



VANDERBILT KENNEDY CENTER  
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES



# Impact of Partnering with Providers through Telehealth and Conferences to Transform Health Care for Adults with Intellectual and Developmental Disabilities

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Janet Shouse, BJ; Jana Dreyzehner, MD;  
Maria Mello, M.Ed., BCBA  
AUCD Conference  
Nov. 6, 2017



**So, Why Do We  
Need the IDD  
Toolkit and  
Trainings for  
Medical  
Providers?**



**IDD Toolkit**



# People with IDD face health disparities

- Complex, difficult-to-treat and more frequent medical conditions
- Difficulties expressing symptoms and pain
- Atypical presentation of ill-health
- Difficulty accessing health care, either physically or financially, or both
- Inadequate or inappropriate health care
- Little or no preventive care

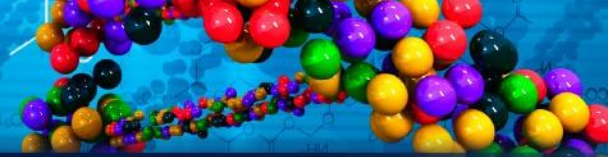


# Concerns of Practitioners

- May have little training or experience with adults with intellectual or other developmental disabilities
- May worry about patients' lack of communication
- Attitudes about people with disabilities
- “Diagnostic overshadowing”
- Issues of consent
- “Overwhelmed”
- Reimbursement issues

(See e.g., Krahn & Fox. J Appl Res Intellect Disabil. 2014;27:431-446)





# Creation of the IDD Toolkit

- Involved Vanderbilt Kennedy Center UCEDD and LEND, University of Tennessee Boling Center UCEDD and LEND, and the Tennessee Department of Intellectual and Developmental Disabilities
- Funded by Special Hope Foundation grant
- Developed an electronic Health Care Toolkit, an adaptation of Canada's "Tools for the Primary Care of People with Developmental Disabilities"
- Dr. Tom Cheetham was instrumental in helping get permission for the adaptation of the Canadian tools



Dr. Tom Cheetham,  
Deputy Commissioner  
of Health Services for DIDD

# HEALTH CARE FOR ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

## Toolkit for Primary Care Providers

HOME +

GENERAL ISSUES +

PHYSICAL HEALTH ISSUES +

HEALTH WATCH TABLES +

BEHAVIORAL AND MENTAL HEALTH ISSUES +

### GENERAL ISSUES

- Communicating Effectively
- Informed Consent
- Informed Consent Checklist
- Adaptive Functioning and Different Levels of IDD
- Office Organizational tips
- Today's Visit Form

### PHYSICAL HEALTH ISSUES

- Cumulative Patient Profile
- Female Preventive Care Checklist
- Male Preventive Care Checklist

These tools, except for Autism table, were developed by the Developmental Disabilities Primary Care Initiative (DDPCI) (2005-2014), Surrey Place Centre, Toronto, Canada, funded by Ontario Ministry of Community and Social Services and Ontario Ministry of Health and Long-Term Care, Surrey Place Centre, and Surrey Place Centre Charitable Foundation. The DDPCI published [Tools for the Primary Care of People with Developmental Disabilities](#) to complement the [Primary care of adults with developmental disabilities: Canadian consensus guidelines](#). All tools © 2011 Surrey Place Centre. Adapted for use in the U.S. by the [Developmental Disabilities Health Care](#)



[www.iddtoolkit.org](http://www.iddtoolkit.org)

- Down Syndrome
- Fetal Alcohol Spectrum Disorder (FASD)
- Fragile X Syndrome
- Prader-Willi Syndrome
- Williams Syndrome
- 22q11.2 Deletion Syndrome

### BEHAVIORAL AND MENTAL HEALTH ISSUES

- Initial Management of Behavioral

ONLINE TRAINING IS AVAILABLE USING

### THE FOLLOWING LINKS

- For health care professionals, training entitled "Appropriate Use of Psychotropic Medications for People with IDD: Helping Individuals Get the Best Behavioral Health Care". (Free CME credit is offered upon completion).





# IDD Toolkit, Phase 2--Online Video Training

- Contracted with TennCare and DIDD in response to Exit Plan for a lawsuit seeking closure of state's developmental centers that included a requirement to offer training for medical providers and individuals with disabilities, families and caregivers about the IDD Toolkit and the use of psychotropic medications
- Medical provider training: Eight 10-15 minute modules, pre- and post-test with CME credit offered
- Individual, family and caregiver trainings: Eight 8-15 minute modules, pre- and post-test
- Video vignettes with adults with IDD playing roles of patients





# IDD Toolkit, Phase 2--Online Video Training

## Module examples:

- Communication Issues
- Common Physical Health Issues
- An Approach to Challenging Behavior
- Autism Spectrum Disorder
- Non-pharmacological Treatments for Challenging Behavior
- Psychotropic Medications



## HEALTH WATCH TABLES

- Autism
- Down Syndrome
- Fetal Alcohol Spectrum Disorder (FASD)
- Fragile X Syndrome
- Prader-Willi Syndrome
- Williams Syndrome
- 22q11.2 Deletion Syndrome

## BEHAVIORAL AND MENTAL HEALTH ISSUES

- Initial Management of Behavioral Crises in Primary Care
- Risk Assessment Tool for Adults with IDD in Behavioral Crisis
- Behavioral Problems and Emotional Concerns-Provider Checklist
- Behavioral Problems and Emotional Concerns-Caregiver Checklist
- Psychiatric Symptoms and Behaviors Checklist
- ABC (Antecedent-Behavior-Consequence) Chart
- Crisis Prevention and Management Planning
- Crisis Prevention and Management Form
- Psychotropic Medication Issues
- Psychotropic Medications Checklist

## REFERENCES

## RESOURCES

- Tips and Resources Fact Sheets

### ONLINE TRAINING IS AVAILABLE USING THE FOLLOWING LINKS

- For health care professionals, training entitled “Appropriate Use of Psychotropic Medications for People with IDD: Helping Individuals Get the Best Behavioral Health Care”. (Free CME credit is offered upon completion).
- Similar free online training for individuals with IDD, their families, conservators, and other caregivers. The modules are in 8- to 15-minute segments that can be completed independently as your schedule permits.





# **“Appropriate Use of Psychotropic Medications for People with IDD: Helping Individuals Get the Best Behavioral Health Care”**





**Family and Caregiver Training**  
**[vkc.mc.vanderbilt.edu/healthtraining](http://vkc.mc.vanderbilt.edu/healthtraining)**

**Prescriber Training**  
**<http://tinyurl.com/Vu-train-idd-meds>**

**(CME credits of 1.5 for AMA, APA and AAFP)**



# **For more information on the IDD Toolkit and our online training**

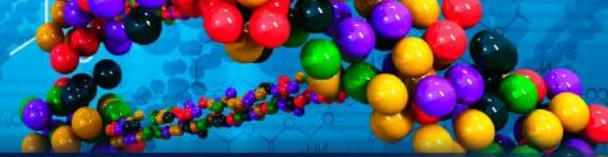
Visit the Diagnostic & Clinical Services  
Poster Symposium

2:00 p.m. - 3:00 p.m.

in

The Grand Ballroom South Salon  
and see Janet Shouse

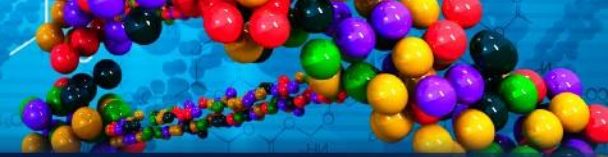




## IDD Toolkit, Phase 3—Videoconferencing

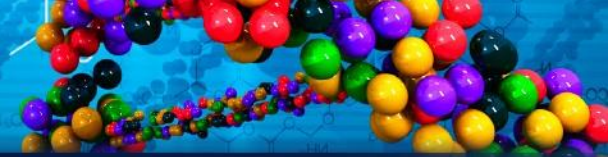
- Received another grant from the Special Hope Foundation, now called WITH, for the telehealth project.
- Videoconferencing with health care providers (physicians, advanced practice nurses and physician's assistants) to build capacity in Tennessee for clinicians to better serve adults with IDD.
- Used Zoom technology.





