**Tuesday July 30, 2024** - Meeting Minutes

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| CHAIRPERSON | Michael Collins |
| TYPE OF MEETING | TN Council on Autism Spectrum Disorder  |
| MEMBERS PRESENT | Cynthia Johnson, Rick Fought, Tara Mohundro, Lana Woodward, Sarah Harvey, Elizabeth Ratliff, Michael Collins, Jacqueline Johnson, Alison Gauld, Tracy Verdun, Shiri Anderson *for Dept. of Commerce and Insurance*,Elizabeth Setty Reeve, Dr. Cooper Lloyd*,* Theresa Sipes, Catherine Pippin, Dirk Strider |
| MEMBERS ABSENT | Toby Compton, William “Will” Edwards, Kimberly Black, Dr. Timothy Cooper |
| QUORUM | There was a quorum of members present for the TN Council on Autism Spectrum Disorder.  |
| STATE DEPARTMENT PARTICIPANT DESIGNEES PRESENT |  |
| DDA STAFF PRESENT | Kimberlee Cantrell, Jenna Martin, Seth Wilson, and Cooper McCormick |
| GUESTS FROM PUBLIC | Anita Teague, Janet Shouse, Michelle Bagby, Jessica Moore, Sam Long, Susan Rollison, Stephanie Clease, Tyler Moore, Robin Wilmoth |

# WELCOME/OPENING REMARKS/INTRODUCTIONS

# MICHAEL COLLINS, CHAIR

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

**PUBLIC INTRODUCTIONS/ROLL CALL**

MICHAEL COLLINS, CHAIR

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| Council members introduced themselves, then members of the public introduced themselves. |

**APPROVAL OF MINUTES**

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

DDA/TRIAD Partnership Update

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| * Jeremy Norden-Paul presented Strengthening Services for Autistic People and Others with Neurodivergent Support Needs
* [TRIAD Partnership Update for Autism Council 7.30.2024.pptx (sharepoint.com)](https://tennessee.sharepoint.com/%3Ap%3A/r/sites/DIDD_LS/DDS/AutismCouncil/_layouts/15/Doc.aspx?sourcedoc=%7B8A8F57A6-2CBF-406D-9A05-0D74A8D9E5AF%7D&file=TRIAD%20Partnership%20Update%20for%20Autism%20Council%207.30.2024.pptx&action=edit&mobileredirect=true)
* **Background:**
	+ The identification and diagnosis of Autism Spectrum Disorder (ASD) continues to increase significantly, especially among children.
	+ According to the Centers for Disease Control and Prevention (CDC), 1 in 36 children in Tennessee (2.8%) are estimated to have ASD. Additionally, ASD rates are 1.3 to 1.5 times higher among Hispanic and Black children.
	+ There is an urgent and ongoing need to ensure autistic people and others with neurodivergent support needs have access to a robust, well-trained network of community providers.
	+ DDA intends to leverage the experience and expertise already available across its statewide provider network, as well as provide enhanced training and support opportunities to ensure the provision of the best, most person-centered, most cost-effective care and support possible.
* **Year 1 Progress**
	+ **Community-Informed Evaluation:** A review of Tennessee’s system of services and supports for autistic people and others with neurodivergent support needs across the lifespan, with the objective of identifying gaps, challenges, and opportunities for innovation.
	+ **Interagency Coordination:** Discussions with other state agencies to strengthen interagency coordination.
	+ **Enabling Technology:** Identification and evaluation of Enabling Technology tools that can help people increase their safety, independence, self-determination, and overall quality of life.
	+ **Quality Improvement Framework-**Create a quality improvement framework that will serve as the foundation for the multi-tiered, competency-based training and certification program for community providers.
* **Year 2 Review**
	+ Training Outline
	+ Enabling Technology Evaluation (continued)
	+ Pilot Evaluation Methodology
	+ Multi-Tiered, Competency-Based Training/Certification Program
	+ Plan for Pilot Implementation and Large-Scale Expansion
	+ Guidance and Recommendations for Continued Investments

