

My child has been diagnosed with **autism**... Now what?

Services and supports available in South Carolina



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Today's Presenter



Catherine Bradley PhD

- Licensed Psychologist
- Professor of Pediatrics
- Developmental-Behavioral Pediatrics
- Medical University of South Carolina (MUSC)

This presentation was created in conjunction with Allie Megale, PhD,
as part of her LEND Fellowship

Language in Autism: Person-First vs. Identity-First

“Individual with autism”

- Person first language emphasizes the value of the person
 - Often preferred by parents
 - Similar to other medical models (cancer)

“Autistic individual”

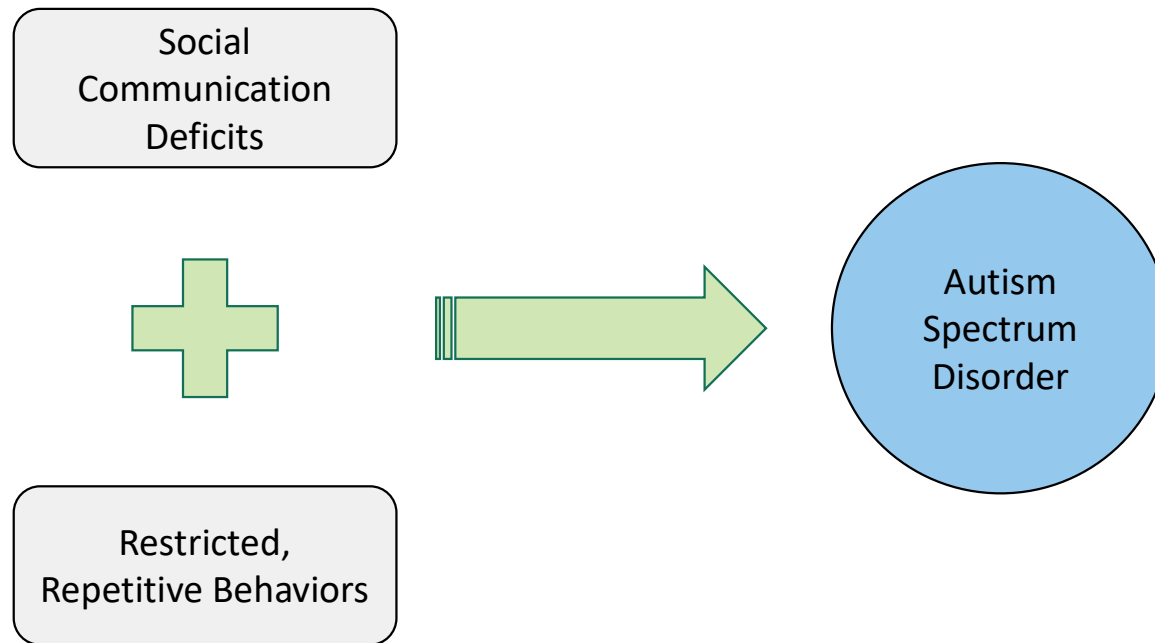
- Identity first language recognizes ASD as an integral party of the person’s identity
 - Often preferred by self-advocates
 - “These are not qualities or conditions that I have. They are part of who I am. Being Autistic does not subtract from my value, worth, and dignity as a person. Being Autistic does not diminish the other aspects of my identity.”¹