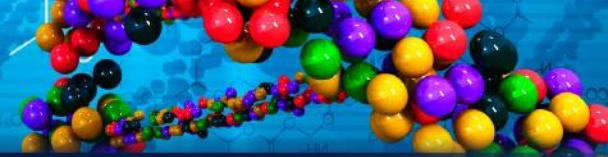
## IDD Toolkit, Phase 3—Videoconferencing

- Recruited 20 providers to participate in 10 monthly live videoconferencing “grand-rounds” type sessions.
- Participants were able to earn 1 AMA PRA CME credit per session attended.
- Participants were required to give consent for research purposes.
- Advisory Council provided guidance and included people with disabilities, family members, staff and faculty.



# IDD Toolkit, Phase 3—Videoconferencing

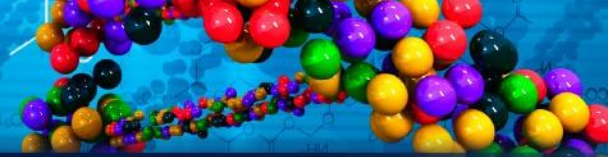
- Didactic built on information from IDD Toolkit.
- Case presentations from community providers to “expert panel” that included:
  - Internal and family medicine
  - Psychiatry
  - Neurology
  - Psychology/behavioral health
  - Occupational therapy
  - Nursing
- Provided practical advice on managing physical and behavioral health concerns in people with IDD.



## IDD Toolkit, Phase 3—Videoconferencing

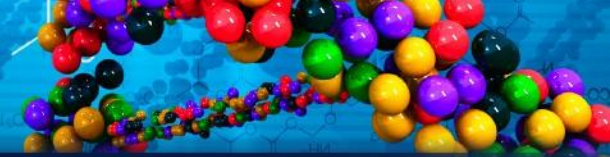
- Outcomes measured via pre- and post-intervention surveys.
- Plan to examine TennCare claims data on patients' emergency department usage, medical hospitalizations, and psychiatric hospitalizations.



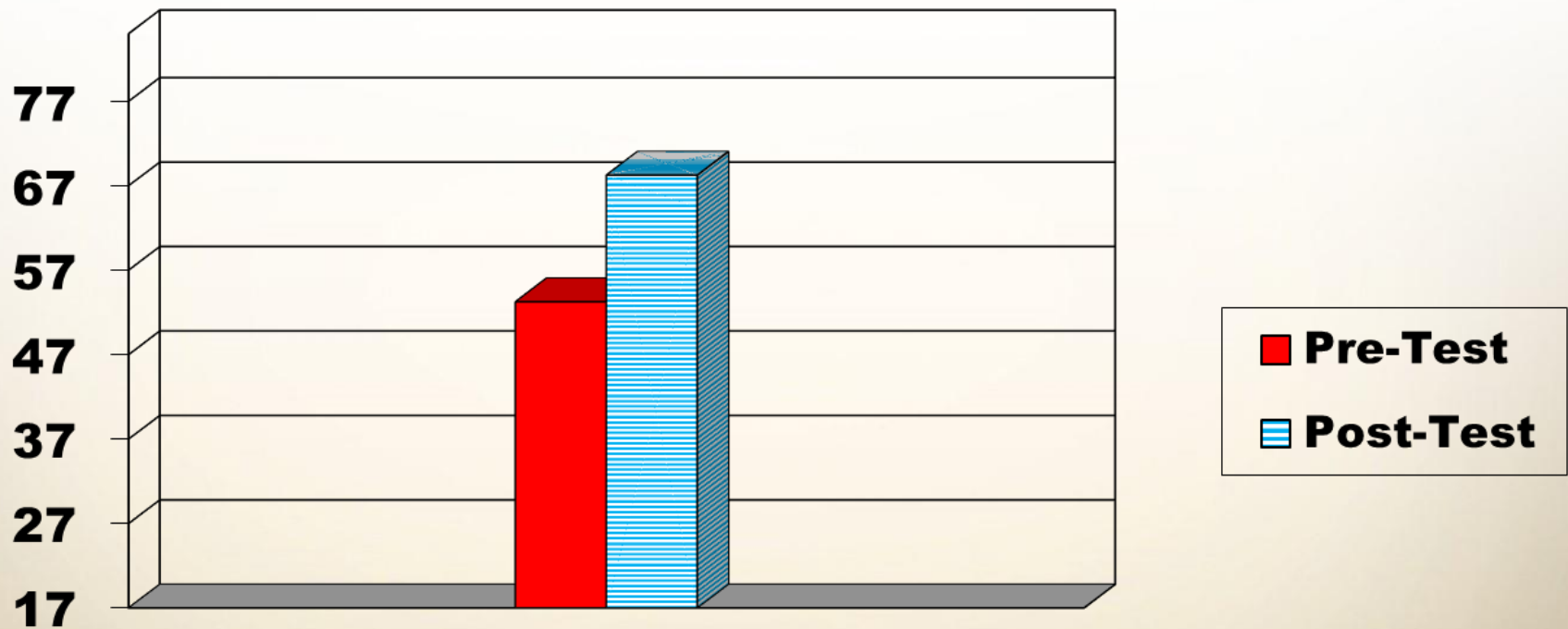


## IDD Toolkit, Phase 3—Preliminary Findings

- Although based on only 8 medical personnel, findings are suggestive
- Total Scores went up dramatically
  - (adding up all 17 items; from 17→85);
    - ❑ All 8 health professionals showed increases from pre-test to post-test scores



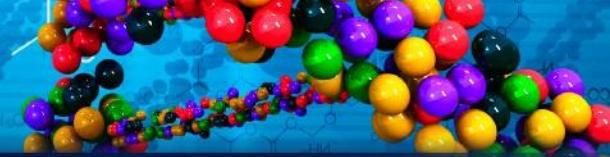
# Pre- and Post-Test Total Score Changes for Participants