 **Contact information:**Jeremy Norden-Paul Holly Gover, Ph.D., BCBA-D, LBA Director of Program Innovation Assistant Professor in Pediatrics, Tennessee Department of Disability and Aging (DDA) Associate Director of Behavioral Outcomes Jeremy.Norden-Paul@tn.gov TRIAD-The Autism Institute at Vanderbilt Kennedy Center (VKC) Holly.Gover@vumc.org * Questions:
	+ Rick asked with the competency-based program are they are going to have it accredited?
		- It makes sense to have something accredited. A direction we want to go. We have not decided on that yet.
	+ Janet Shouse- Will there be additional compensation with the training?
		- Hopes that there will be a value-based payment insensitive to the provider. If someone has greater training, then there should be a way to pay for it. Will all the members of the provider Medicaid waiver go through the training? Will they understand the issues involved? Yes, that is the hope. Multitiered training program. Level of training for case managers called the Navigator and also training for supervisors. Tech training in order for real change to happen. It cannot be all the DSPs and nobody else. It has to be across the board. I hope so and think so and we will answer the question this year.
	+ Will there be additional compensation? Yes, ideally everyone that is providing services should be on the same page as training. Probably be looking at residential providers to start.
	+ Rick stated that they are looking for opportunities and reason for the health providers such as dentists, doctors, nurses, etc. May want to look into it. Mentions interprofessional education and it will get their attention. Give them a reason to work together and it would get some traction.
	+ Jeremy stated that model of integrated care and it is a profound concept.
	+ Sarah Harvey started using NCI and NCAD for quality-of-life determination. Already utilizing it as a quality-of-life survey. Great suggestion and have not connected those dots.
	+ Tara asked if they are planning on partnering with Department of Education so they can receive this training? Yes, we have been discussing it and coordinating efforts. Part of the long term vision but it may be in the second phase.
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Autism Assessment in University and Outpatient Settings: Barriers to Care and Future Directions in TN

