

Sunset Public Hearing Questions for  
**Tennessee Council on Autism Spectrum Disorder**  
Created by Section 4-3-2711, *Tennessee Code Annotated*  
(Sunset termination June 2019)

1. Please provide a brief overview of the Tennessee Council on Autism Spectrum Disorder, including information about the council's creation, statutory duties, administrative attachment, and staff.

The Tennessee Council on Autism Spectrum Disorder was created by Representative Williams HB384 and Senator Overbey SB199 and signed into law by Governor Haslam on April 5<sup>th</sup>, 2017. (A copy of the Bill and summary addition is attached.) The Council is under the administration of the Tennessee Department of Intellectual and Developmental Disabilities (DIDD). Patricia Edmiston, DIDD's Director of Developmental Disability Services, is the DIDD staff liaison to the Council.

The purpose of this Council is to establish a comprehensive statewide long-term plan for a system of care for individuals with autism spectrum disorder and their families. The Council shall make recommendations and provide leadership in program development regarding matters concerning all levels of autism spectrum disorder services, including, but not limited to, health care, education, and other adult, adolescent, and children's services.

2. Provide a list of council members and describe how membership complies with *Section 4-3-2711, Tennessee Code Annotated*. Are there any vacancies on the council? If yes, what is being done to fill those vacancies?

There are 18 members of the Tennessee Council on Autism Spectrum Disorder; each member was nominated from a Tennessee not-for-profit organization that provides supports and services to individuals with autism and their families.

There are no vacancies on the Council at this time. The current Council members:

***Governor Haslam's appointments for individuals on the autism spectrum  
or their family members:***

**West TN Region: (term July 2017 – June 2019)**

Jeness Roth (family member): Memphis, Son is 32

Iseashia Thomas (family member): Memphis, Daughter is 6 and brother is 30

Mary Ellen Chase (family member): Memphis, Son is 31

**Middle TN Region: (term July 2017 – June 2020)**

Quentin Humberd, M.D. (family member and veteran) \* Council CHAIR: Cunningham, Nephew is 34

Beth Malow, M.D. (family member): Nashville, Sons are 20 and 17

Emelyne Bingham (self-advocate): Nashville

**East TN Region: (term July 2017 – June 2021)**

William “Will” Edwards (family member): Knoxville, Son is 5

Michael Collins (family member): Kodak, Son is 16

Roddey Coe (family member and veteran): Ooltewah, Son is 12

*State of Tennessee Department designees:*

**Department of Intellectual and Developmental Disabilities:**

Jeanine Miller, Ph.D., SPE-HSP, Director of Policy, Division of Policy and Innovation

**Department of Health:**

Carolina Clark, MD, MPH, Child Health Medical Consultant

**Department of Education:**

Alison Gauld, Behavior and Low Incidence Disabilities Coordinator, Division of Special Population and Student Support

**Department of Human Services:**

Ginger Day, Autism Spectrum Coordinator for the Tennessee Rehabilitation Center in Smyrna

**Department of Commerce and Insurance:**

Lorrie Brouse, Deputy Commissioner

**Department of Mental Health and Substance Abuse Services:**

Matt Yancey, Assistant Commissioner

**Division of TennCare:**

Vaughn Frigon, MD, Medical Director

**Tennessee Council on Developmental Disabilities:**

Wanda Willis, Executive Director

**Tennessee Commission on Children and Youth:**

Rose Naccarato, KIDS COUNT and Resource Mapping Director (family member)

3. How many times did the council meet in the last two fiscal years? How many members were present at each meeting?

The Council has been in existence since April 5, 2017 and has met five times:

October 4<sup>th</sup>, 2017: Members present: 18 out of 18

January 23, 2018: Members present: 18 out of 18

April 24<sup>th</sup>, 2018: Members present: 16 out of 18

July 24<sup>th</sup>, 2018: Members present: 16 out of 18

October 30<sup>th</sup>, 2018: Members present: 15 out of 18

4. What per diem or travel reimbursement do council members receive? How much was paid to council members in the last two fiscal years?

Per T.C.A. 4-3-2711(g), Council members do not receive a per diem or travel reimbursement for serving on the Council.

5. What were the council's revenues and expenditures for the last two fiscal years?

The Council has had no expenditures or revenue for the last two fiscal years.

6. Is the council subject to Sunshine law requirements (Section 8-44-101 et seq., *Tennessee Code Annotated*) for public notice of meetings, prompt and full recording of minutes, and public access to minutes?

Yes.

7. What policies does the council have in place to address potential conflicts of interest by council members, staff, and employees?

Each Council member is required to sign the DIDD Conflict of Interest and Confidentiality Statement for Committees and Councils.

8. What were the major accomplishments of the council during the last two fiscal years? Specifically, what steps has the council taken to address the responsibilities outlined in *Section 4-3-2711(h)(1) through (7), Tennessee Code Annotated*.

The Council has been in existence since April 5, 2017. During this time all required members were appointed to the Council as outlined in #2 above. The council has held four meetings and has established four working committees each to address an identified issue or need facing individuals with Autism Spectrum Disorder and their families.

The Council members worked with the DIDD Director of Communications to develop a webpage, attached to the Department of Intellectual and Developmental Disabilities website, for the Tennessee Council on Autism Spectrum Disorder. This webpage provides statewide resources for individuals with Autism Spectrum Disorder and their families.

9. What reports does the council prepare on its operations, activities, and accomplishments, and who receives those reports? If available, please attach copies of recent reports.

The Council is not required by statute to prepare a report. However, all agendas and meeting minutes are posted on the Tennessee Council on Autism Spectrum Disorder webpage attached to the Department of Intellectual and Developmental Disabilities website.

10. Does the council have the authority to promulgate rules and regulations? If rules and regulations have been promulgated, please cite the reference.

The Council does not have the authority to promulgated rules and regulations.

11. Describe any items related to the council that require legislative attention and your proposed legislative changes.

There have been no identified items related to the Council that require legislative attention and/or proposed legislative changes at this time.

12. Should the council be continued? To what extent and in what ways would the absence of the council endanger the public health, safety or welfare of Tennessee citizens?

Yes, the Council should be continued. The creation of this council has been long desired by people with autism spectrum disorder and their families, as well as advocacy groups across the State. The Council provides a voice for persons with Autism Spectrum Disorder and their families and per the legislative mandate creates an avenue to make recommendations regarding matters concerning all levels of autism spectrum disorder services, including, but not limited to, health care, education, and other adult, adolescent, and children's services.



DEPARTMENT OF  
INTELLECTUAL AND  
DEVELOPMENTAL DISABILITIES

**CONFLICT OF INTEREST AND CONFIDENTIALITY STATEMENT FOR COMMITTEES AND COUNCILS**

Membership on a committee/council overseen by the State of Tennessee Department of Intellectual and Developmental Disabilities (DIDD) is a position of public trust, and it is the expectation that conflicts of interest be avoided to ensure this trust is not compromised. As such, every member must refrain from participating in any activity, either in a private or official capacity, where a conflict of interest may exist, including associations or interests that could affect the member's ability to perform his or her responsibilities to the committee/council.

Conflict of interest refers to instances in which a committee/council member is in a position of trust and gives, or is in the position to give, preferential treatment to someone and/or attempts to influence public decisions in exchange for personal gain and in a manner which actually or potentially compromises the public interest. A conflict of interest may be direct or indirect and include, but not be limited to, bribery, embezzlement, extortion, and family relationship.

- a. **Bribery** refers to when a person offers, confers, or agrees to confer any pecuniary benefit upon a committee/council member with the intent to influence the member's vote, opinion, judgement, exercise of discretion, or other action in the member's official capacity. Bribery also refers to when a committee/council member solicits, accepts, or agrees to accept any pecuniary benefit upon agreement or understanding that the member's vote, opinion, judgement, exercise of discretion, or other action as a committee/council member will thereby be influenced.
- b. **Embezzlement** refers to when a person, with the requisite intent to deprive, takes or obtains property or merely exercises control over the property without the owner's consent.
- c. **Extortion** refers to when a person uses coercion upon another person with the intent to obtain property, services, any advantage or immunity; unlawfully restrict another's freedom of action; or in an effort to obtain something of value for any entity, impair the entity from the free exercise or enjoyment of any right or privilege secured by the United States Constitution, Constitution of Tennessee, or the laws of the state.
- d. **Family relationship** refers to the committee/council member's mother, father, grandmother, grandfather, sister, brother, son, daughter, or spouse, whether the relationship is by blood, marriage, or adoption, which could potentially impact or be impacted by the participation of the member on a committee or council.

**Prohibited Action/Association:** Committee/council members are prohibited from any action or association which might result in or create the appearance of:

- a. Using membership on a committee/council for private gain;
- b. Giving preferential treatment to any person, agency, or business;
- c. Impeding government efficiency or economy;
- d. Losing complete independence or impartiality;
- e. Making a committee/council decision outside of official channels;
- f. Affecting adversely the confidence of the public in the integrity of the government, including the committee upon which the individual serves;
- g. Entering into or deriving any benefit, directly or indirectly, from any contractual arrangement with DIDD or any other State agency, person, or business;
- h. Having a direct or indirect financial interest that conflicts, or appears to conflict, with his/her duties or responsibilities as a member of the committee/council;
- i. Using, disclosing, or allowing the use of official information which was obtained through or in connection with his or her service on the committee/council which has not been made available to the general public for the purpose of private interest or personal profit of any person, including that committee/council member;
- j. Engaging in a financial transaction as a result of or primarily relying upon information obtained through his or her service on the committee/council; or
- k. Using DIDD or State facilities, equipment, personnel, or supplies for private or personal use or profit.



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Furthermore, in respecting the privacy of persons supported, staff, volunteers, provider agencies, and DIDD, any information obtained as a committee/council member is deemed to be confidential pursuant to T.C.A. § 33-3-103 *et seq.* Professionalism, good judgement, and care shall be demonstrated to avoid unauthorized or inadvertent disclosures of confidential information. Unauthorized disclosure of confidential or privileged information is a serious violation of statutory law and may subject the person(s) who made the unauthorized disclosure to appropriate discipline, including removal/dismissal. The adherence to confidentiality standards are intended to protect the committee members, as well as DIDD, because in extreme cases, a breach of confidentiality may result in personal liability. This confidentiality requirement is not intended to prevent disclosure where disclosure is required by law.

**ACKNOWLEDGEMENT AND CERTIFICATION**

I have read the foregoing Conflict of Interest and Confidentiality Statement presented above and hereby agree to the statements and guidelines contained therein. Furthermore, I affirm that I have not derived any personal profit or gain, directly or indirectly, by reason of my service on this committee/council, and if there is a change in circumstances, I will promptly provide notification as required herein.

COMMITTEE/COUNCIL MEMBER SIGNATURE

DATE

*Jeanene C. Miller*

*10/22/2018*

COMMITTEE/COUNCIL MEMBER PRINTED NAME

*Jeanine C. Miller*

COMMITTEE/COUNCIL

*Autism Council*

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COMMITTEE/COUNCIL MEMBER SIGNATURE

DATE

10/30/18

COMMITTEE/COUNCIL MEMBER PRINTED NAME

Robin Wilmoth

COMMITTEE/COUNCIL

Autism Spectrum Disorder TN Council

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COMMITTEE/COUNCIL MEMBER SIGNATURE

DATE

CClark

10/30/18

COMMITTEE/COUNCIL MEMBER PRINTED NAME

Carolina Clark

COMMITTEE/COUNCIL

TN Council on Autism Spectrum Disorder

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COMMITTEE/COUNCIL MEMBER SIGNATURE

DATE

*Alison A. Gaud*

*10-29-18*

COMMITTEE/COUNCIL MEMBER PRINTED NAME

*Alison A. Gaud*

COMMITTEE/COUNCIL

*Autism Council*

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COMMITTEE/COUNCIL MEMBER SIGNATURE

*Ginger Day*

DATE

*10/30/2018*

COMMITTEE/COUNCIL MEMBER PRINTED NAME

*Ginger Day*

COMMITTEE/COUNCIL

*TN Council on Autism Spectrum Disorder*

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COMMITTEE/COUNCIL MEMBER SIGNATURE

*Lorrie K. Brouse*

DATE

*10/17/18*

COMMITTEE/COUNCIL MEMBER PRINTED NAME

*LORRIE K. BROUSE*

COMMITTEE/COUNCIL

*TN Council on Autism Spectrum Disorder*

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COMMITTEE/COUNCIL MEMBER SIGNATURE

DATE

*Miles Brooks Jr.*

*10/30/18*

COMMITTEE/COUNCIL MEMBER PRINTED NAME

*Miles Brooks Jr.*

COMMITTEE/COUNCIL

*Autism Council/Tennessee Council on Autism Spectrum Disorder*

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COMMITTEE/COUNCIL MEMBER SIGNATURE

DATE  
10/17/18

COMMITTEE/COUNCIL MEMBER PRINTED NAME  
Joseph Matt Yancey

COMMITTEE/COUNCIL  
Autism Council

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DEPARTMENT OF  
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COMMITTEE/COUNCIL MEMBER SIGNATURE

DATE

10/30/18

COMMITTEE/COUNCIL MEMBER PRINTED NAME

Heather Taylor Griffith

COMMITTEE/COUNCIL

TN Council on Autism Spectrum Disorder

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COMMITTEE/COUNCIL MEMBER SIGNATURE

DATE

*Vaughn Frigon MD*

*10/18/18*

COMMITTEE/COUNCIL MEMBER PRINTED NAME

*Vaughn Frigon*

COMMITTEE/COUNCIL

*Autism Council*

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COMMITTEE/COUNCIL MEMBER SIGNATURE

*Wanda Willis*

DATE

*10-17-18*

COMMITTEE/COUNCIL MEMBER PRINTED NAME

*WANDA WILLIS*

COMMITTEE/COUNCIL

*Autism Council*

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COMMITTEE/COUNCIL MEMBER SIGNATURE