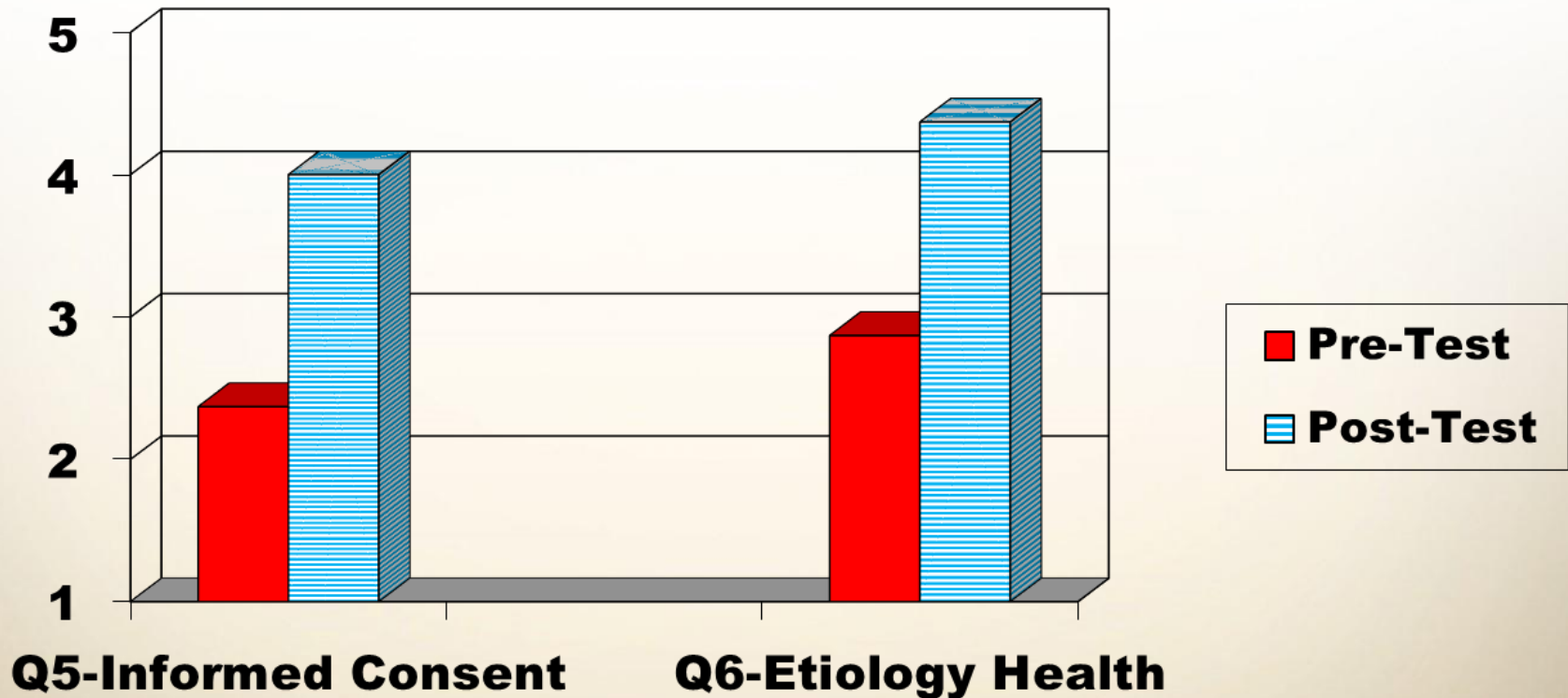


## Items increasing the most

- Of 17 questions asked before and after the 10 (monthly) telehealth sessions, 9 went up at  $p < .05$  levels (4 at  $p < .01$ ).
  - Question 5--I feel confident in obtaining informed consent from adults with IDD ( $p < .003$ )
  - Question 6--I am able to describe the etiology and identified health concerns of specific developmental disorders and syndromes ( $p < .005$ )



# Pre- and Post-Test Scores for Participants





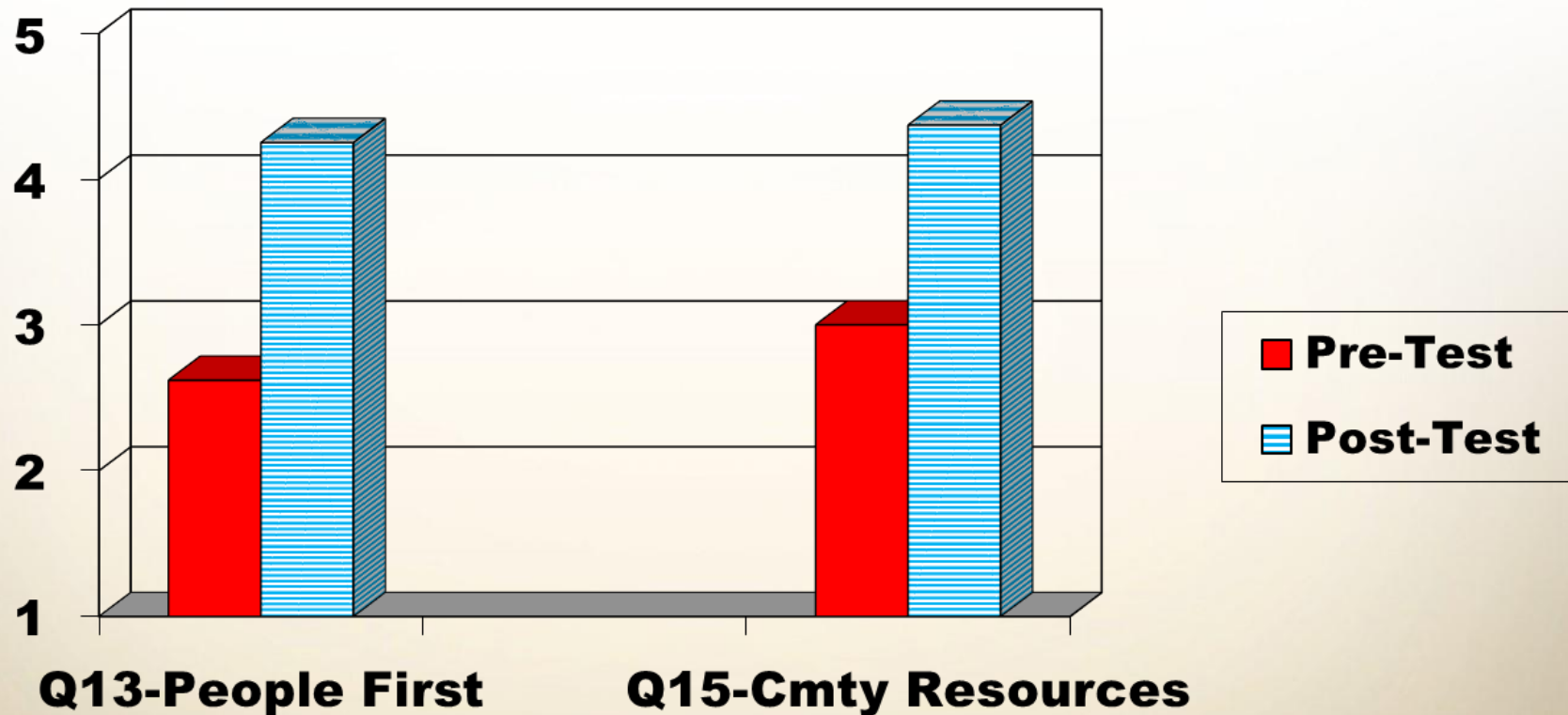


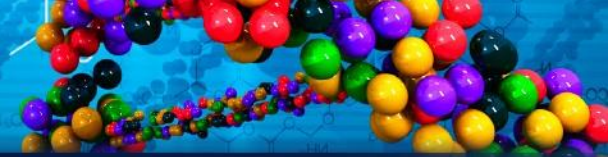
## Items increasing the most

- Question 13--I am familiar with people-first language ( $p < .002$ )
- Question 15--I am able to provide community resources for adults with IDD ( $p < .008$ )



# Pre- and Post-Test Scores for Participants





## IDD Toolkit, Phase 3—Lessons Learned

- Recruiting community providers for monthly midday sessions is difficult.
- Inconsistent participation with core group of 9 out of 20 regularly joining sessions.
- Took about 7 sessions for group to “gel.”
- Most participants were already caring for adults with IDD.
- Initial hesitancy of participants to present a case but increased by final session.
- CME might not be motivating: only 6 of 20 participants sought CME credit.

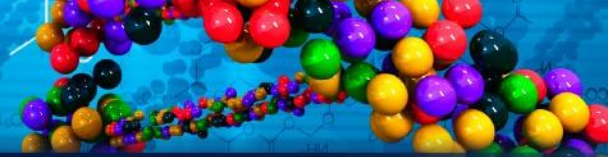


# IDD Toolkit, Phase 3—Lessons Learned

Barriers to evaluating the benefits of the telehealth training on emergency department usage, hospitalizations or psychotropic medication:

- Utilized both 45 ICD-9 codes and 69 ICD-10 codes to try to identify patients with IDD
- Difficulties in identifying patients with IDD in charts due to spotty medical coding for IDD
- Some providers are only able to code for two diagnoses in some electronic medical records, unless provider pays extra fees to this service
- Medical codes listed are often the two diagnoses that are most acute or immediate concerns to provider's specialty





## IDD Toolkit, Phase 3—Positive Feedback

- Several participants said they enjoyed brainstorming with other specialties and disciplines.
- Several have joined as participants in our latest telehealth project.
- One participant joined our panel of clinicians for our latest project.