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| * Rebecca J. Tipton DeClue, Ph.D. presented.
* [Autism Assessment in University and Outpatient Settings\_ Barriers to Care and Future Directions in TN (1).pptx (sharepoint.com)](https://tennessee.sharepoint.com/%3Ap%3A/r/sites/DIDD_LS/DDS/AutismCouncil/_layouts/15/Doc.aspx?sourcedoc=%7B322B3A3A-FEEF-4F8C-B6DA-8973F7B9CBD8%7D&file=Autism%20Assessment%20in%20University%20and%20Outpatient%20Settings_%20Barriers%20to%20Care%20and%20Future%20Directions%20in%20TN%20(1).pptx&action=edit&mobileredirect=true)
* **Autism Care Pathway**
	+ Initial Screening
		- Conduct initial screening or refer for screening by:
			1. Pediatrician or other medical provider
			2. School
			3. Parent
			4. Other Community Providers
	+ Suspected ASD
		- Referral for assessment to:
			1. School (for academic and related services through an IEP)
			2. Psychologist, Neurologist, or other assessment specialist (for services outside of school)
	+ Confirmation of Diagnosis
		- Completion of comprehensive assessment for diagnosis
			1. Assessment procedures that assess multiple domains of functioning and behavior with inclusion of parent and caregivers as partners
	+ Connection to collaborative, multi-specialty care which can include:
		- ABA therapy
		- Psychotherapy
		- Occupational therapy
		- Speech therapy
		- Primary care provider team
		- School team
		- Home-based resources
		- Vocational programming
	+ Continued evaluation of service needs and treatment planning with care team.
* **Best Practice Goals for Diagnostic Evaluation**
	+ Affordable Access to Care
		- Ability to use insurance and/or Medicaid for evaluation to ensure ethical and equitable access to care.
	+ Expeditious Evaluation
		- National Institute for Health and Care Excellence guideline: <13 weeks
	+ Appropriate Assessment Procedures
		- Assessment procedures that assessment multiple domains of functioning and behavior with inclusion of parent and caregivers as partners
		- There are many tools to assess ASD in young children, **but no single tool should be used as the basis for diagnosis.**
* **Tennessee Autism and Developmental Disabilities Monitoring Network (TN-ADDM) 2020 Update**
	+ Black children were 1.5 times as likely to be identified with ASD by age 4-years as White children.
	+ Children who were in the 4-year-old sample in 220 were twice as likely to receive an ASD diagnosis by age 4 compared to the 8-year-old cohort, indicating an improvement in early identification.
* **TN-ADDM 2020 Takeaways**
	+ The number of 8-year-old children identified with ASD in the area covered by TN-ADDM increased from 2.3% (1in 44) in 2018 to 2.8% (1 in 36) in 2020.
	+ 44% of 8-year-old children and 67% of 4-year-old children identified with ASD received a comprehensive developmental evaluation by age 3 years.
	+ Although an increasing number of children with ASD in Tennessee are initially evaluated prior to 3 years of age, many children are still diagnosed at later ages (median age of diagnosis was 48 months of age among 8-year-old children with ASD).
	+ In Tennessee, Black and Hispanic children were more likely to be identified with ASD by age 4 years than were White children.
* **Updates in TN Autism Testing, Summer 2024**
* **Identifying Barriers in Diagnostic Assessment in TN**
	+ How many providers offer assessment for autism in TN?
	+ How many of these providers accept insurance and/or Medicaid for assessment?
	+ What is the timeline for the diagnostic process and how do timelines differ between types of providers?
	+ What are the differences in assessments conducted?
	+ How do diagnostic approaches compare to best practice recommendations?
* **Methodology**
	+ Used various search methods (Google, TN disabilities pathfinder, Autism TN, psychologytoday.com) to create a list of providers that advertise diagnostic assessment.
	+ Called each provider to collect the following information:
		- Confirm diagnostic testing is offered.
		- Timeline for testing process estimates
		- Which insurance companies, if any, are accepted?
		- Age ranges for testing.
		- What type of provider conducts the assessment?
* **Providers Who Accept Insurance (n=41)**
	+ 13 providers accept some form of insurance, but 2 accepted only BCBS.
		- 6 large behavioral health centers
		- 1 academic center
		- 2 medical groups
		- 2 national, online-only programs
		- 2 single providers in private practice
* **Providers Who Accept Medicaid (n=41)**
	+ 5 providers accept some form of Medicaid.
		- 3 large behavioral health centers
		- 1 academic center
		- 1 medical group
* **Providers Accepting Insurance vs Self-Pay**
	+ Average timeline for testing for providers who accept insurance is significantly longer than providers who do not accept insurance.
* **Providers Completing Full Assessments, Insurance vs. Self-Pay**
	+ 9 providers did not provide a comprehensive assessment.
	+ The testing timeline becomes even more significantly different for providers completing full evaluations with insurance.
* **Considerations and Recommendations**
* **Best Practice Goals for Diagnostic Evaluation**
	+ Affordable Access to Care
		- Ability to use insurance and/or Medicaid services for evaluation.
	+ Expeditious Evaluation
		- National Institute for Health and Care Excellence guideline: <13 weeks
	+ Appropriate Assessment Procedures
		- Assessment procedures that assess multiple domains of functioning and behavior with inclusion of parent and caregivers as partners.
		- There are many tools to assess ASD in young children, **but no single tool should be used as a basis for diagnosis.**
* **Why do providers prefer self-pay only?**
	+ Wall Street Journal, 2021
		- Reimbursement rates from insurance are significantly lower than self-pay rates.
		- Paperwork and claims submission time.
		- Audit for notes and billing.
	+ Psychology Today, 2019
		- Reimbursement rates yield significant salary differences ($50,000 annually vs. $165,000 annually for therapists seeing 20 clients weekly).
* **Medicaid Reimbursement in TN**
	+ Nationwide, reimbursement for mental health services by Medicaid is estimated to be 30% lower than commercial insurance and Medicare on average.
	+ State-to-state, there are variability in rates for each service code.
	+ Recent study by Zhu et al. (2023) excluded TN from their analysis of service code reimbursement due to TN being the only state that does not publish a fee schedule.
* **Future Directions**
	+ Develop guidelines to define appropriate autism evaluation procedures.
	+ Improve transparency regarding Medicaid fee schedule.
	+ Close discrepancy between Medicaid, Medicare, and commercial insurance reimbursement rates for service.
	+ Incentivize practitioners for use of insurance and/or Medicaid.
		- Other states are using community mental healthcare programs as an avenue to provide evaluations for individuals with Medicaid and commercial insurance while providing an appropriate salary for providers.
	+ Alternative assessment pathways
		- Vanderbilt’s grant program & TRIAD Research Programs.
* **Questions:**
	+ What is the average cost of an assessment?
		- Self-pay $2,000-$3,000 on average. With insurance it can vary.
* Do you have a list of providers that we can share?
	+ - Yes.
* Anita thank you for the data. It is eye opening.
* Dirk asked why Asians weren’t included in the study.
	+ It was not a data set from me. May have been less significant of a discrepancy.
* Janet asked Dr. Lloyd if according to state law TennCare is supposed to have five providers accept Medicaid. How does it work with network advocacy?
	+ Dr. Lloyd stated that they have teams that work in advocacy. Cannot confirm that five is the number just the number in the study. Dr. Lloyd stated that she does not know but will find out.
	+ Janet asked if the Council can we get those numbers? Dr. Lloyd stated that she will do her best.
* Tara asked do you have the numbers on how many children might be under TEIS or the school system or are parents being told they can still receive some services before diagnosis?
	+ Don’t have the data yet. Focus was on the outpatient setting.
	+ Trying to use the data that we have to help cut down wait times.
* Stephanie Clease commented that she believed the reimbursement rate to be terrible and a lot of billing work. It is harder to stay afloat in private practice by taking kids with Medicaid. Reimbursement needs to be there.
	+ Dr. Lloyd stated that Tennessee is one of some states that only does manage care. Zero fee for service. Many other states have a fee for service plus managed care. The state Medicaid would set the fee for clinical services. Don’t find a fee schedule is because TennCare and the state are not setting the fees. The managed care is setting the fees. Would contact one of the three MCOs and find out the rate.
* Anita stated that TRIAD is providing more virtual assessments for those under age 3.
* Medical providers have multiple billing codes for one visit that they can use whereas phycologist can only use one intake code.
* Alison stated that the Department of Education understands the complexity of evaluation. In 2017 the evaluation requirement did shift and eliminated the requirement of outside diagnosis of autism. School aged children have the opportunity to receive an evaluation inside the school even if they want an outside evaluation.
* Janet asked Alison Gauld if the individual gets an educational diagnosis does it work for SSI Medicaid waiver?
	+ Alison stated that it may or may not apply with what the parents share with the school.
	+ Alison also stated that they need to see the IEP. Not a simple yes or no. There are options that the school can support the family in those situations.
* **Contact information:**