DATE

*Emma Shouse*

*10/30/18*

COMMITTEE/COUNCIL MEMBER PRINTED NAME

*Emma Shouse Garton*

COMMITTEE/COUNCIL

*TN Council on Autism Spectrum Disorder*

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COMMITTEE/COUNCIL MEMBER SIGNATURE

DATE

*Rose Naccarato*

*10/30/18*

COMMITTEE/COUNCIL MEMBER PRINTED NAME

*Rose Naccarato*

COMMITTEE/COUNCIL

*TN Council on Autism Spectrum Disorder*

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COMMITTEE/COUNCIL MEMBER SIGNATURE

DATE

*Jenness M. Roth*

*10/17/18*

COMMITTEE/COUNCIL MEMBER PRINTED NAME

Jenness M. Roth

COMMITTEE/COUNCIL

Council on Autism Spectrum Disorders

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COMMITTEE/COUNCIL MEMBER SIGNATURE

DATE

*[Handwritten Signature]*

*10-15-2018*

COMMITTEE/COUNCIL MEMBER PRINTED NAME

*Tseashia Thomas*

COMMITTEE/COUNCIL

*Tennessee Council on Autism Spectrum Disorder*

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COMMITTEE/COUNCIL MEMBER SIGNATURE

DATE

*Mary Ellen Chase*

*10/30/2018*

COMMITTEE/COUNCIL MEMBER PRINTED NAME

*MARY ELLEN CHASE*

COMMITTEE/COUNCIL

*TN Council on Autism Spectrum Disorder*

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COMMITTEE/COUNCIL MEMBER SIGNATURE

DATE

Quentin A Humbert  
COMMITTEE/COUNCIL MEMBER PRINTED NAME

Oct 30, 2018

Quentin A Humbert  
COMMITTEE/COUNCIL

Council on Autism Spectrum Disorder

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COMMITTEE/COUNCIL MEMBER SIGNATURE

DATE

*Beth Malow*

*10/30/2018*

COMMITTEE/COUNCIL MEMBER PRINTED NAME

*Beth Malow*

COMMITTEE/COUNCIL

*Autism Council*

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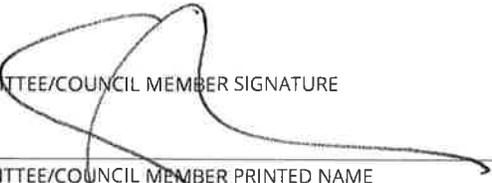
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COMMITTEE/COUNCIL MEMBER SIGNATURE  


DATE  
10/30/18

COMMITTEE/COUNCIL MEMBER PRINTED NAME  
EMELYNE M. BINGHAM

COMMITTEE/COUNCIL  
TN COUNCIL ON AUTISM SPECTRUM DISORDER

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DEPARTMENT OF  
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COMMITTEE/COUNCIL MEMBER SIGNATURE

DATE



10/30/18

COMMITTEE/COUNCIL MEMBER PRINTED NAME

William D Edwards

COMMITTEE/COUNCIL

Autism Council

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COMMITTEE/COUNCIL MEMBER SIGNATURE

DATE

*[Handwritten Signature]*

*10/17/18*

COMMITTEE/COUNCIL MEMBER PRINTED NAME

*Michael L. Collins*

COMMITTEE/COUNCIL

*TN Council on Autism Spectrum Disorder*

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COMMITTEE/COUNCIL MEMBER SIGNATURE

DATE

10-30-18

COMMITTEE/COUNCIL MEMBER PRINTED NAME

RODDEY M. COE

COMMITTEE/COUNCIL

Council On ASD

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DATE

Solita Morris (DIDD Support Staff)

10/31/18

COMMITTEE/COUNCIL MEMBER PRINTED NAME

Solita Morris

COMMITTEE/COUNCIL

TN Council on Autism Spectrum Disorder

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COMMITTEE/COUNCIL MEMBER SIGNATURE (DIDD Staff Liaison) \_\_\_\_\_ DATE \_\_\_\_\_  
*Patricia L. Edmiston* \_\_\_\_\_ *10-25-18* \_\_\_\_\_  
COMMITTEE/COUNCIL MEMBER PRINTED NAME \_\_\_\_\_  
*Patricia L. Edmiston* \_\_\_\_\_  
COMMITTEE/COUNCIL \_\_\_\_\_  
*TN Council on Autism Spectrum Disorder* \_\_\_\_\_

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**TN Council on Autism Spectrum Disorder**

**January 23, 2018, 10:00 a.m. – 2:00 p.m. CST**

**Meeting Agenda**

Hermitage Public Library  
3700 James Kay Lane  
Hermitage, TN 37076

- 10:00 a.m.     **Welcome and Opening Remarks**  
Dr. Quentin Humberd, Council Chair  
Alex Heart, DIDD Assistant Commissioner of Policy and Innovation
- 10:10 a.m.     **Council Introductions**.....Council Members
- 10:20 a.m.     **Public Introductions**.....Public
- 10:25 a.m.     **Review/approval of meeting minutes**.....Council members
- 10:30 p.m.     **TennCare’s Employment and Community First (ECF) Choices**  
Dr. Vaughn Frigon, Medical Director; Patti Killingsworth, Assistant Commissioner and Chief of Long-Term Services and Supports; and Lisa Mills, Deputy Chief of the Division of Long-Term Services and Supports
- 11:30 a.m.     **Vanderbilt Initiative for Autism and the Workforce**.....Dr. Keivan Strassun
- 11:45 a.m.     **Lunch – Sponsored by the TN Dept. of Education**  
**Autism Website discussion**.....Alex Heart
- 12:15 p.m.     **Council Committees**.....Dr. Quentin Humberd  
Information for Families/Service Coordination  
Early Identification/Education  
Healthcare  
Aging and Adulthood
- 12:30 p.m.     **“Pay-off Matrix”** .....Dr. Quentin Humberd/Council Members
- 1:30 p.m.     **Public Input**.....Public
- 1:50 p.m.     **Action Items: conference calls/moving forward**.....Dr. Quentin Humberd/Council Members
- 2:00 p.m.     **Adjourn**

**Next Meeting: Tuesday April 24, 2018**



**TN Council on Autism Spectrum Disorder**

**April 24, 2018, 10:00 a.m. – 2:00 p.m. CST**

**Meeting Agenda**

Tennessee Bureau of Investigation, Training Room 1  
901 R S Gass Boulevard  
Nashville, TN 37216

- 10:00 a.m.    **Welcome and Opening Remarks**  
Pat Edmiston, DIDD Director of Developmental Disability Services  
Dr. Quentin Humberd, Council Chair
  
- 10:05 a.m.    **Council Introductions**.....Council
  
- 10:15 a.m.    **Public Introductions**.....Public
  
- 10:20 a.m.    **State Department Services and Resources** .....Council Members:  
Dept. of Insurance and Commerce, DIDD, DOE, DOH, DHS, DMHSA, TCDD,  
Commission on Children and Youth, and TennCare
  
- 12:00 p.m.    **Lunch – Sponsored by Sertoma Center (Knoxville)**
  
- 12:30 p.m.    **“Pay-off Matrix” (for last three committees)**.....Dr. Quentin Humberd  
Early Intervention/Education, Healthcare, Aging/Adulthood
  
- 1:30 p.m.    **Discussion and Council vote on Committee Action Steps**.....Council
  
- 1:45 p.m.    **New Autism Council Website and possible videos**.....Cara Kumari, DIDD  
Director of Communications
  
- 2:00 p.m.    **Adjourn**

**Next Meeting: Tuesday July 24, 2018**



**TN Council on Autism Spectrum Disorder**

**July 24, 2018, 10:00 a.m. – 2:00 p.m. CST**

**Meeting Agenda**

Tennessee Bureau of Investigation, Training Room 1  
901 R S Gass Boulevard  
Nashville, TN 37216

- 10:00 a.m.    **Welcome and Opening Remarks**  
Dr. Quentin Humberd, Council Chair
- 10:05 a.m.    **Council Introductions**.....Council
- 10:10 a.m.    **Public Introductions**.....Public
- 10:15 a.m.    **Approval of Minutes from the 4/24/18 meeting**.....Council
- 10:20 a.m.    **Legal concerns and the development of a “Legal Toolkit”** .....Cindy Gardner, Attorney with the Special Needs Law Center
- 11:30 a.m.    **ABLE TN**.....David Ward, Financial Outreach Executive, ABLE TN, Tennessee Department of Treasury
- 12:00 p.m.    **Lunch – Sponsored by the Dept. of Mental Health and Substance Abuse Services**
- 12:30 p.m.    **Public comments**
- 12:40 p.m.    **Discussion and Council vote on Committee Action Items**.....Council Information for Families/Service Coordination, Early Intervention/Education, Healthcare, and Aging/Adulthood
- 2:00 p.m.    **Adjourn**

**Next Meeting: Tuesday July 24, 2018**



**TN Council on Autism Spectrum Disorder**

**October 4, 2017, 10:00 a.m. – 2:00 p.m. CST**

**Meeting Agenda**

Tennessee Bureau of Investigation, Training Room 1  
901 R S Gass Boulevard  
Nashville, TN 37216

- 10:00 a.m.    **Welcome and Opening Remarks**  
Pat Edmiston  
Dr. Quentin Humberd  
Commissioner Debbie Payne
- 10:15 a.m.    **Council Introductions**.....Council
- 11:15 a.m.    **Public Introductions**.....Public
- 11:20 p.m.    **History of the TN Council on Autism  
Spectrum Disorder/Legislation**.....Carol Westlake
- 11:45 a.m.    **Lunch**
- 12:15 p.m.    **History of Autism Summit Team**.....Carol Westlake
- 12:30 p.m.    **The Tennessee Autism Plan 2014**.....Carol Westlake/  
Dr. Humberd
- 1:30 p.m.    **Discussion/Planning**.....Council
- 1:50 p.m.    **Action Items**.....Dr. Humberd
- 2:00 p.m.    **Adjourn**

At some point during the meeting the State of TN photographer will stop by to take an official picture of the new TN Council on Autism Spectrum Disorder.

**Next Meeting: TBD**



**TN Council on Autism Spectrum Disorder**

**October 30<sup>th</sup>, 2018, 10:00 a.m. – 2:00 p.m. CST**

**Meeting Agenda**

Cloverbottom Campus  
275 Stewart’s Ferry Pike  
One Cannon Way (auditorium)  
Nashville, TN 37216

- 10:00 a.m.    **Welcome and Opening Remarks**  
Dr. Quentin Humberd, Council Chair
- 10:05 a.m.    **Council Introductions**.....Council
- 10:10 a.m.    **Public Introductions**.....Public
- 10:15 a.m.    **Approval of Minutes from the 7/24/18 meeting**.....Council
- 10:20 a.m.    **Inclusion and the Tennessee Education system**.....Cale Horne, Ph.D.,  
Coordinator for the Chattanooga Inclusive Education Working Group and Co-Chair  
of the Chattanooga 2.0 Inclusive Education and Opportunities Action Team
- 11:30 p.m.    **Lunch – Sponsored by the TN Council on Developmental Disabilities**
- 12:30 p.m.    **Public comments**
- 12:40 p.m.    **Legislative Sunset Hearing and Conflict of Interest Form**.....Pat Edmiston
- 12:45 p.m.    **Report of committees and discussion on action steps**.....Council
- 1:55 p.m.    **Review of 2019 Council meetings**.....Pat Edmiston
- 2:00 p.m.    **Adjourn**

**Next Meeting: Tuesday January 30<sup>th</sup>, 2019**

## TN Council on Autism Spectrum Disorder “Backwards Imaging” Review/Focus

### Conference Call notes: January 9<sup>th</sup>, 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.

*Dr. Humberd explained to each call that he had noted to the margin of each bullet point from the backwards imaging exercise what category the topic seems to fall under. (This document is attached.) Charge is to put meat on the bones of the “backward imaging” exercise from the first council meeting. At the next meeting, we hope to decide by bullets, which are the most effective and achievable goals.*

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

##### **Present on the call:**

Jeanine Miller (DIDD Policy Director), Carolina Clark (Pediatrician/Medical Consultant DOH), Iseashia Thomas (Family Member West TN), Will Hines (Asst. Deputy of Policy Contracts and Compliance TennCare Long Term Services and Supports), Lisa Mills (TennCare Deputy Chief of Long Term Services and Supports), Wanda Willis (Executive Director, TN Council on Developmental Disabilities)

Dr. Humberd welcomed the group and thanked them for their time. Either Lisa Mills or Shannon Nehus will be taking Will's place in the future.

- Dr. Humberd has noted what might need to change from a policy perspective for these ideas to be achieved. All of the ideas are important, but we need to hone them down a bit.
- It may be beneficial to have the State Departments share with the Council how families enter their systems and what services they offer over the lifespan. (This will be discussed as a future agenda item for the Council, possibly in April.)

Bullet 1 - Will stated that it may be helpful to have the agencies who are administrative entities on the council to provide an overview of how people enter their services to try to identify where the gaps are. Wanda suggested that one approach that we might consider is to convey information from the point of view from a family who has just had a child diagnosed on the spectrum and to approach the various service systems as they would be needed through the lifespan. Dr. Humberd asked that Iseashia, as a mother of a child on the spectrum and an adult sibling on the spectrum, to provide her perspective of accessing assistance.

Bullet 2 - Dr. Miller stated that information available in databases like Kids Central and Disability Pathfinder is not set up where we can see what individual needs are developmentally over the lifespan. Question for council is what agency would be the lead on creating such a system.

Bullet 3 - Iseashia has a unique perspective regarding the gap that needs to be filled when transitioning caregivers.