## IDD Toolkit, Phase 3—Standalone Sessions

- In an effort to attract additional Tennessee providers, we have recently offered three sessions that only require registration—no consent forms or research component.
- Email invitation was inadvertently shared more broadly, and 29 providers from across the U.S. and Canada have registered.
- Sessions are focusing on physical health, transition to adult care and mental and behavioral health.



## IDD Toolkit, Next Steps

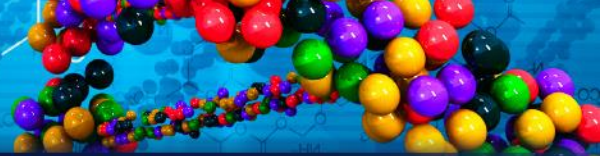
- Continue to build a “community of practice” for Tennessee providers.
- Develop a similar series of live videoconferences for related disciplines, including social workers, counselors and disability organization staff, based on the IDD Toolkit.
- In collaboration with TennCare and DIDD, consideration of a new online training series.
- Develop a Tip Sheet on outcomes-based data that shows the impact of these programs.



# Thanks to Our Team

- Tom Cheetham, MD
- Beth Ann Malow, MD
- Paul Dressler, MD
- Taylor Fife, DNP, APRN-BC
- Bruce Davis, PhD, BCBA-D
- Karen Wills, MS, OTR/L
- Kevin Sanders, MD
- Elisabeth Dykens, PhD
- Jon Tapp, technical wizard



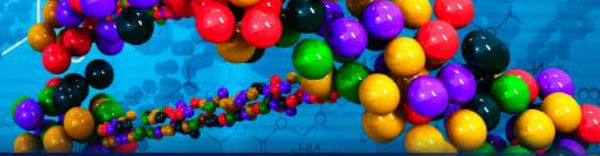


# Special Thanks



*Working for Inclusive and Transformative Healthcare  
Foundation*

The mission of WITH Foundation is to promote the establishment of comprehensive health care for adults with developmental disabilities designed to address their unique and fundamental needs.



# Reflections of a Participating Physician

Jana Dreyzehner, MD

- Child and Adolescent and Adult Psychiatrist
- Extensive experience in caring for children, youth and adults with intellectual and developmental disabilities
- Participant in 10-month telehealth project
- Member of the current panel of clinicians for our three standalone telehealth sessions



# Reflections of a Participating Physician

Importance of building this learning community :

To be ready when a physician is ready with useful information and support

- Most physicians don't consider themselves as specializing in this population-- very little formal training in medical school
- Most don't access CME focused on this population
- Most who are seeking learning opportunities are in response to current patient challenges



# Reflections of a Participating Physician

Engaging Physicians- Carrot and Stick- Does it take both?

- Stick- very limited - CME gold card to avoid some added paperwork of completing prior authorization worksheet when prescribing psychotropics for persons with IDD
- Carrot- is it worth it? Very few even claimed CME. What they want is good use of their time- a good value for the time cost.

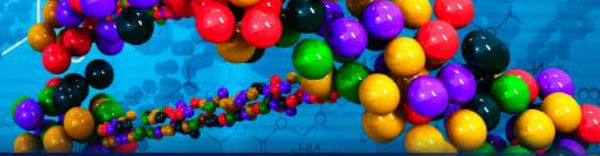




# Reflections of a Participating Physician

The Carrot - What makes it worth the physician's time?

- Opportunity to talk through cases to get pertinent consultation not otherwise readily available
- Assistance to work past diagnostic overshadowing - brainstorm creative ideas to address actual needs in various domains - not just treating a diagnosis with an algorithm
- Sense of community - not feeling isolation
- Multi-disciplinary team- access to other professionals
- Being pointed to resources that are helpful, timely, and may not otherwise have been known to the physician



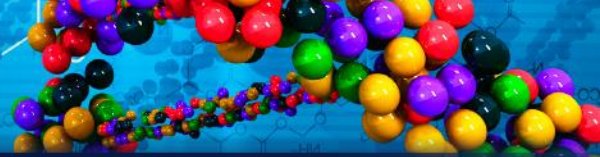
# Video-conferencing Technology for Training and Outreach

Maria P. Mello, M.Ed., BCBA  
Vanderbilt University



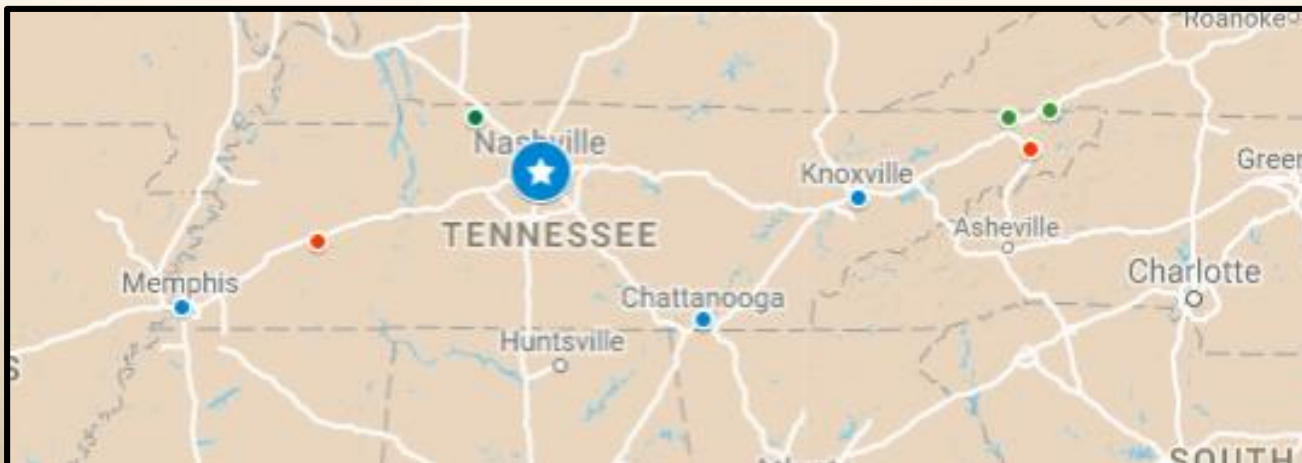
# Overview

- Background in Tennessee and rural regions
  - Behavior Analysts
  - Volunteer Advocacy Project
- Technology
  - Zoom Overview
  - Advantages of using Zoom

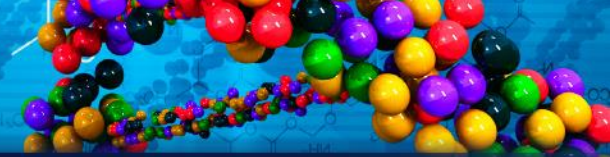


## Background: Tennessee

- Approximately 67% rural and 33% non-rural
- Bordered by 8 states
  - North: Kentucky and Virginia
  - East: North Carolina
  - South: Alabama, Georgia, and Mississippi
  - West: Arkansas and Missouri
- Major cities: Nashville, Memphis, Jackson, Chattanooga, Knoxville, and Tri-Cities (Johnson City, Kingsport and Bristol)
- Travel time: approximately 8 hours East-West, 2 hours North-South