Rebecca DeClue, PhD, NCSP, HSP Ryan Coleman, PhD, NCSPPsychologist, Heritage Medical Associates Assistant Professor of Pediatrics1622 Westgate Cir. Vanderbilt University Medical CenterBrentwood, TN 37027 ryan.coleman@vumc.org rtiptondeclue@gmail.com  |
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**COMMITTEE BREAKOUTS/UPDATES**

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| **ADVOCACY AND COMMUNICATION****presented by Michael Collins*** Jolene Sharp has rolled off the Council. Therefore, there is now an open position for Chair of the Advocacy and Communication Committee. If you are interested, please put your name forward for vote at the next Council meeting.
* Bylaws-comes from a motion from the Advocacy and Communications Committee. Official motion from the Advocacy and Communication Committee to enact the Bylaws as written in the draft provided to each Council member prior to the meeting (draft titled “Council on ASD Bylaws-Final Draft for Council Vote 7-25-24”). Cynthia seconds. Vote taken. All members approved the bylaws (as drafted) to be enacted. None opposed. The Council on Autism Spectrum Disorder Bylaws are now officially enacted.
* Pat Edmiston and Advocacy Award-comes as a motion.
	+ Establish an award for advocacy. She did a lot of the work to get the Council running.
	+ Should it be Pat or Patricia? Edited to Patricia Edmiston Leadership and Advocacy Award.
	+ Comes from the Advocacy and Communication Committee as a motion to approve the award and to enact the form provided to each Council member prior to the meeting (draft titled “Pat Edmiston advocacy award nomination form”) with the revision of using “Patricia” instead of “Pat.” Rick seconded. Vote taken. All members approved. None opposed.
* Mileage legislation has passed in the General Assembly in the 2024 Sessions. Official as of July 1, 2024. It does apply to Middle Tennessee members. Accordingly, Council members may now submit reimbursement for mileage to attend the quarterly meeting, starting with this current meeting.

**EDUCATION AND EARLY INTERVENTION****ELIZABETH RATLIFF, COMMITTEE CHAIR** * White paper has little to no data on informal dismissals. Root causes being lack of special education teachers. Lack of recourses to the schools. High turnover.
	+ [2024 Special Education White Paper (tndisability.org)](https://www.tndisability.org/2024-special-education-white-paper)
* Committee discussed providing better supports for parents in the IEP process from elementary to high school. Discussion moved to focus on self-advocacy.
* Committee discussed how to support teaching staff-equip and regulate and monitor LEAs in school systems and the question of accountability across the state.
* Committee also discussed school-based behavioral health liaisons.