Bullet 4 - Iseashia finds that each agency gives different information that is not necessarily correct information. At minimum, we need a system that provides consistent information across all service-delivery entities.

- Pat - Common theme is that we want every family across the state to be able to access assistance and correct and consistent information.
- Dr. Humberd - Most of the bullets involve changing policy and/or systems of care.

Bullet 10 - Connecting families to legal supports is one area that is outside of policy and/or systems of care. Pat stated that there are specialty attorneys to whom we refer families who face losing Social Security benefits, need assistance with conservatorships, Special Needs Trusts, etc. Iseashia asked if this is something that can be included in the one-stop-shop system that we are trying to build.

Bullet 17 - Tennessee Promise - Dr. Miller was a mentor for this program. The transition training is very generic. A recommendation could be to develop a customized training for people with I/DD. This is a two year program offered at a Community College.

- Lisa provided a preview of Long Term Services and Supports discussion for next full meeting. ECF CHOICES serves adults of all ages. The primary support of ECF CHOICES came from legislature who funded 2,700 places to be filled by June 30, 2018. The impetus was to provide services to people who have been on the DIDD waiting list, as well as people with disabilities other than ID.
- Dr. Humberd asked Will how difficult it would be for TennCare to interface with other agencies to create a system to address the issues on the list. Will stated that it is not difficult to interact with other agencies. His experience has been that financing has been more of a barrier than bureaucratic red tape. TennCare staff are readily available to make connections, but funding sources have been a problem in the past.
- Have non-profit entities like Autism Tennessee, The Arc TN, and TN Voices, been engaged in training/awareness? Is there anything to prohibit this? Wanda stated that there are several opportunities for connecting with the provider network for people who are currently in services. There is not one real organized way.
- There are venues like the annual Disability MegaConference to convey information. One approach for the TN Disability Pathfinder would be to have a specific page for Autism that addresses lifespan services. Information needs to be digestible for families. Lisa also suggested that Area Agencies on Aging and Disabilities have mandates to be one-stop-shop resources.

Dr. Humberd asked Carolina how she sees the Dept. of Health, who has physical presence in all 95 counties through the local health departments that coordinates care, interfacing with these efforts. Certainly, training for these individuals on how to assist families with navigating resources would be beneficial. The Care Coordinators could benefit from “navigation training.”

One concern is that “Children’s Special Services” (as a program for children with a variety of disabilities offered through the Dept. of Health) does not provide health and/or medical services for individuals with ASD.

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

### **Present on the call:**

Jenness Roth (Family Member), Roddey Coe (Family Member East), Kim Black (DIDD Director of Residential Services/Family Member), Will Edwards (Family Member East, Attorney in Estate Planning and conservatorships), Rose Naccarato (TN Commission on Children & Youth, Family Member), Alison Gauld (Dept. of Education)

Question for Will - How do we connect families for appropriate legal advice?

### **Early Identification:**

Bullet 1 - Dr. Humberd stated that other states are successfully addressing this. Dept. of Education would be the lead agency on policy change for this.

Bullet 2 - Implies that families are getting inaccurate diagnoses. What do we mean by "fighting"?

- Jenness stated that there is an unwillingness among pediatricians who are not willing to give a complete diagnosis until children have been to a tertiary center (not wanting to say "autism").
- Roddey stated that he has seen the perspective of the primary pediatrician refusing to make diagnosis without consulting a specialist, which in his area (Chattanooga) involves a nine month wait. Assistance is available prior to diagnosis, but families are not aware of how to access that.
- Dr. Humberd stated that we already have systems in place to identify children who are at risk. There needs to be an interagency agreement about how to do it and how to sustain it.

Bullet 3 - Support System –

- Will stated that Knox County has a centralized database, which has been helpful. Non-profit support has been loosely coordinated.
- Roddey stated CAC has volunteer run support groups. These are irregular. Diagnosis is a still a nine month wait. Therapies are a six to nine month wait. If not on TennCare, there just aren't any ABA services.
- Can we consider an "insurance mandate?" Rose stated that she recently was able to benefit from this ABA coverage for her child (through her State of TN insurance), but prior to that, this was out-of-pocket expense. Families struggle with finding balance between how much of their resources to pour into the child(ren) in need of services without it being at the expense of the rest of the family's needs.
- Training for parents is not the only answer. Jenness agreed. Some parents do not possess the skillset required to work intensively with children who need services, and there is a degree of shaming that exists from the provider world implying that natural supports are not doing their part at home. Dr. Humberd stated that we do not currently have the workforce statewide to address this issue. We need to develop an appropriate treatment workforce.

### **Education:**

Most of these bullets may need to be addressed by our Dept. of Education council member.

- Roddey stated that it is important that families are educated about IDEA and state law because the schools are not.
- TN Specialized Training for Educating Parents (STEP) instruction is very generalized. Jenness stated that there is nothing that would prohibit STEP from developing specialized training related to ASD. Still, the workforce behind administering that poses a challenge. We may consider having a representative from STEP come present at a future council meeting.

The Dept. of Education's "Partners in Education" (PIE) conference is coming up February 5<sup>th</sup> – 8<sup>th</sup>. This is helpful information, but it really covers minimum compliance.

Dr. Humberd asked Alison to consider providing a written summary of what DOE's best practices/current system of care are on these issues for a quarterly council meeting. This will be for a future meeting (not the meeting on Jan. 23<sup>rd</sup>.)

Rose wondered if something could be done through "TN Promise" in the way of career goals to promote paraprofessionals in the school system.

CCNR: Childcare Resource and Training Center (for day care centers). We need to examine the current system of care, gaps, barriers, and workforce training.

Three points identified to bring back to council are:

- Current Dept. of Education system/Best Practices
- Special Education issues
- Workforce Development/Training

### **Healthcare: 1:00 p.m. – 2:00 p.m.**

#### **Present on the call:**

Iseashia Thomas (Family Member, West), Jeanine Miller (DIDD Director of Policy), Dr. Beth Malow (Family Member, Middle), Will Edwards (Family Member, East/Attorney, Estate Planning and Conservatorships), Janet Shouse (Community Member/ Vanderbilt Kennedy Center/Family Member)

Bullet 1 - How can we get providers in every county involved with monthly telehealth conferencing.

- Dr. Malow stated that this concept is driven by a desire and need to link resources. She stated that Vanderbilt is trying to minimize inpatient stays through telehealth. Providers do seem to be interested in doing this. An issue with implementation would be the cost. Dr. Malow stated that it would really just require setting up a Zoom account. The biggest cost would really be of time. However, buy-in could be achieved by viewing this as a reinvestment in quality of services, networking, etc. Dr. Malow suggested that presenting this complex information in a more simplified way could go a long way.
- Dr. Miller stated that DIDD is about to rollout remote supports so that people can have less on-site supervision.
- Dr. Bruce Davis, DIDD Director of Behavior Supports, has done a lot of groundwork with Resource Tennessee to get the mental health and I/DD fields building relationships.
- Training on new CPT coding for 2018 could also be incentive that allows billing for complex patients and remote support from specialists for rural doctors.
- Janet stated that her agency has difficulty in getting buy in from primary care providers for adults. How do we bring parity to healthcare services where a person does not have to be poor to qualify for services?
- Do we focus just on ABA, or do we focus on all therapies? Discussion of an "insurance mandate" again and there may be a task force set up to study this during this legislative session. TennCare patients are better served but there is a lack of certified BCBA's.

Can we establish a contact with insurance providers who could provide us with a breakdown of schedules of benefits for people with ASD, sort of a payout matrix? How would we go about getting this information? We discussed partnering with the insurance carriers and asking for their schedule of benefits for individuals with ASD. How would we get a point of contact? Maybe discuss this with Lorrie Brouse (our council member from the Dept. of Commerce and Insurance).

- We have the “Autism Equity Act” mandating ABA for individuals with ASD under 12 years old.
- The transition from pediatrics to adult medical services is challenging!
- Access to resources has much to do with policies and procedures, as well as workforce and education.
- Dr. Miller stated that psychiatrist and psychologist were deleted from the 1915c waiver language about 6 years ago.

Dr. Malow mentioned that Disability Day on the Hill is February 14<sup>th</sup>. It may be worthwhile to mention to the council and possibly have some representation there. Council members are encouraged to attend, however they should attend as “individuals” who can mention that they are members/Governor appointments to the TN Council on Autism Spectrum Disorder. The council cannot attend as a group for lobbying purposes.

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

#### **Present on the call:**

Michael Collins (Family Member, East), Ginger Day (ASD Coordinator, Tennessee Rehabilitation Center, Dept. of Human Services), Dr. TA McDonald (Community Member/Vanderbilt Kennedy Center, Family Member), Janet Shouse (Community Member/Vanderbilt Kennedy Center/Family Member), Alex Heart (DIDD Assistant Commissioner of Policy & Innovation)

Dr. Humberd asked for feedback on current job availability.

- Dr. McDonald wants to discuss recreation and leisure, as well as employment. Social engagement opportunities are challenging. What do we do for people who are not socially and emotionally ready for employment? Employment is still very important to many people, so she will let others speak to that.
- Ginger stated that the employment landscape for people with ASD looks bleak in rural areas. What makes autism adults different than other clients are primarily their styles of communication? Also, sensory issues. Many employers will make accommodations if they are aware of those needs. She and another staff at TRC have developed an autism-specific training, but it has not been implemented yet.
- VR counselors have no specific training with regards to individuals with ASD, therefore they have issues working with some people on the spectrum.
- There seems to be a 50% drop-off in employability for people with autism, in contrast for people with other disabilities.

Dr. McDonald stated that there is a group of people with ASD who are 2/3 their age both socially and emotionally. What we are seeing is that development is stretched out. An 18 y/o is actually socially and emotionally 12 y/o. As they age, their interests mature. These individuals would benefit from post-secondary education of some kind. Currently, they can enter an I/DD program. Some go to college, but drop in and out because they are ready for college on some levels, but not on others. There are a number of people who discover that they are interested in learning to drive in their 20's, when high school was the time to learn that.

- Janet mentioned VR Orders of Priority where only the most severely diagnosed people are served, whereas those who do qualify for those services are often deemed “too disabled” to work.

- Parents are experiencing variability across the state with what they are hearing and what they are receiving.
- Michael's 16 y/o son scored extremely high on spacial relationships, but he still enjoys children's televisions shows. The challenge will be to find employment that is not beneath his intelligence, but is also realistic for him to be successful.

While building blocks to employment and employment options are a focus of this workgroup, also of concern is transitional planning for adults whose primary caregivers are aging and/or unable to provide care. This system of care has yet to be developed, which would be one of the biggest challenges of this council. While we can't put a system in place overnight, is there something that can be done to ease the financial burden that families face.

TennCare will be presenting Long Term Services and Supports (LTSS) at the upcoming quarterly council meeting, but those numbers currently represent 2,700 people. If we believe in the increasing numbers of people actually being diagnosed and needing services, LTSS is not going to be able to keep up with those numbers. Across the board, families of people with autism spectrum disorder are significantly financially impacted before their loved one even reaches adulthood.

Michael stated that delivery method of services in Tennessee comes through several different channels, and that means there are multiple levels of administrative dollars being unnecessarily spent that could really be addressing ground-level needs.

- Fears: there are a lot of concerns in the area of aging parents, as well as issues with the DSPs and PAs. "How do we support families...and families across the income spectrum?" This should be the message from the Council.
- "Let the people in charge know that this is a crisis!"
- We need a plan for finding the unidentified adults with ASD and how to assist them with entering the service system.

## **TN Council on Autism Spectrum Disorder Conference Call notes: April 3<sup>rd</sup>, 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.

2. 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.

3. 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.

4. 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.

5. 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 6<sup>th</sup>.

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.

## **TN Council on Autism Spectrum Disorder Conference Call notes: June 26<sup>th</sup>, 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, was 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:**

Dr. Humberd, Iseashia Thomas (Family Member, West TN), Pat Edmiston

This committee is looking at how valuable information is communicated to families. There was discussion around the fact that there is a Health Department in all 95 counties and there is a Title V – Children’s Special Services (CSS) coordinator in all the Health Departments. Individuals on the autism spectrum are not eligible for the CSS program is that is their only diagnosis. In addition, the Tennessee Commission on Children and Youth (TCCY) has regional councils that cover all 95 counties. Dr. Humberd is a member of the Mid-Cumberland Council.

Question: How do we integrate people with ASD at the time of diagnosis with the information and services presented by all the State Departments at the last Autism Council meeting? How does someone enter our “System of Care?”

#### **Action Items:**

##### **1. Developing a “Life Span Approach” with a map and timeline to enter services:**

- Birth to 3 years old (TEIS)
- 3 to 5 years old (pre-school, Headstart, etc.)
- 6 to 21 years old (local school system)
- 22+ years old (employment, Social Security, legal information, etc.)

Under each age category there will be details of information related to:

- Diagnosis
- Standards for eligibility
- Consistent and accurate information for families – possible “Family Navigators” in each County Health Department

Examples of information to include:

- County Health Department links...and what would the barriers be to equipping the disability specialists at the local Health Departments with additional autism specific resources?
- Live link to the Department of Education, Special Education supervisor contact information
- Vocational Rehabilitation and employment information and resources
- Link to Employment and Community First (ECF) Choices Waiver under TennCare
- Legal information: conservatorship and alternatives to conservatorship

## **2. Connecting families to legal and financial supports**

- Cindy Gardner, a private attorney with the Special Needs Law Center, has been 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 will discuss conservatorship and alternatives to conservatorship and the new Supported Decision Making legislation.
- In addition, we have invited David Ward, Financial Outreach Executive, ABLE TN, Tennessee Department of Treasury, to present at the July meeting regarding financial resources for families and individuals with ASD.

## **3. TN Promise transition training**

- TN Promise is not ASD specific. Who could develop customized training as a two year program at a community college? TN Promise prepares and pays for college, which is different from employment. Idea for training individuals with autism to access TN Promise for vocational education. We need more clarity around this issue.