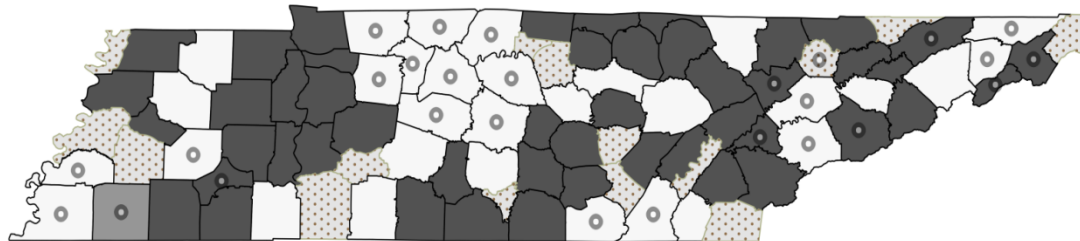






# Behavior Support Services in TN

*SLPs (S) and BCBAs (B) Coverage  
by Tennessee Counties*



*SLPs & BCBAs*

	YES BCBAs & YES Speech Language Pathologists
	NO BCBAs & YES Speech Language Pathologists
	NO BCBAs & NO Speech Language Pathologists
	Yes BCBAs & NO Speech Language Pathologists

○ = Non-rural counties

Mello,  
Goldman,  
Urbano, &  
Hodapp (2016)



# Distance and time traveled to get behavior services

- Rural families averaged 35.7 miles and about 42 minutes
- Non-rural families averaged 14.14 miles and about 21 minutes

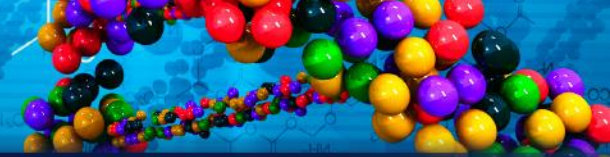
Summary of distance and time traveled to behavior services by rural and non-rural families.

Family	Distance to Behavior Service (in miles)	Time to Behavior Service (in minutes)	Service in the same or different county?	Service in Rural or Non-rural County?
1	1	2	Same	Rural
2	95	90	Different	Non-Rural
3	60	60	Different	Non-Rural
4	23.2	33	Different	Non-Rural
5	77.3	90	Different	Non-Rural
6	47.9*	55*	Different**	Non-Rural**
7	156	160	Different	Non-Rural
8	14.10	21	Different	Rural
9	18.9	31	Different	Non-Rural
10	33.1	48	Different	Rural
11	26.5	40	Different	Rural
12	130*	120*	Different**	Non-Rural**
13	20.4	25	Same	Rural
14	59.6	60	Different	Non-Rural
15	31.3	40	Different	Non-Rural
16	13.9	17	Same	Rural
17	67.4	83	Different	Non-Rural
18	3.1	6	Same	Rural
19	14.7	21	Different	Rural
Rural Families	35.7 (SD=27.42)	42.47 (SD=27.43)	21.1% Same 78.9% Different	57.9% Non-Rural 42.1% Rural
Non Rural Families	14.14 (SD=9.98)	20.54 (SD=11.60)	76.9% Same 23.1% Different	100% Non-Rural counties

\*=Distance and time traveled by service provider to family home.

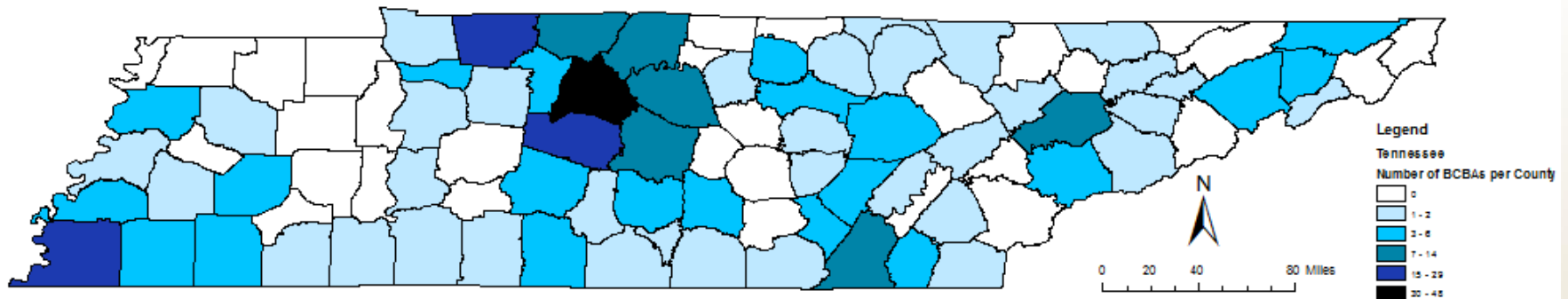
\*\*=In home services provided by non-rural provider from a different county than the respondent's home county.

Note. All totals for time and distance traveled for rural and non-rural families were conducted without outliers as indicated in Analyses section.



# Behavior Analysts in TN

Number of BCBAs Who Provide Services Per County in TN



Participants primary work counties:

Davidson (34.0%, N=32), Shelby (14.9%, N=14), Montgomery (10.6%, N=10), Williamson (7.4%, N=7), Hamilton (6.4%, N=6), Knox (4.3%, N=4), and Cumberland (2.1%, N=2).

Mello, Sanderson, Staubitz, & Juarez (in preparation)

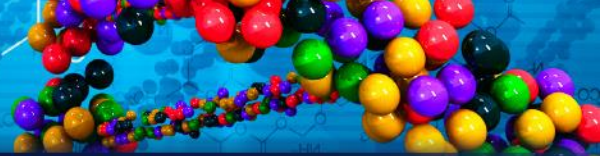


# Traveling to Provide Services

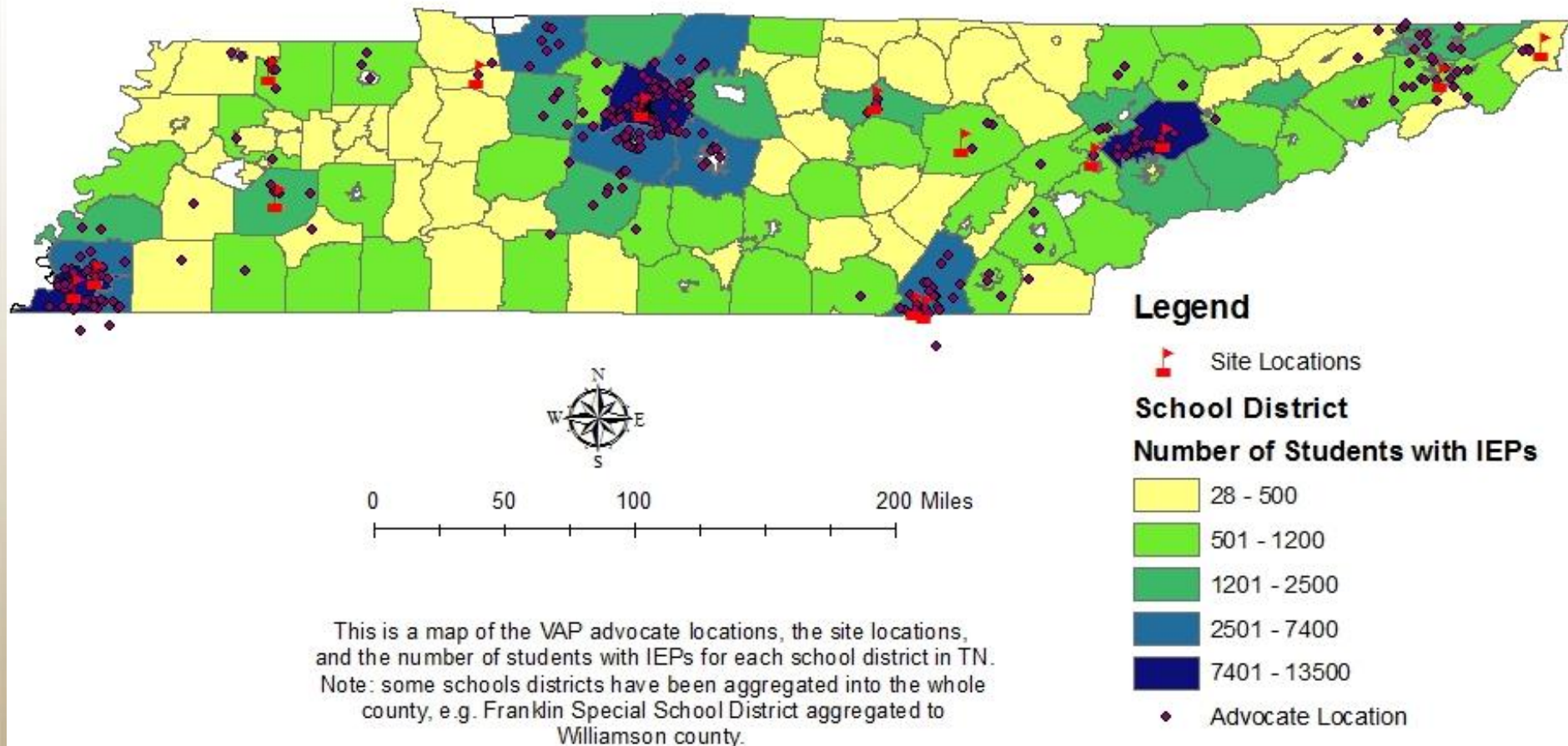
- 76.1% (N=67) reported that they traveled to provide services.
- 48.3% (N=28) traveled between schools to provide services.
- The minimum distance traveled was an average of 12.83 miles (sd=21.68) and the maximum distance was an average of 61.90 (sd=45.14).
- 18.2% (N=16) said they provide services in other states, which included Kentucky (9.6%), Georgia (4.3%), Alabama (1.1%), and Mississippi (1.1%).
- Worked in 2.7 (sd=3.05) counties outside of their primary work county.
- An average of 36.68% (sd=32.8%) of the time was spent providing direct services.
  - On scale 1-5 (1= never; 5= always) participants averaged 1.5 to providing online training to clients