**HEALTHCARE COMMITTEE****TARA MOHUNDRO, COMMITTEE CHAIR*** Committee discussed a provider shortage in adult setting for those in independent living situations. Tara stated that agencies are trying to get rid of more difficult individuals. She believes the issue is a lack of funding, personnel, etc. Committee came up with a list of questions and provide them to the agencies.

**AGING AND ADULTHOOD****RICK FOUGHT, COMMITTEE CHAIR*** Rick is now attending the Housing Workgroup with DDA and TNCO which is discussing capacity issue and equable housing prices. Rick then read from his notes from attending the meeting:
* Housing pricing is outpacing the increases in SSI income.
* Considering congregate housing opportunities and looking at Medicaid’s home and community-based settings rule.
* What is and not permissible under ADA Title 2 regulations.
* Alternative approaches such as Bright Stone and Our Place Nashville.
* Trying to pull in the credit unions to have programs that would give property owners to achieve favorable lending rates.
* Kentucky was able to amend their homestead plan to give preferential status for ppl with IDD for section 8 vouchers. Led to more affordable rent. Would like to find a good contact so Tennessee can amend their homestead plan and do something similar to Kentucky.
* Facilitate building homes on land to purchase houses at or below market value. It would be like a down payment assistance grant. Concerns are regarding maintenance and repair and is often not factored in. Suggestions to create reserve funds to handle maintenance and repairs. Funds could come from Clover Bottom, etc. Habitat for Humanity may collaborate.
* Meeting of the Housing Workgroup for July was cancelled. Will follow up next month.
* Rick stated he would like to see somebody speak to the Council regarding Jillian’s Law and add to the agenda for the next meeting. Alison Gauld stated to reach out to the authors of the bills and to share his story with them. Stories are what create and change bills.
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| **PUBLIC COMMENT** |
| * Changes on the Council-Jolene has stepped down from the Council. New appointee will be Dirk Strider. Michael Collins, Roddy Coe, and William Edwards are rolling off the Council. New Chair effective August 1st is Sarah Harvey. Vice Chair position is open. Council members who are interested should step forward and at the next quarterly meeting the Council would vote for both the Vice Chair position and the Chair of the Advocacy and Communication Committee.
* Leah Nichols, Robert Stoffel, Jennifer Holder are new Council members effective Aug. 1.
* Vice-Chair-Vacancy for the Advocacy/Communications Committee-interested in being chair that is a separate role.
* The three new council members from East can volunteer to be the chair of the Advocacy/Community Committee
* Dirk handed out a card with a QR code on it that leads to a survey. Dirk states that anyone with disability, family of someone with a disability or provider can take the survey. Do not need a formal diagnosis to take the survey. Handed out a survey.
* Janet brought up an issue of whether under the1915c waiver if an individual damages property whether they have to pay restitution. If a person isn’t doing this, it on purpose then they may not be held responsible. The human rights committee has to make a determination. Is there a similar process in ECF CHOICES?
	+ Michael asked if it was owned by the provider agency or a third party? Janet does not know.
	+ Janet states the policy for 1915c waiver they don’t have to be held responsible. Michael wasn’t sure if it is a requirement. Michael stated that we need to find out through ECF CHOICES what the rule is.
* Anita noted that the DDA statewide Planning and Policy Council has an integration workgroup that meets virtually the first Monday of the month. 2:00 pm CST. Looking at how to continue to integrate the system effectively.
* Stephanie Clease- asked if a packet for resources was available? Stated she thought it would be helpful for families. Family navigators can be helpful for new families. These two things could be helpful. Pathfinder is helpful but you have to know what you are looking for and not sure if it covers everything.
* Alison-are you suggesting that Pathfinder have a clear starting point? The Pathfinder app is not as comprehensive for autism. Autism Tennessee has been a great resource.
* BNA launched their sunflower program. Partnered with them that is on their disability page. [Welcome to the Nashville International Airport (flynashville.com)](https://flynashville.com/)
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| ADJOURNMENT/NEXT MEETING DATE |
| The date of the next meeting will be Tuesday October 29, 2024, 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 10/29/24, meeting.  |

Respectfully submitted,

Seth Wilson, DDA Senior Associate Counsel

DDA Office of General Counsel