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

#### **Present on the call:**

Dr. Quentin Humberd, Jenness Roth (Family Member, West TN), Roddey Coe (Family Member, East TN), Will Edwards (Family Member, East TN), Rose Naccarato (TN Commission on Children & Youth, Family Member), Kim Black (Community Member, Family Member, DIDD Director of Residential Services), Rachel Jrabe-Rice (for Lorrie Brouse with the Dept. of Commerce and Insurance), Cari Parr (New Community Member and Special Education Teacher, Middle TN), Crissonya Phillips, (New Community Member, Family Member, DIDD Director of HCBS Settings), and Pat Edmiston

The committee discussed issues related to the Tennessee Early Intervention System (TEIS), 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.

Legal and financial concerns were discussed and these will be addressed at the next full council meeting in July.

Cari Parr, our new committee member from Rutherford County, is a special education teacher that developed a website for Middle Tennessee families: “Pick up the Pieces, TN.” We discussed having a live link to this on the DIDD Autism Council’s new website. She explained that in addition to the educational diagnosis, students have always had to have a medical diagnosis. As

of July 1<sup>st</sup>, 2017, the medical diagnosis is no longer a requirement. Students with autism spectrum disorder fall under the educational diagnosis.

“KidsCentralTN” is vague relating to autism spectrum disorder. Rose explained that the Tennessee Commission on Children and Youth is currently in the process of taking over the administration of the KidsCentralTN website. They are going to hire a new staff person to oversee this website.

Roddey shared the “ASD Hub.org” website information that is a joint venture/partnership between the Autism Society of East TN and the Autism Society of Knoxville. This website is specifically for families in East Tennessee and has listings of agencies, psychiatrists, etc. We discussed having a live link to this on the DIDD Autism Council’s new website.

### **Action Items:**

#### **1. TEIS leadership to provide thumbnail sketch of services, 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.
- Dr. Humberd agreed to follow up with his contact at TEIS.
- It seems to be a burden to be a TEIS provider and contract with them. Example: the UT Boling Center is not a TEIS provider. Can there be a waiver for the UT Boling Center to allow them to become an EIRA (Early Intervention Resource Agency)?
- 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.
- Early identification does not do us any good without a workforce to serve those children (as identified below).

#### **2. Department of Education eligibility criteria changing and how it filters down to the teachers**

- Educational impairments vs. classroom issues for eligibility
- Children 18 to 24 months old have their PCP do an initial “screening” and many do not get the second recommended screening and “drop off the radar.”
- As the students get older, their therapy services (PT, OT, and SLP) are reduced for “lack of progress” and it falls on the teachers to work on their IEP goals.
- Therapy and other related services are being left off the student’s IEP so that the school system does not have to provide the service.

### **3. Workforce development for therapists and Direct Support Professionals**

- Where does this workforce come from? Possible reimbursement through TennCare for developmental therapy (not ABA) services is being discussed. Dr. Humberd stated that reimbursable services is another part of the issue. There has to be a licensed person supervising the techs to be a reimbursable service.
- There is a workforce crisis and Governor Haslam and the legislature just passed a mandatory pay increase for all Direct Support Professionals under the DIDD 1915c Waivers.

### **4. Parents need to know their rights in the education system**

- Parents and teachers do not know their rights and as a result, IEPs are not being written so that the student gets what he or she needs.
- There is a huge lack of information being distributed to families regarding their rights and the IEP process.
- The IEP must be written properly so that the student gets what he or she need.
- Parents need to know that it is ok to take someone with them to the IEP meeting. They need information about local and statewide resources such as The Arc TN, STEP, and the Volunteer Advocacy Program at Vanderbilt.
- There is a Family Advisory Council/Exceptional Education Parents in Davidson County and a Parent Advisory Council in Knoxville, both through the Special Education Departments and run by parents. Knoxville has a full-time parent liaison with Special Education through Knox County. This would be very beneficial in all counties.
- Dr. Humberd asked about strategies to educate families about IDEA. 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.
- 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.

### **Healthcare: 1:00 p.m. – 2:00 p.m.**

#### **Present on the call:**

Dr. Quentin Humberd, Dr. Beth Malow (Family Member, Middle TN), Will Edwards (Family Member, East TN), Rachel Jrabe-Rice (for Lorrie Brouse with the Dept. of Commerce and Insurance), and Pat Edmiston

The goal of this committee is to have providers in every county of Tennessee engaged in a monthly tele-health 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 this 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.

Tele-health speaks to both exchange of information from provider to patient, but also to provider to provider regarding the healthcare of the patient. It is also about interfacing with clinicians in the community.

### **Action Items:**

#### **1. Ask TennCare to participate in a feasibility discussion regarding tele-health incentives.**

- Dr. Humberd emailed Dr. Frigon, Medical Director for TennCare, about this. A WebEx conference call has been scheduled for Friday July 20<sup>th</sup> at 10:00 with Dr. Humberd, Dr. Frigon, and Dr. Malow. Pat Edmiston will be on the call to take notes.
- Dr. Malow will develop a brief presentation of what the ECHO model looks like for the benefit of the entire council. She will share this information at the July 24<sup>th</sup> council meeting as the Healthcare committee discusses their action items.
- There was discussion about tele-medical vs. tele-health. Dr. Malow will share this information at the full council meeting.

#### **2. Ask the Department of Commerce and Insurance what can be done to level the playing field so that people do not have to be poor (and on TennCare) 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.
- There needs to be more equality of services between TennCare and private insurance.
- Rachel shared that a mandate passed stating that “some behavioral health services need to be treated like other services without a higher co-pay.”
- Rachel will reach out to insurance providers and look specifically at autism services and benefits. She has access to the major insurances companies on the “Exchange” (which is the Affordable Care Act Market Place).
- Some insurance carriers are not regulated by the Department of Commerce and Insurance. For their information, a person can call “Consumer Insurance Services” to get specific answers to those provider questions.

- This committee would like to develop a “chart or grid” of what services insurance companies provide for individuals with ASD. The council can decide what specific elements we want on the grid.

### **3. Healthcare providers will be trained to serve people with ASD throughout their lifespan.**

- Perhaps Title V coordinators (CSS Program) through the Department of Health could also be utilized in this effort as recommended by the Information for Families committee.
- We would like “Family Navigators” in all local health departments to assist families with appropriate information (as stated in the first committee report).

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

### **Present on the call:**

Dr. Beth Malow (Family Member, Middle TN), Lyn Bingham (Self-Advocate, Middle TN), Alice Chamberlain (New Community Member, Family Member, and Employment Specialist with Frontier Health, East TN), and Pat Edmiston

The goal of this committee is for adults diagnosed with an ASD have access to person-centered services that support the person to live with as much independence as possible.

Perhaps the council would be able to take all of the available resources and make them easy to navigate, as it seems that navigating resources for both the person with ASD and the caregiver is difficult.

Lyn shared that she has a colleague at Vanderbilt (Julie Taylor) that has been doing research with women with ASD over 50 years old and the fact that they “drop off the charts.” The research is looking at what happens and why.

### **Action Items:**

#### **1. Training for VR providers around Autism Spectrum Disorder**

- Alice shared that she is an Employment Specialist with Frontier Health in Greeneville and as a vendor, she works with the VR counselors. She and her co-workers do the bulk of the service, create the plans, and do the job search. The Autism Specific training developed by VR is “offered and NOT required” by the employment vendors. This is a huge issue!
- This committee would like to say that all VR counselors AND contracted employment vendors must have the ASD specific training.
- Dr. Malow and Dr. Humberd noted that there is outdated DMS diagnosis information on the first part of the VR Autism Specific Training provided to this committee by Ginger Day several months ago.

- Dr. Humberd met with Tara Cunningham with Specialisterne, USA. She is working with Vanderbilt to host an on-line platform of training and education through Specialisterne, Vanderbilt University, and NADD, along with Dr. Keivan Stassun (who presented this program at the last two Autism Council meetings). This is an on-line “Pre-ETS” which is the Pre-Employment Transition Service for high schools. This will assist with getting students into good jobs.
- There is a concern that the VR counselors are not consistently going into the schools and meeting with the students when they turn 14 years old to begin the transition process.

## **2. More adults with ASD being able to self-advocate**

- There is a “Boot Camp” for students through VR and it is not meeting capacity because families do not know about it. Dr. Malow’s son is currently attending and will share the curriculum with the council. The committee asked: how was the Boot Camp developed, what are their standards, etc.
- Lyn asked if we receive data and/or useful data from VR regarding successful employment for people with ASD and the answer is no.
- Alice shared that as an employment vendor, Frontier Health has a “Fidelity Review” and that their supported employment is evidence based. They provide “follow along” when someone is successful in a job for 90 days. This can be discussed with Ginger Day, the council member from DHS/VR.
- TN Disability Pathfinder seems to have gaps for people with ASD and their families. The website is updated every month. It seems difficult for a person with ASD to navigate to find services in their community.

## **3. Transition from education to adulthood and employment**

- This action item crosses all the issues in the first two action items, however we wanted it listed as a concern from this committee.

**DEPARTMENT OF INTELLECTUAL AND DEVELOPMENTAL DISABILITIES  
TN COUNCIL ON AUTISM SPECTRUM DISORDER  
MEETING MINUTES  
HERMITAGE PUBLIC LIBRARY  
3700 JAMES KAY LANE, HERMITAGE, TN 37076  
JANUARY 23, 2018**

CHAIRPERSON	Chair, Dr. Quentin Humberd
TYPE OF MEETING	TN Council on Autism Spectrum Disorder
MEMBERS PRESENT	Emelyne Bingham, Mary Ellen Chase, Carolina Clark, Roddey Coe, Michael Collins, Ginger Day, Will Edwards, Dr. Vaughn Frigon, Alison Gauld, Rachel Jrade-Rice (proxy for Lorrie Brouse), Dr. Beth Malow, Dr. Jeanine C. Miller, Rose Naccarato, Jenness Roth, Iseashia Thomas, Wanda Willis, Matt Yancey
MEMBERS ABSENT	None
QUORUM	There was a quorum of TN Council on Autism Spectrum Disorder members present.
DIDD STAFF PRESENT	Alex Heart, Solita Morris
GUEST PRESENTERS	Patti Killingsworth, TennCare Chief of Long-Term Services and Supports Lisa Mills, Ph.D., TennCare Deputy Chief of Long-Term Services and Supports Keivan Stassun, Ph.D., Vanderbilt Center for Autism and Innovation
GUESTS FROM PUBLIC	Dean Fox (ARC TN), Carrie Parr, Janet Shouse (Vanderbilt Kennedy Center), Carol Westlake (TN Disability Coalition),

**Call to Order/Introductions/Approval of Meeting Minutes**

Dr. Humberd called the meeting to order. He provided an overview of the council's charge and stated that the biggest challenge over the next 3 years will be to develop a strategy that addresses level of need over the lifespan for people with Autism. He stated that the 4 subcommittees met on January 9, 2018, and identified focus areas. He thanked DIDD for providing administrative support, as well as the public for their interest and participation. Council introductions were followed by public introductions. The public was asked to hold input until after sub-committee reporting. Dr. Jeanine Miller motioned to approve the minutes from the October 4, 2017, meeting of the council. Wanda Willis seconded the motion. The council voted in favor of approving the minutes as submitted.

**TennCare Employment and Community First (ECF) CHOICES – Patti Killingsworth, Dr. Lisa Mills, Dr. Vaughn Frigon**

The ECF CHOICES Program presentation is included as an attachment with these minutes.

Ms. Killingsworth stated that it is an honor to spend time with so many people and families who are vested in improving services for people with developmental disabilities. She cited an excerpt from the October 4, 2018, meeting minutes, which states “Person-centered supports cannot end when a child with autism becomes an adult with autism. We want better for our fellow Tennessean. We want them to thrive in their communities, live in homes that they like, and work in jobs that they love”. TennCare agrees. The Employment and Community First (ECF) CHOICES Program started on July 1, 2016, to assist people with intellectual and developmental disabilities, including individuals on the Autism spectrum, to achieve these goals. This is the first time that a community-based long-term support program has been offered that includes people with developmental disabilities other than intellectual disabilities, which includes Autism. Everything about the program is designed to provide supports across the lifespan, which includes engaging with families while a child is still at home to begin planning for the future in education, transition to employment, active community participation and community living, all to achieve the highest level of independence and choice. People being served range in age from children to elderly, and include individuals with a range of service and support needs.

**There are 3 different benefit groups:**

Group 4 Essential Family Supports – This benefit group is primarily for children under the age of 21 who have intellectual and/or developmental disabilities and who live at home with their families, however, adults age 21 and over who have I/DD and are living with family may also enroll in this group if they may be safely and appropriately served in this group. Addresses wraparound supports to school and EPSDT that are needed to plan and prepare for children to become adults and transition to employment and community living. For fiscal year 2017, there were a total of 500 slots for Group 4. There were 300 additional slots added for FY 2018, and an additional 75 slots have been moved to Group 4 from Group 5. There are currently 34% of enrollees represented in Group 4.

Group 5 Essential Supports for Employment and Independent Living – This benefit group is primarily for adults age 21 and over who have I/DD, however, TennCare can grant exceptions for adults age 18-20 who are not living with family. This group assists adults to achieve employment and community living goals and to fully engage in community life. For fiscal year 2017, there were a total of 1,000 slots. There were 600 additional slots added for FY 2018, and 75 slots have been moved from Group 5 to Group 4. There are currently 56% enrollees represented in Group 5.

