants to create a report for that year. Any draft which is going to be voted on by the Council has to be circulated 24 hours before it is presented to the Council for a vote.
* Sarah stated that she is strong supporter of having a report. First, we just received an approval for funding for mileage reimbursement. Second, we need to show on paper on what is taking place. Being able to share the information back to what is meaningful. People with autism deserve to know about their history of their rights.
* Seth stated that it would be in conjunction with DDA communications which has helped with the reports in the past. Cooper McCormick would be a good contact to help with the reports. However, DDA communications will help with formatting, etc. They are not going to draft the report. That is for the Council to do.
* Sarah asked if there is anything negative that suggest that this is not a great idea? Are we opening ourselves up for criticism?
* Jennifer asked when does it need to be completed by?
* Seth stated that it is the discretion of the Council.
* Cooper stated that we could turn it around pretty quick. Planning and Policy Councils are required to do annual reports and we are collecting information from them now. Like to have the final document by January.
* Seth stated another factor to consider if wanting a paper copy in addition to a digital copy is that there is a process for getting things printed at the State which takes some time.
* Sarah asked if we want a report?
* Motion to do a report by Cynthia. Jennifer seconded. Motion passed. Elizabeth Ratliff and Jennifer Holder volunteered to help.
* Sarah stated that she would like to have it by March for Disability Day on the Hill.
* Kim asked if it could be sent out in committees will work on it together?
* Seth stated that the next meeting is not until a week or two before the meeting. If really want to have it all approved and ready to go by March, then would need to have draft sent out prior to those January meetings.
* Sarah stated that she would like to have it started by Thanksgiving. Jennifer volunteered to help.

**PUBLIC COMMENT**

* Karley Fazao-invited by Janet. Self-advocate. Written peer review medical articles. Very appreciative to be here and see the work that is being done.
* Colleen asked what work is the committee doing on the standardization for treatment hours for ADA therapy?
* Sarah stated that she cannot speak to the past as the Department of Health handles all of that and we do contribute to the different departments and would be willing to if they made the ask.
* Colleen stated that there is a 13-20 age gap. Would like to see the resources.
* Janet stated that private equity has gotten into the ADA business.
* Seth reminded the Council members to fill out the travel reimbursement form. If not have gotten refund back from last time email Seth, Kim, or Jenna.

**ADJOURNMENT/NEXT MEETING DATE**

The date of the next meeting will be Tuesday January 28, 2025, 10:00 a.m. – 1:00 p.m. Central Time. The Council will meet in-person at the TN Dept. of Labor and Workforce Development, PEARL Room, 220 French Landing Drive, Floor 1B, Nashville, TN 37243. An Outlook meeting invitation will be sent to Council members. This information will additionally be provided in the Public Meeting Notice for the January 28, 2025, meeting.

Respectfully submitted,

Jenna Martin, DDA Director of Developmental Disability Services

Liaison to the TN Council on Autism Spectrum Disorder

DDA Office of General Counsel