Mello, Staubitz, Sanderson, & Juarez (in preparation)





# Volunteer Advocacy Project





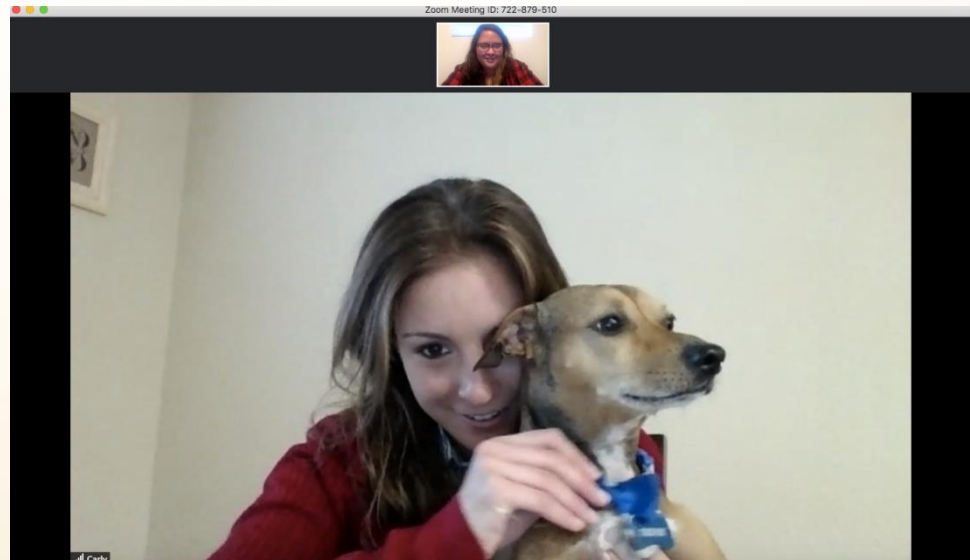
# Outreach to more remote areas

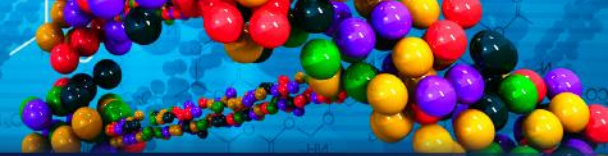
- Train professionals in remote areas by using distance learning
- Provide services to families located in remote areas
- Professional development across the state



# What is Zoom?

- Web/Video conferencing program/provider
- Zoom is easy to use
- A computer with a webcam, a smartphone or a tablet is all that's needed





# Zoom Meetings

Zoom - Free Account

MM Maria Mello ● ▼ ⚙️ Settings



Start with video



Start without video



Join



Schedule



Share screen



Home



Meetings



Contacts



Chats

Schedule a new meeting

Topic:

When

Start:

Duration:  Hr  Min

Time Zone:

☐ Recurring meeting

Video (when joining a meeting)

Host: ☒ On ☐ Off

Participant: ☒ On ☐ Off

Audio Options

☐ Telephone Only ☐ VoIP Only ☒ Both

Meeting Options

☐ Require meeting password

☐ Enable join before host

☐ Mute participants on entry

☐ Use Personal Meeting ID 562-028-6554

☐ Record the meeting automatically on the local computer

[Advanced Options ^](#)

Calendar

☒ iCal ☐ Google Calendar ☐ Outlook ☐

Upcoming Recorded ↺

Personal Meeting ID (PMI)  
**562-028-6554**

☐ Always use PMI for instant meetings on this computer

Today

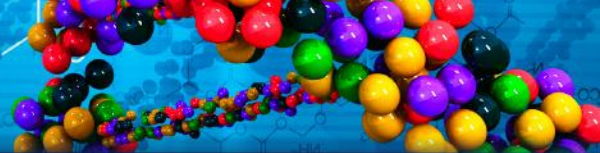
07:00 PM to 08:00 PM  
Topic: My Meeting  
Meeting ID: 722879510

Settings

Home Meetings Contacts Chats

Home Meetings Contacts Chats





# Create a Meeting on the website

Topic

My Meeting

Time

Oct 17, 2017 7:00 PM Central Time (US and Canada)

Add to



Google Calendar



Outlook Calendar (.ics)