Language in Autism: Person-First vs. Identity-First

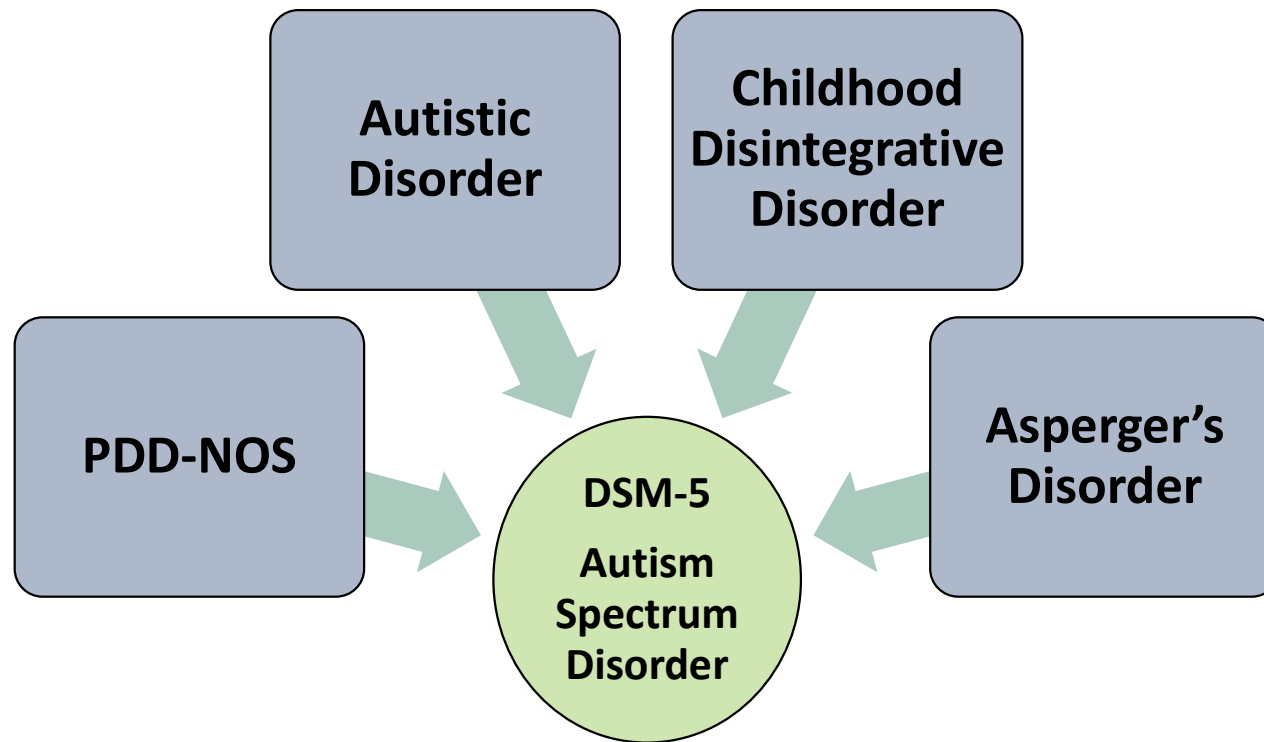
- Social Model vs. Medical Model:
 - Neurodiversity/difference vs neurodevelopmental disorder
 - Terms such as “disorder,” “symptom,” & “impairment” are used throughout, but with acknowledgement of the importance of environmental adaptations and supports to promote acceptance, understanding, and inclusion

What is Autism?

DSM-5 Autism Spectrum Disorder



DSM-5 Autism Spectrum Disorder



“Where Are They on the Spectrum?” ...

- Severity indicators are part of DSM-5
 - Social Communication and Interaction
 - Repetitive/Stereotyped Behaviors (RRBs)
- Serve as quick indicators and may not be clinically useful or appropriate
- Describe how much support a child needs at that time
 - Not necessarily about their level of impairment
 - Will likely change as they get older

State Resources

Department of Disabilities and Special Needs (DDSN)

- South Carolina DDSN is the state agency that plans, develops, coordinates, and funds services for South Carolinians with severe, lifelong disabilities
 - Intellectual disability and related disability
 - **Autism spectrum disorder**
 - Traumatic brain injury
 - Spinal cord injury and similar disability
- To apply, call the Eligibility Intake Number: 1-800-289-7012

DDSN Continued...

- Once determined eligible, families can take advantage of the following non-waiver services:
 - Early Intervention (3-6 years who fall into the High-Risk eligibility category)
 - Vocational Rehabilitation Services
 - Genetic Testing
 - Family Support Funds
 - Family Arranged Respite Funds
 - Case Management
 - Referrals for Basic Needs
 - Transition Coordinators (16-24 years)
 - Individuals with an Autism Diagnosis who become DDSN eligible will be placed on the *ID/RD Waiver* and *CS Waiver waitlists*.

TEFRA (Katie Beckett)

- Provides Medicaid coverage for children based on their disability, rather than family income/resources
- Especially beneficial for children that have private insurance as many private insurance plans do not cover therapies (Speech, OT)
- Family Connection of South Carolina can help with the application process
 - <https://www.familyconnections.sc.org/tefra-download/>

BabyNet

- BabyNet is South Carolina's early intervention system for children (under age 3) with developmental delays
- Matches the needs of children with professional resources available within their community
 - Common services: Early Intervention (EI), Speech, Occupational, Physical Therapies
 - Often provided in the child's home
- Anyone can make a referral by calling 1-866-512-8881
- Provides service coordinator and assists with transition to school-based services (starting at 33 months)



Supplemental Security Income (SSI)

- Provides monthly payments to adults and children with disabilities who have income and resources below specific financial limits
- Eligibility for children:
 - (If under 18) if the child has a medically determinable physical or mental impairment or combination of impairments that causes “marked and severe functional limitations”
- Request an appointment with SSA representative to file for benefits
 - <https://www.ssa.gov/>
 - 1-800-772-1213

Educational Supports and Resources

Medical Diagnosis vs. Educational Classification

Medical Diagnosis

- Requires a comprehensive assessment completed by a healthcare professional
- Diagnosis is based on DSM-5 criteria
- Qualifies children for **outpatient** services, such as ABA, Speech, or Occupational Therapy
- Focuses on impact of autism in various areas (e.g., behavioral concerns, self-help skills)

Educational Classification

- Requires an evaluation through the school district (i.e., Child Find Evaluation)
- Classification is based on federal and state definitions
- Qualifies children for **educational** services and supports
- Focuses on impact of autism on learning and in the educational environment