Group 6 Comprehensive Supports for Employment and Community Living – This benefit group is for adults age 21 and older who have I/DD and need a more intensive level of supports and services to plan and achieve employment and community living goals. TennCare can grant exceptions for adults age 18-20 who are not living with family. Part of the target population for this group is youth with higher support needs that are graduating high school who may not yet be enrolled in the program, to ensure that these youth and their families know that there are next steps and supports for transition to adulthood. For fiscal year 2017, there were a total of 200 slots. An additional 100 slots were added for fiscal year 2018. There are currently 10% enrollees represented in Group 6.

The ECF CHOICES Program is a Medicaid Program, so a person must qualify for Medicaid to qualify. If a child meets an institutional level of care assessment, eligibility pathways can be pursued that waive parents' income. Income can currently not exceed \$2,250/month.

Dr. Mills provided an overview of the 8 Enrollment Priority Categories, which may be viewed in the presentation that is included with these minutes.

There is also a Reserve Capacity Enrollment Category for immediate and urgent needs for services, such as people whose caregivers are 75 and older, assistance moving out of a nursing home or ICF/IID, at risk of harm or danger, serious medical/behavior challenges, etc.

#### **Program Capacity and Current Enrollment:**

The legislature initially funded 2,700 slots. There are 2,279 enrolled as of January 1, 2018, which is 84% of program capacity.

Of the 2,279 people enrolled, 601 (26.4%) have an Autism Spectrum Disorder (ASD) diagnosis. Of these 601 people; 50% are in Group 4, 39% are in Group 5, and 11% are in Group 6. Also of these 601 people; 43% are under the age of 21, 56% are between ages 21-62, and 1% is over age 62. There are currently enrollees with ASD in 75 of the 95 counties in Tennessee.

#### **Questions/Answers/Comments/Responses**

**Q:** Are those who are enrolled actually receiving services?

**A:** Not necessarily. Once enrolled, there is up to a 30-day assessment and planning period to determine service needs. Immediate service needs are identified and addressed more quickly.

**Q:** What are the barriers to expanding the program?

**A:** Funding is the biggest barrier to expanding the program. Initially, it was unknown how many people would present for services to know how much funding to request. System capacity was also

unknown. This entailed moving people into community-based services at a pace that was more rapid than ever before. It is important to be thoughtful and intentional about how to educate the legislature about the need for continued support and increased funding to increase capacity for services.

Funding request for this budget year is for two new groups. One is for children and youth living at home with families who have severe behavioral support needs. This group would integrate behavioral health and mental health with other LTSS supports. The second group is for adults with significant behavioral support needs, including people who have extensive involvement with criminal justice system. This funding would come from vacated slots in the three intellectual disability waivers, which are now closed to new enrollments. This funding from vacated slots is also expected to support additional Group 4, 5 and 6 slots as of July 1, 2018, but a determination of how many new slots may be created has not yet been made and is subject to the budget process. Once funds are approved, those are recurring dollars. The issue is having the funding that will be needed to support still more people.

**Comment:** Ms. Gauld stated that everyone that she has referred to the program has been approved. These are families of children who have been grateful to know that there are supports and opportunities for their transition into adulthood and employment.

**Q:** What is being done about the population who are not Medicaid eligible?

**A:** TennCare intends to implement eligibility system changes in the near future to enable people, who are not Medicaid eligible due to earned income, to be eligible for the ECF CHOICES Program. This already has federal approval. However, it is clear that a broader solution than what TennCare is able to offer is needed.

**Comment:** It does not seem appropriate that families have to become impoverished in order to qualify for needed services.

**Comment:** Ms. Chase stated that she has a son who is age 30 who does not receive SSI. She was encouraged to apply anyway and was denied. ECF is a wonderful program, but there are families like hers that cannot benefit who still need services.

**Response:** Only the income of person in the institution/nursing facility counts. ABLÉ accounts are also an option that can exempt assets, and income earned on those assets, for purposes of Medicaid eligibility. However, it is important to note that income contributed to an ABLÉ account, by an account beneficiary, cannot be disregarded as countable income for purposes of Medicaid eligibility, even though once the income is in an ABLÉ account (and becomes part of the person's assets) it is disregarded in determining if a person meets the asset limits for Medicaid eligibility. Dr. Mills recommended the Council consider inviting an expert on ABLÉ accounts to present to the group at a future meeting.

**Q:** If we make people employable, how do we ensure that supports to sustain employment are in place?

**A:** Benefits counseling specific to employment (called Work Incentives Benefits Counseling) is a covered service in the ECF CHOICES Program.

### **Services and Supports offered**

Not everyone needs everything offered. The services and supports offered allow people to customize their supports to fit what they need. TennCare doesn't want to ever under-support or over-support a person. Services can be changed over time, as a person's goals, needs and circumstances change.. One of the things in process of being implemented in a transitional rate for Community Living Supports. Oftentimes, the person is moving out of family home or a more restrictive setting to a community living arrangement and it is unknown what specific supports will be needed. That transitional reimbursement structure will initially allow for a more structured and intensive support by the Community Living Supports provider, so they can accurately identify the level of support a person will need over the longer term. It is important that the program not wrap people so tightly in services that growth and independence and natural/family supports are discouraged.

It has become evident that newly enrolled members and their families, who are not in crisis, are taking their time in selecting providers and considering what services and supports will help them meet their goals. The national workforce shortage is real and will require new strategies to recruit and retain high quality staff. Partnerships between Vocational Rehabilitation, affordable housing developers/landlords, employers, etc., are vital to the success of the program and to helping people achieve outcomes that matter to them. Currently, 80% who participated in Employment Exploration service decided that they want to work.

Employment outcomes for people w/ASD – 22.5% of working-age enrollees are working in competitive integrated employment for an average wage of \$8.31/hour for an average 14 hours/week.

### **Opportunities around ABA and Behavioral Analysis**

Dr. Frigon stated that the work of ECF is groundbreaking. He discussed the 5-pronged Medical Necessity Criteria. This statute is provided below:

1200-13-16-.05 MEDICAL NECESSITY CRITERIA. (1) To be medically necessary, a medical item or service must satisfy each of the following criteria: December, 2007 (Revised) 7 MEDICAL NECESSITY CHAPTER 1200-13-16 (Rule 1200-13-16-.05, continued) (a) It must be recommended by a licensed physician who is treating the enrollee or other licensed healthcare provider practicing within the scope of his or her license who is treating the enrollee; (b) It must be required in order to diagnose or treat an enrollee's medical condition; (c) It must be safe and effective; (d) It must not be

experimental or investigational; and (e) It must be the least costly alternative course of diagnosis or treatment that is adequate for the enrollee's medical condition. (2) The convenience of an enrollee, the enrollee's family, the enrollee's caregiver, or a provider, shall not be a factor or justification in determining that a medical item or service is medically necessary.

The Medically Necessary policy has been turned over to Managed Care Organizations (MCOs). The MCOs are using these medical necessity guidelines to determine ABA necessity.

**Q:** How is consistency across MCOs being established?

**A:** Policy has been discussed with each of the MCO directors. TennCare's goal is to ensure that MCOs are consistently applying rules and definitions. ABA is considered and monitored the same as any other health service.

**Q:** What is the age criteria for ABA, and is safety is part of that? **A:**

Yes, safety is considered in the 5 prongs.

**Q:** What about least-expensive alternative? Does this imply that medication, even if it does not provide progress, would be used because it is the least expensive course? Medication may be the least expensive, but ABA would be the more long-term solution.

**A:** The attending physician needs to accurately document the plans of care for individuals. TennCare has a robust appeals process, and situations where ABA would ultimately be less costly over time would be approved. TennCare supports interventions that are alternatives to pharmacological substitutes.

**Q:** What is the navigating the process?

**A:** The self-referral process is on-line. Also, health care providers are responsible for making people aware and assisting them with the process. There have been various informational materials distributed in the mail, and presentations and trainings. The first point of entry would be PCP.

**Comment:** Mr. Coe stated that strengthening relationships with the PCP is not really practical on top of all of the specialized services that come into play. Depending on where in the state the PCP is and where specialized appointments are, the time just isn't there to build a relationship with the PCP.

**Response:** The most important relationship will be with the PCP, as that doctor will either mostappropriately refer or eliminate the need for extraneous referrals.

### **Vanderbilt Initiative for Autism and the Workforce – Dr. Keivan Stassun**

Dr. Stassun's presentation may be accessed at:

<https://vanderbilt.box.com/s/advvggf0gwq1tycd2yizd9fpwpjegydb>

The Initiative for Autism and Innovation is focused on developing a community-based model pipeline of research and employment that supports neuro-diversity in the workplace by emphasizing strengths and abilities that often accompany ASD and leveraging those strengths. The pilot of pipeline is The Nashville Model. Psychometrics probes the kinds of abilities that research tells us often accompany ASD that go beyond standard IQ testing. A partnership with

The Precisionists, Inc. (TPI) is employing ASD adults that TPI has contracted with other companies to allow people to perform the job at the TPI site to provide safe first step for people to do the work, and then hopefully transition to full work at the company site. For more information, please visit: <http://vu.edu/autismandinnovation/>.

**Q:** Is what is described at the TPI equivalent to a sheltered workshop and/or in conflict of the HCBS Settings Rule?

**A:** TPI is a for-profit agency that is hiring individuals as a specialized workforce.

**Comment:** Dr. Frigon pointed out that many agencies are looking to alternative workplace solutions, so this type of arrangement where employees are not actually working on-site will not seem so unusual.

### Council Committees

Dr. Humberd reminded the council of its charge is to assess the current and future state of ASD services. Part of its job is to be the agent that ensures that there is cross-system communication. If there are budgetary needs, the council needs to raise awareness to those to ensure that those whom it is charged to represent are not overlooked.

Dr. Humberd asked that the 4 informal workgroups be formally established sub-committees. He asked the council if these adequately capture the overall charge of the council. Mr. Coe motioned to formally establish the workgroups as sub-committees, and Mr. Collins seconded the motion. The motion was approved. A minimum of one interim conference call will occur between the sub-committees, not necessarily to be facilitated by Dr. Humberd. Dr. Malow suggested that there be an information-sharing website so that the sub-committees can see what each other are doing. Ms. Heart stated that the state just transitioned to the Adobe Management System. DIDD has a placeholder site for this council. This can house whatever resources that the council wants to put on there. There are some limits to how it can look cosmetically because of branding. Dr. Malow stated that having sub-committee action items visible would be helpful to sub-committees that have similar or overlapping topic items. Ms. Gauld suggested that the chairs of the 4 committees can also meet in advance of sub-committee calls. Dr. Humberd stated that he will plan to audit all of the sub-committee conference calls, while not taking such a lead role.

### Info for Families/Service Coordination

This sub-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. 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 identified by this committee:

- Ask administrative agencies on the council to provide a map of how people and families enter their services. Perceived gaps?
- Kidcentraltn and Disability Pathfinder. What agency would be the lead in creating such an aligning system for lifespan approach to lifespan info about ASD? Ms. Clark is on the kidcentraltn steering committee.
- 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 may have some suggestions.
- TN Promise transition training is not ASD specific. Who could develop customized training as a 2-year program at a community college? Ms. Roth 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. Ms. Gauld stated that TN Promise prepares and pays for college, which is different from employment.
- Consistent information sharing across agencies.

**Early Identification/Education**

- Diagnosis of Autism v. Developmental Delay – Whatever the diagnosis, services must match the needs.
- Information for school psychiatrists – Presentation on what training they receive.

**Healthcare** – This report was tabled until the April meeting.

**Aging and Adulthood** – This report was tabled until the April meeting.

**Action Items/Wrap-Up**

- Disability Day on the Hill – February 14, 2018. Ms. Westlake encouraged everyone to attend. Legislators really need to hear that people care about the ABA issue. Everyone can attend and state that they are on the council and thank the legislature for establishing the council, but they cannot state that they represent the council. Disability Day on the Hill Community Reception: The Tennessee Disability Coalition and other advocacy organizations are hosting a Community Reception at the Millennium Maxwell House Hotel in MetroCenter the Tuesday evening before DDH from 5-7pm. Join other disability advocates, elected officials and key government officials for appetizers, drinks and an opportunity network with others in a relaxed setting. There is no cost to attend but registration is required.
- Dr. Malow will provide a list of resources for distribution to the council.

- Sub-committee conference calls will be scheduled in advance of the April meeting. Volunteers to chair those sub-committees will be appreciated.

### **ADJOURNMENT AND NEXT MEETING DATE**

There being no further business, the meeting adjourned.

The date of the next meeting is Tuesday, April 24, 2018, from 10:00a.m. - 2:00pm CT at the Tennessee Bureau of Investigations, Training Room 1, 901 R S Gass Boulevard, Nashville, TN 37216.

Respectfully submitted,  
Solita Morris, CAP, Policy Coordinator  
Department of Intellectual and Developmental Disabilities  
Citizens Plaza – 9<sup>th</sup> Floor  
400 Deaderick Street  
Nashville, TN 37203  
[Solita.morris@tn.gov](mailto:Solita.morris@tn.gov)

**DEPARTMENT OF INTELLECTUAL AND DEVELOPMENTAL DISABILITIES  
TN COUNCIL ON AUTISM SPECTRUM DISORDER  
MEETING MINUTES  
HERMITAGE PUBLIC LIBRARY  
3700 JAMES KAY LANE, HERMITAGE, TN 37076  
JANUARY 23, 2018**

CHAIRPERSON	Chair, Dr. Quentin Humberd
TYPE OF MEETING	TN Council on Autism Spectrum Disorder
MEMBERS PRESENT	Mary Ellen Chase, Carolina Clark, Roddey Coe, Michael Collins, Ginger Day, Will Edwards, Dr. Vaughn Frigon, Alison Gauld, Rachel Jade-Rice and Miles Brooks (proxy for Lorrie Brouse), Dr. Beth Malow, Dr. Jeanine C. Miller, Rose Naccarato, Jenness Roth, Emma Shouse (proxy for Wanda Willis), Heather Taylor Griffith (proxy for Matt Yancey)
MEMBERS ABSENT	Emelyne Bingham, Iseashia Thomas
QUORUM	There was a quorum of TN Council on Autism Spectrum Disorder members present.
DIDD STAFF PRESENT	Pat Edmiston, Alex Heart, Solita Morris
GUEST PRESENTERS	Cara Kumari (DIDD), Dr. Keivan Stasson (Vanderbilt Autism and Innovation Center)
GUESTS FROM PUBLIC	Vanessa Bell, Katie Lee, Jacqueline Nigrelli, Amy Rader, Babs Tierno, Janet Shouse, Carol Westlake

**Call to Order/Introductions/Approval of Meeting Minutes**

Dr. Humberd welcomed the council and guests. Introductions were made around the room. Dr. Humberd reminded the council that membership is a balance of half governmental agencies and half community (East, Middle, and West). The minutes from the January 23, 2018, were reviewed and approved as submitted.