Yahoo Calendar

Meeting ID

722-879-510

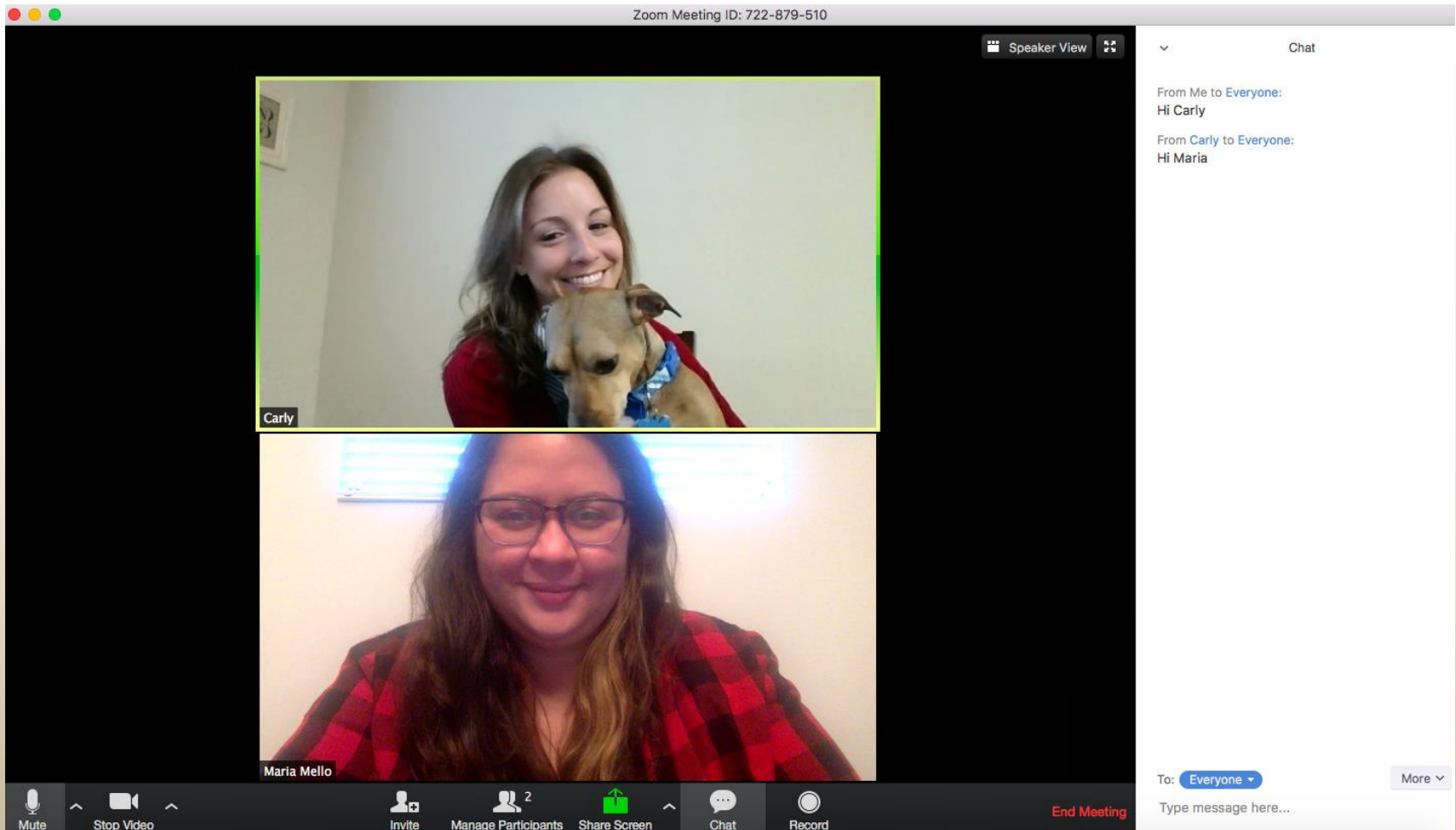
Join URL:

<https://zoom.us/j/722879510>

[🔗 Copy the invitation](#)

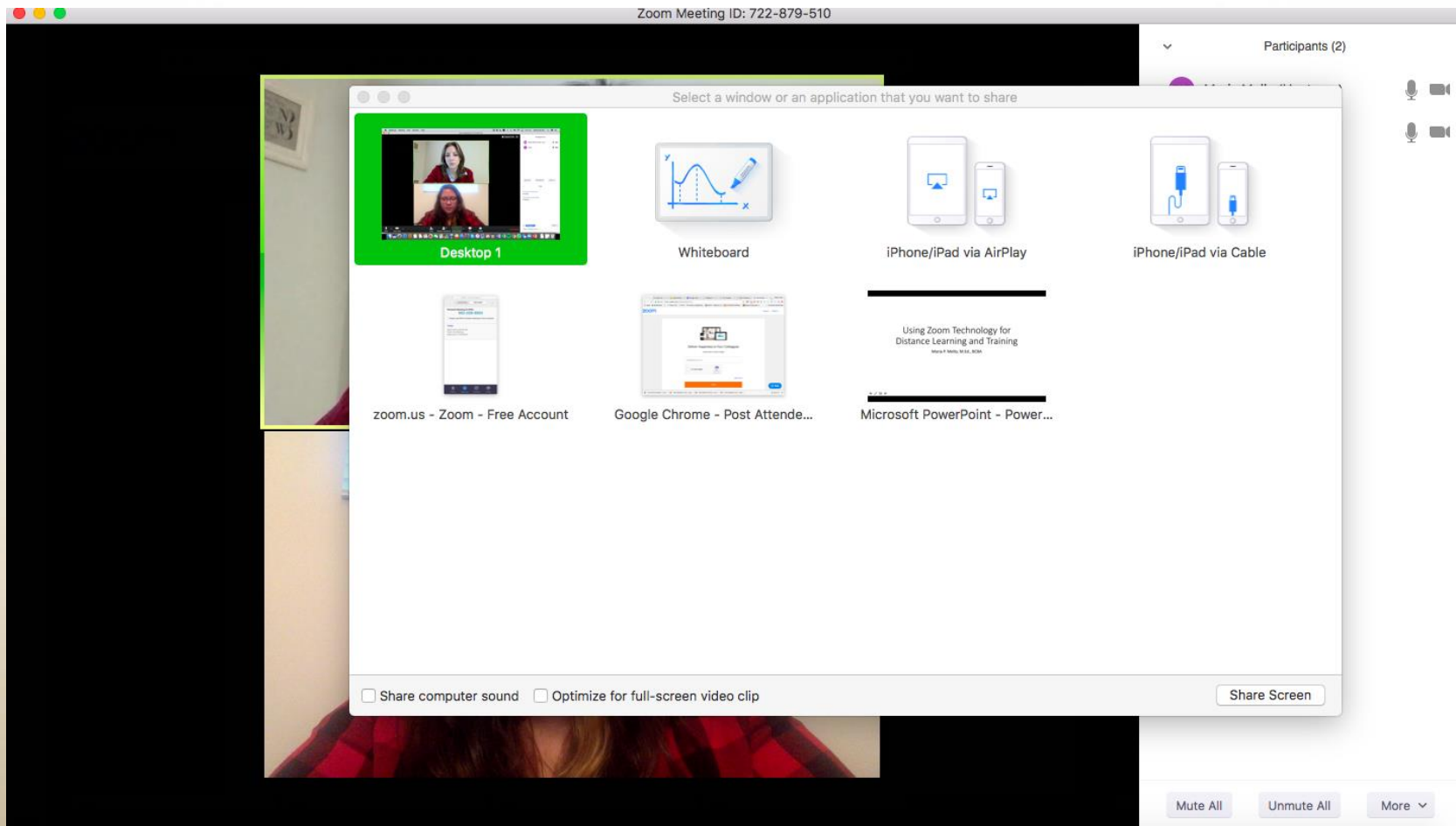


# Features of Zoom: Chat and split screen



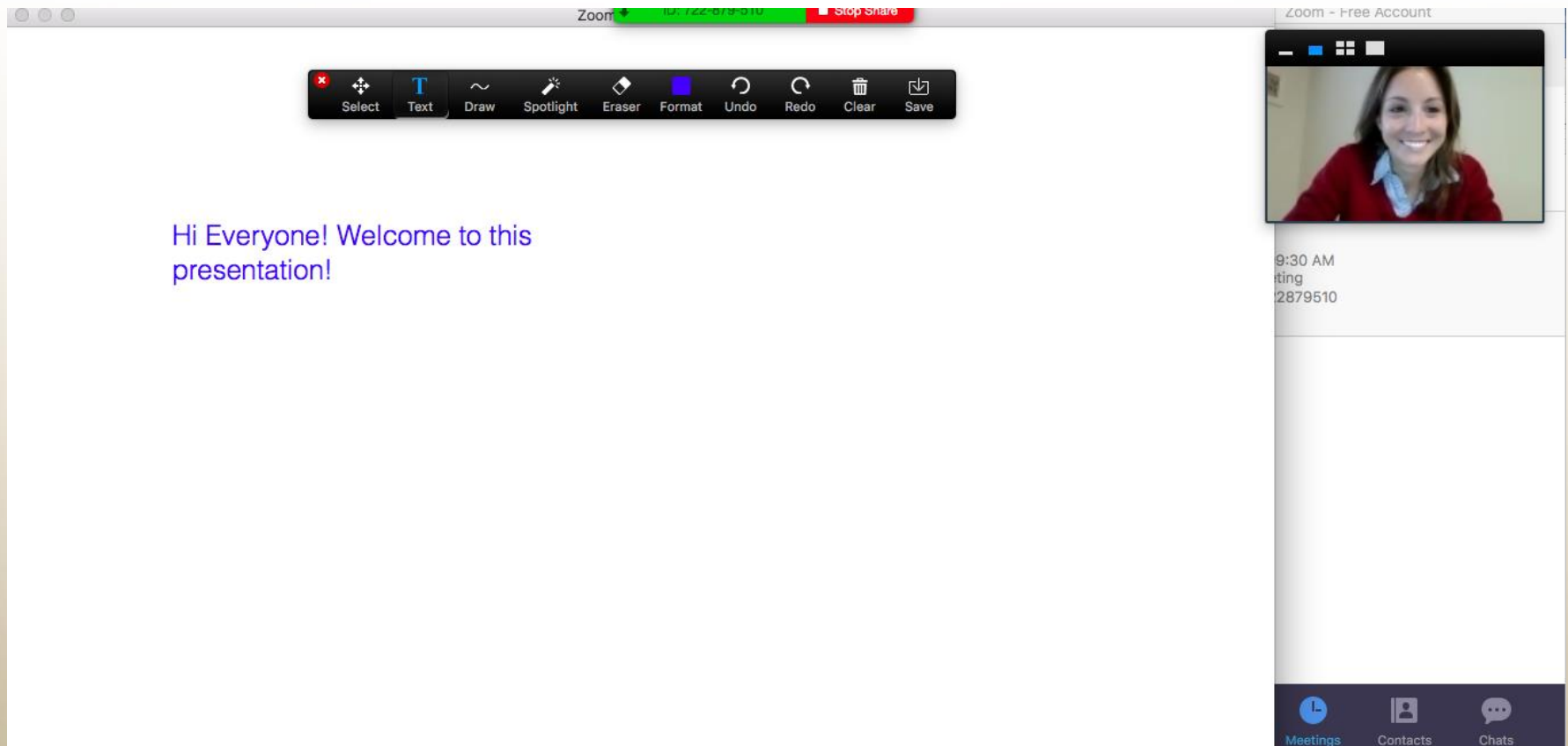


# Features: Share screen for iPod/iPad





# Features: White board

A screenshot of a Zoom whiteboard interface. At the top, there's a toolbar with icons for Select, Text, Draw, Spotlight, Eraser, Format, Undo, Redo, Clear, and Save. Below the toolbar, the text "Hi Everyone! Welcome to this presentation!" is displayed in a purple font. On the right side, there's a video feed of a woman with long brown hair, wearing a red sweater, smiling. Below the video feed, the text "9:30 AM", "ting", and "2879510" is visible. At the bottom right, there's a navigation bar with icons for Meetings, Contacts, and Chats.

Zoom - Free Account

Zoom - Free Account

Stop Share

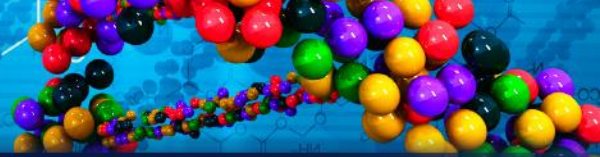
Select Text Draw Spotlight Eraser Format Undo Redo Clear Save

Hi Everyone! Welcome to this presentation!

9:30 AM  
ting  
2879510

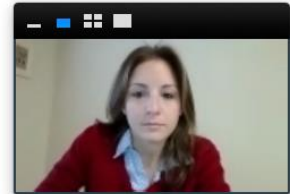
Meetings Contacts Chats





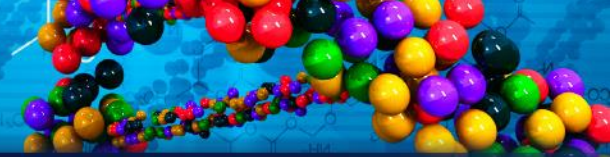
# Features: Share PowerPoint

ID: 722-879-510 Stop Share



## Using Zoom Technology for Distance Learning and Training

Maria P. Mello, M.Ed., BCBA



# Features: Annotate on PowerPoint

The image shows a Zoom meeting interface. At the top, there is a toolbar with icons for Mute, Stop Video, Manage Participants (showing 2 participants), New Share, Pause Share, Annotate, Remote Control, and More. Below this is a green bar with the ID 722-879-510 and a red Stop Share button. Another toolbar below that includes Mouse, Select, Text, Draw, Spotlight, Eraser, Format, Undo, Redo, Clear, and Save. The main area displays a presentation slide with the title "Using Zoom Technology for Distance Learning and Training" and the presenter's name "Maria P. Mello, M.Ed., BCBA". On the right side, there are two video thumbnails of participants: a woman with glasses in a red plaid shirt and another woman in a red sweater. At the bottom left, there are navigation icons for back, forward, and search.

Using Zoom Technology for  
Distance Learning and Training

Maria P. Mello, M.Ed., BCBA



# Features: Manage participants

Zoom Meeting ID: 722-879-510

Speaker View

Participants (2)

- Maria Mello (Host, me)
- Carly

Chat

- Stop Video
- Make Host
- Allow Record
- Rename
- Put on hold
- Remove

Mute All Unmute All More

Chat

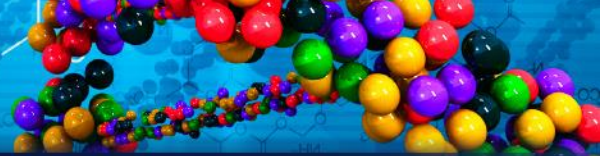
From Me to Everyone:  
Hi Carly

From Carly to Everyone:  
Hi Maria

To: Everyone More

Type message here...

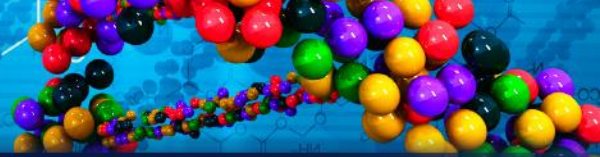
End Meeting



# Ways we have used Zoom

- Training professionals, service providers, and families across Tennessee
- Online social skills group for young adults with Prader-Willi syndrome across the United States
- Conducted interviews and data collection with participants





# Advantages of Zoom for distance learning and training

- Zoom is free to use
  - Host meetings of up to 40 minutes
  - If you require longer sessions or more participant access, there are other plans for with per-month costs
- No cap on the number of meetings you can host
- Host up to 100 participants
  - Participants do not need a Zoom account themselves
- Easy to use and navigate
- Can be used on any device, even phone
- Record meetings easily
- Chat, screen share, video record, and other features
- Access through calling in by telephone if they do not have Internet connection
- Access to more rural areas



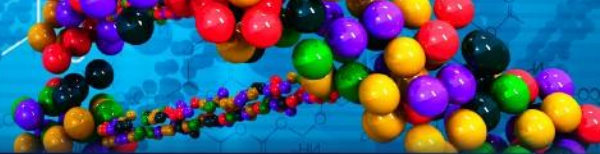
# References

- Mello, M. P., Goldman, S., Urbano, R. C., & Hodapp, R. M. (2016). Services for children with autism spectrum disorder: Comparing rural and non-rural communities. *Education and Training in Autism and Developmental Disabilities*, 51(4), 355-365.
- Mello, M. P., Staubitz, J., Sanderson, K., & Juarez, P. Descriptive study of work experience of behavior service providers. *Manuscript in preparation*.



# Questions or Comments?





# Thank You!



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