The minutes from the sub-committee conference calls, which took place on April 3, 2018, were referenced with regard to action steps, which will be discussed later during the meeting. One across-the-board action item was for government agency council members to submit an informational statement regarding how their agencies interface with autism spectrum services.

**TennCare** – Dr. Frigon distributed a presentation outlining where TennCare stands on payment reform issues, which is included with these meeting minutes. The budget is currently \$12.2 million. He discussed cost-effectiveness and appropriate outcomes. Some of the programs that have been put into place to optimize care are the Long-Term Services and Supports (LTSS) Program, Primary Care Transformation via Patient-Centered Medical Homes, and Acute Episodes of Care. The Episodes of Care prong resulted in over \$10 million savings in 2015, and \$14.5 million in 2016. TennCare’s goal over time is to increase the flow of information to front-line healthcare providers.

Dr. Frigon stated that Tennessee was the first state to operate through the Managed Care Organizations (MCOs), and 30 states have come to Tennessee to see how to operate through MCOs.

**Question:** What is the transition of policy in how MCOs are implementing Applied Behavioral Analysis (ABA) coverage?

**Answer:** In October of 2017, each MCO developed its own guidelines around ABA. As long as ABA services meet medical necessity criteria, they are covered. Specific examples of individuals who are not receiving the care that they need would be helpful in addressing these issues.

**Question:** How is the program specifically training providers to address Autism Spectrum Disorder (ASD)?

**Answer:** One way this is addressed is through training vendors who will work with providers and Primary Care Physicians (PCPs).

**Comment:** Dr. Malow suggested incentivizing PCPs in non-monetary ways. There could be low-cost/high-yield ways to engage PCPs who are not currently engaged in addressing ASD issues.

**Comment:** The CDC will be announcing next week where Tennessee stands in number of people diagnosed with ASD.

**Department of Health (DOH)** – Dr. Clark distributed a presentation, which is included with these meeting minutes. Among the strengths of the DOH service delivery system are promotion of developmental screening, developmental screening training for home visitors, etc. “Welcome Baby” is an evolving program where all new parents are furnished with information about monitoring for disabilities. KidCentralTN is a website from the Governor’s Children’s Cabinet and is designed to be a one-stop shop for navigating resources for children.

Among weaknesses in service delivery is a lack of focus on subsequent care coordination for children or adults with autism. Children with autism or developmental delay do not qualify for the Children’s Special Services (CSS) program.

Opportunities include Community Health Access and Navigation in TN (CHANT) and collaboration

with DOH and Child Care Resource and Referral Network.

Threats include services not being near enough to home or affordable for some people and no lifespan service delivery.

**Question:** What physical disabilities qualify for CSS?

**Answer:** That is outlined in legislation, which Dr. Clark will share with the council.

**Question:** Is DOH working with Customer Focused Government (CFG) on TeamTN? TeamTN is a website where personal profiles are automatically connected with resources.

**Answer:** We are not sure of the connection but will try and find out.

**Question:** How many profiles are on KidCentralTN?

**Answer:** It is a widely used resource.

**Tennessee Commission on Children and Youth (TCCY)** – Ms. Naccarato reported that her agency does not provide direct services. What they do is advocate and encourage collaborations. There has not been a strong focus on ASD, but in the Fall they will be the new home of KidCentralTN. It will be administered by Strategic Technology Solutions (STS). They also house the Council on Children’s Mental Health and the Home Visiting Leadership Alliance. In addition, they have Regional Council staff in all nine developmental districts across Tennessee. These are all places that could be avenues to raise awareness and encourage networking.

**Question:** How do we get ASD on the advocacy agenda for TCCY?

**Answer:** Ms. Naccarato will take concerns and issues of the council back to the agency.

**Question:** Where does TCCY reporting go?

**Answer:** Reporting goes to the Legislature and is on the website.

**Department of Human Services (DHS)** – Ms. Day distributed a presentation on services and supports for people with ASD to the council, which is included with these meeting minutes. The focus on the presentation was the work of Tennessee Rehabilitation Center’s (TRC’s), Vocational Rehabilitation (VR) Program. The presentation contains statistical data around people with ASD in TN. There are currently 17 TRC centers across the state. TRC-Smyrna is one of eight (8) nationwide comprehensive vocational rehabilitation training centers. TRC also has a Comprehensive Vocational Evaluation Service, Employment Readiness Program, Traumatic Brain Injury (TBI) Program, and Visual Impairment Services (VIS) Program. They offer support services for many needs, including ASD.

23.4% of the TRC student body has ASD (that is 111 people). A Social Skills Training Boot Camp is offered to people with ASD. VR served 611 people with ASD in 2016-2017.

**Question:** What training are counselors receiving around ASD? Is a certain amount of ASD training required?

**Answer:** Recent work with the Vocational Rehabilitation Development Group has been beneficial in helping counselors recognize ASD. There will be a set amount required in the future.

**Question:** Is current employability of student body with ASD (1 in 5) anticipated to increase?

**Answer:** Yes. There are several direct-support programs to work with young people who are interested in going straight to work out of high school.

**Question:** Is any kind of longitudinal research being done to follow-up with individuals to determine if they are still working after 1+ years?

**Answer:** That will be something that is tracked.

**Question:** Who is eligible for Vocational Rehabilitation?

**Answer:** People with a diagnosis of a documented disability that causes barrier to employment are eligible. Eligibility is determined by the Comprehensive Vocational Evaluation.

**Question:** What is the order of priority?

**Answer:** For funding purposes, TRC only serves people who meet priority categories 1 and 2. Individuals have to have a primary and secondary diagnosis that poses impediments to employment.

**Question:** What level of independence is required to attend TRC?

**Answer:** People enrolled in a program at TRC need to be able to navigate the campus safely.

**Question:** How many people get kicked out of TRC?

**Answer:** There are causes for termination, such as drug use or other rule violations that lead to suspensions and/or expulsion.

**Question:** Is transportation or driver's education part of the services offered?

**Answer:** Assistance with transportation is provided. Driver's Education is offered in the communities. Most graduates will rely on public transportation. There is not currently a driver education service

offered to people with Autism.

**Question:** Is there a waiting list?

**Answer:** There is no waiting list at this time.

**Question:** Is the Boot Camp still open? Is transportation provided?

**Answer:** Yes, Boot Camp is still open. Transportation is not provided.

**Question:** Do services take into account goals to go on to post-secondary education, rather than employment.

**Answer:** Yes.

**Department of Mental Health and Substance Abuse Services (DMHSAS)** – Heather Taylor Griffith, Office of Children, Young Adults & Families, provided handouts, which are included with these meeting minutes. DMHSAS does not provide direct services. They contract with providers. Its focus is on services and supports that are best practices that are not reimbursed.

The Regional Intervention Program (RIP) for children ages 2-6 with behavioral challenges is a free service that does not require diagnosis. This data-driven program is grounded in ABA principles.

They administer the Planned Respite Program (children with Serious Emotional Disturbance (SED) or SED/ASD) and Respite Vouchers (either/or).

They administer the System of Care Across Tennessee Grant that implements a high-fidelity wraparound approach. This program can serve ASD, as long as a mental health diagnosis is also present.

The Office of Crisis Services and Suicide Prevention addresses a spectrum of services, including ASD. There are 4 mental health institutes across the state that also serve people with ASD.

Ms. Taylor Griffith also discussed the Individual Placement and Support model collaboration with DIDD around employment.

**Question:** Is there an ongoing emphasis on getting people first trained and then employed?

**Answer:** Yes. There is a lot of opportunity to increase awareness and increase peer voice. DMHSAS is exploring building capacity through peer involvement and advocacy.

**Question:** Where are the Family Support Specialists housed?

**Answer:** Family Support Specialists are housed at schools and provider agencies.

**Question:** How does DMHSAS interact with TN VOICES for Children?

**Answer:** They are one of the providers for Family Support and Advocacy. They also partner via information sharing and networking.

**Question:** Do diagnoses of anxiety or Attention Deficit Hyperactivity Disorder (ADHD), in addition to ASD qualify?

**Answer:** Yes.

**Question:** Is there information on wraparound supports about what ASD is and what it looks like in children?

**Answer:** That is something that could be improved.

**Question:** What is the RIP waiting list like?

**Answer:** It varies by county.

**Question:** How can RIP be expanded to all 95 counties?

**Answer:** Funding is a consideration, as well as capacity. It depends on who would be willing to take that on. DMHSAS does hope to grow the program.

**Question:** Does TN VOICES for Children offer support for families?

**Answer:** That is under Family Support and Advocacy, so that is something that they offer.

**Tennessee Council on Developmental Disabilities** – Emma Shouse distributed a fact sheet, which is included with these meeting minutes. This council is mandated through the Developmental Disabilities Act. They have 21 governor-appointment council members.

**Question:** Where does scholarship money come from?

**Answer:** Federal and State council budget.

**Department of Education (DOE)** – Ms. Gauld distributed several handouts, which are included with

these meeting minutes. The scope of DOE services is birth through 22. One of the most complicated aspects is determining how autism services fit into the Individual Education Plan (IEP). To be eligible, two prongs must be met. The goal of the DOE is to provide what is needed in terms of services and supports without removing anything. There is a legal requirement of standard. This standard can be exceeded, but services cannot be less than the standard. At the point of IEP, something has to be given up in order to get that intensive assistance. Special Education services are intended to come into play as a last resort. The goal is to get students back to general education as soon as possible.

Special Education SWOT – Individualized is strength (specific to person), weakness (loss of richer experience of general education interaction), opportunity (chance to focus on improvements), and threat (how to ensure needs are met w/o formula). The goal of the agency is honor restrictive environments, which are set by the students. Educator jargon is a weakness. Parents being active members of the IEP team is a constant effort. Opportunities are in engagement with stakeholders. Anyone who has met a child is a stakeholder. Recommendations from this council are an opportunity. Threats would be medical v. school diagnoses. Medical diagnosis assumes a need within schools. Medical diagnosis does not mean anything unless there is an impact on students. There are not enough specialists/therapists across Tennessee.

**Question:** What is the difference in diploma and certificate?

**Answer:** A diploma is federally recognized. A certificate could be a GED or other document. The IEP diploma is not federally recognized.

**Question:** Is work done to train after school care providers for children with ASD?

**Answer:** That would be at an agency's own cost. That is not a school system matter.

**Question:** Is there any movement to create aftercare through the DOE that would be trained in ASD?

**Answer:** There is no funding or capacity for that within DOE.

**Department of Intellectual and Developmental Disabilities (DIDD)** – Dr. Jeanine Miller provided a listing of DIDD services, which is included with these meeting minutes. She noted that the Intensive Behavioral Residential Service (IBRS) is no longer offered, as it cannot be made compliant with the HCBS Settings Rule. DIDD works with TennCare in various aspects of the Employment and Community First (ECF) CHOICES Program. DIDD staff are involved with intake for enrollees who do not have an MCO, as well as in a Protection from Harm capacity. An FAQ for the Family Support Program is included in this information. Lastly, an overview of the Seating and Positioning Clinics was provided.

In terms of strengths, DIDD staff are extremely qualified and dedicated. DIDD is accredited through the Council on Quality and Leadership (CQL) and continues to improve in that area. Opportunities would be to increase funding for Family Support; develop training and policy around Supported

Decision Making; and expand other “unseen” services. Threats include the Direct Support Professional (DSP) staffing/retention crisis. Weaknesses include a resistance to change.

**Question:** Is it correct that there is no waiting list for Family Support and that it is either approved or not?

**Answer:** Correct.

**Question:** Is the Seating and Positioning Clinic open to community or just waiver recipients?

**Answer:** This is a community service. In order to be served, the person must have specified insurance or self-pay.

**Question:** How many provider agencies serve people with ID in the state?

**Answer:** There is directory of provider agencies on the website. It is over 300. Dr. Miller will run a query to find out how many people in DIDD services also have ASD.

**Question:** Are there any unintended consequences for DIDD with the implementation of the ECF CHOICES Program?

**Answer:** This question was deferred to Carol Westlake from the Developmental Disabilities Coalition. Ms. Westlake stated that family conversations relative to this focus on figuring out how to serve people with more significant needs. ECF is an opportunity to serve younger people fresh out of school who want to explore work. New service groups 7 and 8 may be the answer to these concerns.

**Department of Commerce & Insurance (DCI)** – Miles Brooks distributed an informational paper describing mandated benefits for ASD, which is included with these meeting minutes. Statute only covers children 12 and under. There is proposed legislation that would cover any age. The agency does not have direct oversight of people with ASD over 12 years old. They oversee policy.

### **Discussion on Sub-Committee Action Steps - Council**

Dr. Humberd provided an overview of the Information for Families conference call and action steps identified. In addition, he reviewed the Early Identification/Education sub-committee.

Pat stated that the Autism Summit Team is very interested in this council’s sub-committees, and they want to help move the councils’ agenda forward by supporting it with science and data.

There was discussion about Voices4Choices. This program is through Family Voices of Tennessee and is a part of the Tennessee Disability Coalition, which was awarded a Robert Wood Johnson Foundation Consumer Advocacy for Transformation grant. This funding enables Family Voices and the Tennessee Disability Coalition to enhance input into Tennessee’s evolving ECF Choices program. ECF

Choices serves people with intellectual and developmental disabilities, and Voices4Choices is seeking input of "consumers," (defined as those who have applied and/or are receiving services, their families and their conservators) at "Listening Sessions" that will be held across Tennessee. The two year Voices4Choices project will provide training and support for ECF members, family members and conservator to serve on advisory councils created by TennCare and the managed care organizations (BlueCare, United Health Care, and Amerigroup).

### **Update on Vanderbilt Center for Autism & Innovation – Dr. Keivan Stassun**

Dr. Stassun presented a follow-up to his January presentation. His handouts are included with these meeting minutes. Development for online certification courses Pre-ETS and VR professionals through the Vanderbilt Kennedy Center that has the seal of approval from Specialisterne USA, Vanderbilt, and NADD using a stackable credentials model. Now working on a state by state level to get people to sign on. Courses will be available in January.

### **Autism Council Website/Videos – Cara Kumari, DIDD Director of Communications**

Ms. Kumari presented the development of the website for the Autism Council. This will be where membership information, agendas/minutes/reports, and community resources are housed.

Ms. Kumari needs input from the council regarding main page design and content. She referenced the Minnesota website as an example of people with ASD in the community.

Ms. Kumari would also like to publish one-one-one interviews of members who are willing. Janet Shouse suggested publishing a video about first steps after diagnosis.

All suggestions for content and design may be submitted to [cara.kumari@tn.gov](mailto:cara.kumari@tn.gov).

### **Action Items/Next Steps**

- Cindy Gardner, Attorney, will be asked to attend our next Council meeting to assist with putting together a "Legal Toolkit" for families.
- ECHO/Tele-health Presentation
- Voices4Choices program and upcoming Listening Sessions across the State (sponsored by the Tennessee Disability Coalition)
- Education for Parents (STEP – Support Training for Exceptional Parents, etc.)
- ABLE TN Presentation

### **Adjournment/Next Meeting Date**

There being no further business, the meeting adjourned.

The date of the next meeting is Tuesday, July 24, 2018, from 10:00a.m. - 2:00p.m. (Central Time) at the

Tennessee Bureau of Investigations, Training Room 1, 901 R S Gass Boulevard, Nashville, TN 37216.

Respectfully submitted,  
Solita Morris, CAP, Policy Coordinator  
Department of Intellectual and Developmental Disabilities  
Citizens Plaza – 9<sup>th</sup> Floor  
400 Deaderick Street  
Nashville, TN 37203  
[Solita.morris@tn.gov](mailto:Solita.morris@tn.gov)



DEPARTMENT OF INTELLECTUAL AND DEVELOPMENTAL DISABILITIES  
 TN COUNCIL ON AUTISM SPECTRUM DISORDER  
 MEETING MINUTES  
 TENNESSEE BUREAU OF INVESTIGATIONS  
 901 R S GASS BOULEVARD, NASHVILLE, TN 37216  
 JULY 24, 2018

CHAIRPERSON	Chair, Dr. Quentin Humberd
TYPE OF MEETING	TN Council on Autism Spectrum Disorder
MEMBERS PRESENT	Mary Ellen Chase, Dr. Carolina Clark, Roddey Coe, Michael Collins, Ginger Day, Will Edwards, Dr. Vaughn Frigon, Miles Brooks (proxy for Lorrie Brouse), Dr. Beth Malow, Dr. Jeanine Miller, Rose Naccarato, Jenness Roth, Wanda Willis, Heather Taylor Griffith (proxy for Matt Yancey), and Iseashia Thomas (via telephone for first half of the meeting)
MEMBERS ABSENT	Emelyne Bingham and Alison Gould
QUORUM	There was a quorum of TN Council on Autism Spectrum Disorder members present.
DIDD STAFF PRESENT	Pat Edmiston, Robin Wilmoth, Krystyne Brown, and Crissonya Phillips
GUEST PRESENTERS	Cindy Gardner, Attorney with the Special Needs Law Center, and David Ward, Financial Outreach Executive, ABLE TN, Tennessee Department of Treasury
GUESTS FROM PUBLIC	Katie Lee (TennCare), Shannon Nehus (TennCare), Janet Shouse (Vanderbilt Kennedy Center), Carol Westlake (Tennessee Disability Coalition), Cari Parr (Special Education Teacher, Rutherford County), Dr. Toni Whitaker (UT Boling Center in Memphis), and Angelica Moore (Student)

### **Call to Order/Introductions/Approval of Meeting Minutes**

Dr. Humberd welcomed the council and guests. Introductions were made around the room. The minutes from the April 24<sup>th</sup>, 2018, were reviewed. Jeanine Miller made a motion to accept the minutes as written and Jenness Roth seconded the motion. The minutes were approved as written.

### **David Ward, Financial Outreach Executive, ABLE TN, Tennessee Department of Treasury**

David Ward was invited to share the ABLE TN program with the Council. (His ABLE TN brochure and Power Point presentation are attached to these minutes.) ABLE TN "Achieving a Better Life Experience" is designed to help Tennesseans with disabilities set aside money to pay for future qualified expenses. ABLE TN allows a person with a disability to open a savings account for \$25 via the Tennessee Department of Treasury on-line. The account must be in the person with a disability's name. A person can have up to \$15,000 per year and up to \$100,000 (over time) without it effecting their Social Security or Medicaid (TennCare) benefits. There is a \$350,000 lifetime limit in the account. Funds in excess of \$100,000 will be treated as a resource. There is a "U-Gift" code for family and friends to use in order to deposit directly into the person's account at any time (for birthdays, graduation, holidays, etc.).

Tennessee was the second state to pass legislation opening ABLE accounts and anyone could upon an account here. Now there are 33 states with ABLE accounts. Currently there are 1833 ABLE TN accounts and 60% of those are for individuals outside of Tennessee. Now only Tennessee residents can open an ABLE TN account. There are \$11,341,236 in total assets at this time.

Question: Can a person that has a Representative Payee over their Social Security checks and finances open an ABLE TN account? This question was specific to the individuals that live at the West, Middle, and/or East Community Homes and the State of Tennessee is their Rep Payee.

Answer: NO for now. This is an issue with the federal legislation. David and Cindy Gardner agreed to look into this issue more and try to figure it out, as many of these individuals could open ABLE TN accounts now.

More details of the ABLE TN account is outlined in the attached brochure and Power Point. They can be reached at: 855-922-5386, their website is: AbleTN.gov, their e-mail address is: [able.tn@tn.gov](mailto:able.tn@tn.gov), and/or you can view them on YouTube at: [youtube.com/user/tntreasury](https://www.youtube.com/user/tntreasury).

### **Cindy Gardner, Attorney with the Special Needs Law Center**

Cindy Gardner was invited to assist the Council members with the development of a "Legal Toolkit" for families and people with Autism Spectrum Disorder. (Her handouts are attached to these minutes.) There was a lot of discussion around having a central place for families to access legal

information and resources. There are currently resources on the TN Pathfinder website, however they cannot make recommendations. The Council talked about how to structure the information and it was agreed that everyone would like the "Legal Toolkit" as a resource page on the new TN Council on Autism Spectrum Disorder's website when it is up and running (inside the DIDD website). Again, this would only have resources and not specific recommendations.

The Council would like videos on the website by both Cindy and David Ward explaining legal and financial considerations. This was discussed as part of a possible technical assistance project through DIDD. These videos and resources can be broken down into the "Lifespan Approach" discussed below with regards to specific considerations at difference ages.

Cindy discussed Power of Attorney, conservatorship, and the new legislation around Supported Decision Making. There is an issue in Tennessee around lack of training programs for conservators. Tennessee, by definition, has "limited" conservatorships (being as limited as possible with regard to removing an individual's rights). The wording will be "over the person" or "over the estate" and most of the individuals with developmental disabilities do not have an estate. If so, the Court oversees those conservatorships. "Over the person" usually involves control over healthcare (medical and therapy), education, where the person is going to live, and finances. (Finances may not be a part of the conservatorship document if the person has a Representative Payee.) Regarding finances, there is a new option of a "True Link" ([truelinkfinancial.com](http://truelinkfinancial.com)) card that is tied directly to someone's checking account. The usage can be monitored and the parents or conservators can set limits, such as \$40.00 a week or can restrict certain purchases, but there is a \$10.00 a month fee.

### **Special Needs Trusts:**

*1<sup>st</sup> Party Special Needs Trust (also called the "Oops trust"):* a trust is created for the person with a disability and it can hold money, land, house, cars, etc. and is usually opened as a result of a large inheritance (but not always). If the person dies before the age of 55, the State of Tennessee will waive making a claim against the person's estate, including the Trust. If the person dies after the age of 55, the State may get reimbursed the amount that was spent on them through TennCare.

*3<sup>rd</sup> Party Special Needs Trust:* a trust that is created using someone else's funds (not the SSI recipient) and can be "free-standing or can be established in another person's Will (like a parent and/or grandparent). If the individual with a disability passes away, the original Will stipulates who gets the Special Needs Trust. This keeps the State of Tennessee from recouping money spent on the person.

There was a lot of discussion around Autism Spectrum Disorder (ASD) and applying for SSI, SSDI, and the appeals process with the medical diagnosis. (This information is on the attached handout.) There

needs to be a detailed and accurate paper trail of evidence, as the Social Security requirements do not change and the person with ASD can often apply at age 18. There is concern with documentation over time and as the person gets closer to 18 they need to have an updated evaluation and/or good documentation. The IEP should note all "deficits and challenges" as opposed to how well the person is doing. There is a need to get the Department of Education on board, as students with ASD no longer need to have a medical diagnosis, only an educational classification. Council members recommended that Cindy present at the Department of Education's Special Education PIE Conference (Partner's in Education) that will be in February 2019. This would be a great opportunity to educate teachers on how to better document in the IEP in order for the student to apply for SSI at the age of 18.

Cindy shared the possibility of partnering with the "Conservatorship Association of Tennessee" (catenn.org) as they provide training and outreach. Cindy agreed to continue working with the Council as they move forward toward developing legal resources for families and individuals with ASD.

### **Public Comments**

Carol Westlake shared a new program with the Council that is a partnership between Family Voices and the Health Department. They are developing a "Youth Advisory Council." The purpose of the Youth Advisory Council is to bring together youth or young adults (ages 14-24) to advise and collaborate with TN Department of Health on activities, programs, policies and resources affecting the health, wellness, and transition of youth in our state. The group meets quarterly. It is an opportunity to meet other young people, with and without special health care needs, and to socialize and discuss issues. For more information, interested youth and families can contact Jama Mohamed, Youth Program Coordinator at Family Voices of Tennessee, Tennessee Disability Coalition: [jama\\_m@tndisability.org](mailto:jama_m@tndisability.org).

### **Discussion and Vote on Committee Action Items - Council**

The four committees of the Council met via WebEx conference calls on June 26<sup>th</sup>, 2018. Each committee developed action items to be discussed and voted on by the full Council. There was a lot of discussion around each action item from the four committees and the original action items developed. In each area, there were items that need more information and research. Several of the action items were merged together to create one solid action item from each committee.

#### **1. Information for Families/Service Coordination:**

This committee agreed to develop a "Lifespan Approach" with the following breakdown of ages:

Birth to 3 years old (TEIS)

3 to 5 years old (pre-school, Headstart, etc.)

5 to 21 years old (local school system)

21+ years old (employment, Social Security, legal information, etc.)

Under each age category the Council discussed examples of what information would be important to include as we move forward: diagnosis, standards for eligibility, consistent and accurate information for families, with a possible "Family Navigator" in each County Health Department, links to the Department of Education, Special Education supervisor's contact information, legal and financial resources, etc.

The Council agreed that they need to get additional information regarding Tennessee Promise. They would like data and also consider having someone come speak to the Council as this program relates to individuals with ASD.

Jeanine Miller made a motion to accept the following action item. Jenness Roth seconded the motion and it was passed by the full Council:

**Action Item:** *The Autism Council will develop a "Lifespan Approach" with a resource map and timeline of suggested actions for families and individuals that will include available resources, and will provide additional information on legal and financial supports.*

## **2. Early Intervention/Education:**

There was a lot of discussion around all four original action items, especially the concerns with TEIS (Tennessee Early Intervention System). There seems to be an issue with the workforce, as well as overburdened caseloads. The Council agreed that they would like meaningful data from TEIS and would like to invite someone from TEIS to present to the full Council.

The action item relating to workforce development (recruitment, retention, and technical assistance) was put on hold.

Roddey Coe made a motion to accept the following action item. Miles Brooks seconded the motion and it passed by the full council:

**Action Item:** *The Autism Council will promote parent, teacher, and administrator training across the early intervention and education system, and support a collaborative approach for individuals and families concerning educational rights and responsibilities.*

### **3. Healthcare:**

On July 20<sup>th</sup>, Dr. Humberd, Dr. Malow, Dr. Frigon, and Pat Edmiston participated on a conference call to discuss the ECHO project (“Extension for Community Healthcare Options”) and tele-health opportunity for physicians across Tennessee. (The notes from this call are attached to these minutes.) Dr. Frigon informed the Council that he will be meeting with the Medical Directors of the three MCOs (BlueCare, Amerigroup, and United Health Care) in order to discuss these options for their doctors. After meeting with them, he will set up a time for Dr. Humberd and Dr. Malow to meet with the Medical Directors to discuss “Healthcare Medical Homes” and the tele-health process as it relates to early identification and treatment of people with ASD. All the TennCare funding funnels through the MCOs and there is no fee for service billing. Dr. Malow shared a handout and explained the ECHO project (and it has been attached to these minutes).

This committee had previously discussed having the Department of Commerce and Insurance develop a “chart or grid” of what services insurance companies provide for individuals with ASD (for the companies that they oversee). It was agreed that this action item needs more research and we may have someone from this department present insurance information to the full Council.

Jeanine Miller Jeanine Miller made a motion to accept the following action item. Michael Collins seconded the motion and it was passed by the full Council:

**Action Item:** *The Autism Council will collaborate on the development of a System of Care based on principles of the Medical Home that supports the provision of comprehensive health services statewide and utilizes technology to provide both services for patients and training for healthcare providers serving individuals with ASD and their families across the lifespan.*

### **4. Aging/Adulthood:**

Vocational Rehabilitation (VR) counselors are now receiving training around Autism Spectrum Disorder. Ginger Day provided the training table of contents to the Council before the last meeting. It

was discovered that this training is not required of the contracted vendors with VR, which everyone had an issue with. We would like this to be required, which may require a contract and/or policy change through VR.

Regarding the action item around better educating self-advocates, Dr. Beth Malow shared that one of her sons recently went through the VR "Bootcamp" and really enjoyed it. Ginger Day agreed to share the curriculum with the Council. There seems to be a lot of different opportunities for self-advocates to benefit from and the Council agreed to gather more information around this topic.

Dr. Humberd made a motion to accept the following action item. Dr. Beth Malow seconded the motion and it passed by the full council:

**Action Item:** *The Autism Council will promote training for Vocational Rehabilitation (VR) professionals across the State, and will work to build collaborations and develop policies that provide for successful transitions from educational services into adulthood and meaningful employment.*

### **Action Items/Next Steps**

- Invite someone to present from the TN Promise program at a future Council meeting.
- Invite someone from TEIS to present at a future Council meeting.
- Invite the Department of Commerce and Insurance to present data on their regulated insurance companies with regards to services for people with ASD.

### **Adjournment/Next Meeting Date**

There being no further business, the meeting adjourned at 2:00 p.m.

The date of the next meeting is Tuesday, October 30<sup>th</sup>, 2018, from 10:00a.m. - 2:00pm CT at the Tennessee Bureau of Investigations, Training Room 1, 901 R S Gass Boulevard, Nashville, TN 37216.

Respectfully submitted,  
Patricia Edmiston, Director of Developmental Disabilities  
Department of Intellectual and Developmental Disabilities  
Citizens Plaza – 9<sup>th</sup> Floor  
400 Deaderick Street  
Nashville, TN 37203  
[patricia.edmison@tn.gov](mailto:patricia.edmison@tn.gov)

**DEPARTMENT OF INTELLECTUAL AND DEVELOPMENTAL DISABILITIES  
TN COUNCIL ON AUTISM SPECTRUM DISORDER  
MEETING MINUTES  
TENNESSEE BUREAU OF INVESTIGATIONS, TRAINING ROOM 1  
901 R S GASS BOULEVARD, NASHVILLE, TN 37216  
OCTOBER 4, 2017**

MEETING CALLED BY CHAIR & FACILITATOR	Chair, Dr. Quentin Humberd & Pat Edmiston
TYPE OF MEETING	TN Council on Autism Spectrum Disorder
MEMBERS PRESENT	Emelyne Bingham, Lorrie Brouse, Mary Ellen Chase, Carolina Clark, Roddey Coe, Michael Collins, Ginger Day, Will Edwards, Dr. David Collier (proxy for Dr. Vaughn Frigon), Alison Gauld, Dr. Beth Malow, Dr. Jeanine C. Miller, Rose Naccarato, Jenness Roth, Iseashia Thomas, Emma Shouse (proxy for Wanda Willis), Heather Taylor (proxy for Matt Yancey)
MEMBERS ABSENT	
QUORUM	There was a quorum of TN Council on Autism Spectrum Disorder members present.
DIDD STAFF PRESENT	Commissioner Debbie Payne, Kimberly J. Black, Alex Heart, Cara Kumari, Solita Morris, Theresa Sloan
GUESTS	Will Hines (TennCare), T.A. McDonald (Vanderbilt Kennedy Center), Cecilia Melo-Romie (Vanderbilt Kennedy Center), Susan Rollyson, Janet Shouse (Vanderbilt Kennedy Center), Carol Westlake (Presenter, TN Disability Coalition),

**Call to Order/Welcome from Commissioner Debbie Payne**

DIDD Council Liaison and DIDD Director of Developmental Disabilities Services Pat Edmiston introduced Chairperson Dr. Quentin Humberd who called the meeting to order and introduced DIDD Commissioner Debbie Payne to offer opening remarks.

Commissioner Payne welcomed the council and thanked the members for their willingness to take on this long-overdue initiative. When Governor Haslam asked Commissioner Payne what worries her the most, her response was the service delivery system around autism. Not only does the service-delivery system need to focus on early screening and intervention, but just as importantly, on services throughout the lifespan. Person-centered supports cannot end when a child with autism becomes an adult with autism. We want better for our fellow Tennesseans. We want them to thrive in their communities, live in homes that they like, and work in jobs that they love. She looks forward to working with the council to make Tennessee the service-delivery model for people with Autism and their families.

### **The Origins of the Tennessee Autism Council – Carol Westlake, TN Disability Coalition**

Ms. Westlake's presentation is attached with these minutes. Ms. Westlake placed the Autism Planning project in context by reminding the group that 15 years ago the Centers for Disease Control (CDC) reported the prevalence of Autism to be 2-3 per 1,000. By 2009, when Tennessee convened an Autism Summit Team, the estimate was 1 in 110. Today, 1 out of every 68 children is diagnosed with Autism Spectrum Disorder. The Autism Planning Project began under the auspices of the Summit Team in 2010, and culminated with the Autism Plan and the legislation to establish the TN Council on Autism Spectrum Disorder. There have been many valuable thoughts, assessments, collaborations, and planning efforts over the last 15 years, but now is an exciting time for action.

### **Solving the Autism Puzzle for Tennessee – Dr. Quentin Humberd**

Dr. Humberd's PowerPoint presentation is attached with these minutes. The presentation featured an overview of work that has taken place in Tennessee prior to the establishment of the council including: Senate Joint Resolution 567 and The Tennessee Developmental Disabilities Expansion Plan in 2002; a history of the START Program (<https://www.tnaap.org/programs/start/start-overview>); the 2009 Tennessee Comptroller of the Treasure, Offices of Research and Education Accountability (OREA) reports about public services for infants, children, and youth with autism in Tennessee (The OREA reports may be accessed at:

<http://www.comptroller.tn.gov/orea/PublicationDetails?ReportKey=e7d186c5-eea3-4616-8328-43ef1a917741>); the Federal Region IVA Learn the Signs – Act Early (LTSAE) Summit in 2009; the

Tennessee Act Early Team, which meets semi-monthly with the goal to create a plan to build, improve, and sustain a coordinated system of care for children and youth with Autism Spectrum Disorders/Developmental Disabilities; and the Autism Plan for Tennessee 2014.

Dr. Humberd stated that informed policy discussions may require more comprehensive autism data than is currently available. Policymakers may wish to consider the following points related to this issue:

- Federal and state laws require the Tennessee Department of Education's (TDOE) Division of Special Education to collect data on children with autism receiving education services.
- Federal and state laws do not require service provision data on children from birth to age 3 to be categorized by specific disabilities. Such data could provide specific information on statewide capacity for early identification of and intervention for autism.
- While the Individuals with Disabilities Education Act (IDEA) data alone is not appropriate for estimating statewide autism prevalence, it may be useful for generating autism prevalence when combined with other data sources, such as medical diagnostic information. Some states have developed Autism Registries to develop prevalence estimates, evaluate services, and inform constituents of available resources.
- Tennessee does not receive grants for collecting data exclusively on autism.
- Most Tennessee laws affecting autism services affect all children with developmental disabilities; therefore, any policy change to those laws – unless specified otherwise – would alter all developmental disability services.

### **Backwards Imaging Exercise - Council**

Notes from this exercise are attached with these minutes. Dr. Humberd facilitated an exercise in which each council member was asked to consider the areas of Early Identification, Service Coordination/Information for Families, Education, Healthcare, and Aging/Adulthood. He then asked each person to write down at least one outcome for one or more of those categories that they would like to see achieved at the end of 3 years and to then describe to the council the steps that would have been taken to achieve that goal.

### **Action Items/Wrap-Up**

Based on the discussion that took place during the Backwards Imaging exercise, it was agreed that sub-committees would convene for each of the categories identified to continue work in the interim of the quarterly council meetings so that forward momentum is maintained. Each council member self-assigned themselves to their committee(s) of interest. Dr. Humberd and Pat Edmiston will participate in all of these sub-committee meetings to the extent that their schedules permit.

### **ADJOURNMENT AND NEXT MEETING DATE**

There being no further business, the meeting adjourned.

The date of the next meeting is Tuesday, January 23, 2018, from 10:00a.m. - 2:00p.m. at the Tennessee Bureau of Investigations, Training Room 1.

Respectfully submitted,  
Solita Morris, Policy Coordinator  
Department of Intellectual and Developmental Disabilities  
Citizens Plaza – 9<sup>th</sup> Floor  
400 Deaderick Street  
Nashville, TN 37203  
[Solita.morris@tn.gov](mailto:Solita.morris@tn.gov)



October 14, 2018

Ms. Pat Edmiston  
Director of Developmental Disability Services  
Department of Intellectual and Developmental Disabilities  
400 Deaderick Street  
Nashville, TN 37243

Dear Ms. Edmiston:

On behalf of the DIDD Developmental Disabilities Policy and Planning Council (DDPPC), it is my pleasure to submit this letter of support for the Tennessee Council on Autism Spectrum Disorder as it participates in its first Sunset hearing. Autism impacts nearly 1 in 67 individuals and is one of the most common developmental disabilities in existence today. Despite its prevalence, our system of services and supports lacks the expertise necessary to effectively support this population of individuals to maximize their quality of life. One of the many challenges to effectively supporting this population is the extreme variations in needs of people on the autism spectrum. While we have some expertise in supporting people with more significant forms of autism, the system has little experience supporting people on the spectrum who have IQs over 70.

The Tennessee Council on Autism Spectrum Disorder has taken critical steps to helping DIDD and other government departments identify the needs of people with autism across the lifespan. In the short time that this council has been in existence, they have developed concrete goals and outcomes for the Council that can positively impact Tennesseans on the autism spectrum. The Tennessee Council on Autism Spectrum Disorder has accomplished these tasks without costing the state additional money. They work closely with the DIDD DDPPC and with the Autism Summit Team – a statewide group of people committed to sharing information about efforts made to better support people on the autism spectrum across the lifespan, including early diagnosis and intervention.

The Tennessee Council on Autism Spectrum Disorder is a benefit to Tennesseans with developmental disabilities and the DIDD DDPPC supports its reauthorization.

Should you have any questions, please contact me at [cguiden@thearcn.org](mailto:cguiden@thearcn.org) or 480-236-9722.

Sincerely,

Carrie Hobbs Guiden  
Executive Director, The Arc Tennessee  
Chairperson, DIDD DDPPC

*For people with intellectual and developmental disabilities*



## **PUBLIC NOTICE**

**The Department of Intellectual and Developmental Disabilities  
Tennessee Council on Autism Spectrum Disorder  
will conduct their next meeting on**

**Tuesday, January 23, 2018  
10:00 a.m. – 2:00 p.m. CST**

**Hermitage Public Library  
3700 James Kay Lane  
Hermitage, TN 37076**

**This meeting is open to the public, space permitting.**

**For additional information or if you require ADA assistance,  
please contact  
Solita Morris at 615-253-6097**

## **PUBLIC NOTICE**

**The Department of Intellectual and Developmental Disabilities  
TN Council on Autism Spectrum Disorder  
will conduct their next meeting on**

**Tuesday, April 24, 2018  
10:00 a.m. – 2:00 p.m. CST**

**Tennessee Bureau of Investigations  
Training Room 1  
901 R S Gass Boulevard, Nashville, TN 37216**

**This meeting is open to the public, space permitting.**

**For additional information or if you require ADA assistance,  
please contact  
Solita Morris at 615-253-6097**

## **PUBLIC NOTICE**

**The Department of Intellectual and Developmental Disabilities  
TN Council on Autism Spectrum Disorder  
will conduct their next meeting on**

**Tuesday, July 24, 2018  
10:00 a.m. – 2:00 p.m. CST**

**Tennessee Bureau of Investigations  
Training Room 1  
901 R S Gass Boulevard  
Nashville, TN 37216**

**This meeting is open to the public, space permitting.**

**For additional information or if you require ADA assistance,  
please contact  
Solita Morris at 615-253-6097**

## **PUBLIC NOTICE**

**The Department of Intellectual and Developmental Disabilities  
TN Council on Autism Spectrum Disorder  
will conduct their next meeting on**

**Tuesday, October 30, 2018  
10:00 a.m. – 2:00 p.m. CT**

**Middle TN Regional Office  
One Cannon Way, Conference Room  
275 Stewarts Ferry Pike  
Nashville, TN 37214**

**This meeting is open to the public, space permitting.**

**For additional information or if you require ADA assistance,  
please contact  
Solita Morris at 615-253-6097**

## **PUBLIC NOTICE**

**The Department of Intellectual and Developmental Disabilities  
TN Council on Autism Spectrum Disorder  
will conduct its first meeting on**

**Wednesday, October 4, 2017  
10:00 a.m. – 2:00 p.m. CST**

**Tennessee Bureau of Investigation  
901 R S Gass Boulevard  
Nashville, TN 37216  
Training Room 1**

**This meeting is open to the public, space permitting.**

**For additional information or if you require ADA assistance,  
please contact  
Solita Morris at 615-253-6097**