Child Find

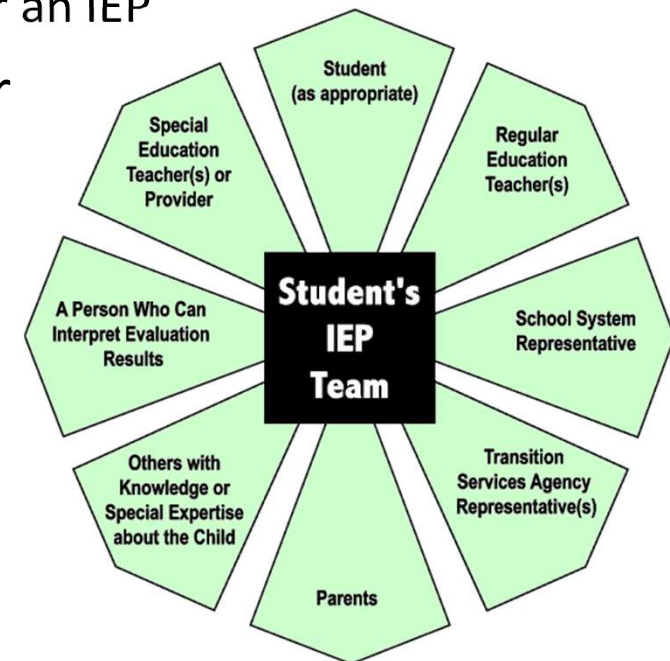
- Each state is required to identify, locate, and evaluate all children with disabilities who need special education and related services
- A school evaluation is required for your child to receive services in school
- Child Find services start at age 3 when children age out of BabyNet
 - You can approach the school district prior to 3rd birthday, and students can start on their 3rd birthday
 - Children do NOT need to be toilet trained

How do I request a Child Find Evaluation?

- **If your child is not already in school...**
 - Contact your school district office to request a Child Find Evaluation
 - “I have a preschool aged child with autism and I would like to have him/her evaluated for special education services”
 - If your child receives services through BabyNet, ask your early interventionist to assist with this transition
 - The school is required to serve children with special needs....
 - The classroom cannot be “full”
- **If your child is already in school...**
 - Contact your child’s teacher or principal and request an evaluation

Individualized Education Program (IEP)

- The written educational plan for a student receiving special education and related services
 - Having autism does not automatically qualify you for an IEP
- Includes goals and objectives for the school year
- Common Related Services:
 - Speech-Language Pathology
 - Audiology
 - Interpretation Services
 - Physical Therapy
 - Occupational therapy



504 Plan

- Student who do not need special education, but need changes in the regular school program to learn
 - Children with 504 plans CANNOT receive speech or other special education services
- Typically focused on accommodations that ensure academic success and access to learning environment
- Must have a disability that limits a major life activity (definition is broader than IDEA's definition that guides IEPs)

Therapies and Interventions

A quick note about therapies...

- Therapies may be school-based or outpatient
 - In most cases a child can receive both!
- Outpatient services are typically covered by insurance and/or Medicaid
- Private insurance companies (BCBS, Tricare, United etc.) vary in their coverage of outpatient therapies
 - Having secondary Medicaid through TEFRA can ensure that outpatient services are covered

Speech Therapy (ST)

- Speech-language pathologists (SLPs) work with people who have problems with speech, language, and swallowing
- Common goals:
 - Help the person communicate in more useful and functional ways
 - Improve spoken language
 - Nonverbal skills (signs or gestures)
 - Alternative Augmentative Communication (AAC)
 - Sign language
 - Picture exchange communication systems (PECS)
 - iPads
 - Speech output devices (e.g. Dynavox)

Occupational Therapy (OT)

- Occupational therapy focuses on things you want and need to do in your daily life
- For people with autism, OT often focuses on:
 - Activities of daily living (bathing, dressing, eating)
 - Play skills
 - Sensory issues
 - Fine motor skills
 - Learning strategies
 - Self-Care
 - Some OTs will work with feeding and swallowing challenges

American Occupational Therapist Association: <https://www.aota.org/about/what-is-ot>

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<https://www.autismspeaks.org/occupational-therapy>

Physical Therapy (PT)

- Focuses on increasing strength, improving balance, and helping with fine and gross motor development.
- Promotes independence, participation, motor development and function, strength and endurance, enhances learning opportunities, eases challenges with daily care giving

What is Applied Behavior Analysis (ABA)

- Applied Behavior Analysis (ABA) is an evidence-based treatment and is recommended by the American Psychological Association
- ABA focuses on improving skills like communication, self-help skills, and social skills
- Every ABA program is individualized for a specific child
 - Some are “comprehensive” and might involve 25-40 hours per week (usually for younger learners)
 - Others are focused on a specific set of goals and may involve fewer hours per week (usually for older learners)

Controversy about ABA

- Often based on early versions of ABA which used punishments
 - No longer used in ABA
- “ABA is too hard/repetitive”
 - Modern ABA is often naturalistic and play-based
- “ABA is only for kids with problem behaviors”
 - ABA’s Primary Aim: focus on building skills
- “ABA tries to force people to fit neurotypical standards”
 - Focus on strengths and growing independence
 - Goals are developed based on family priorities

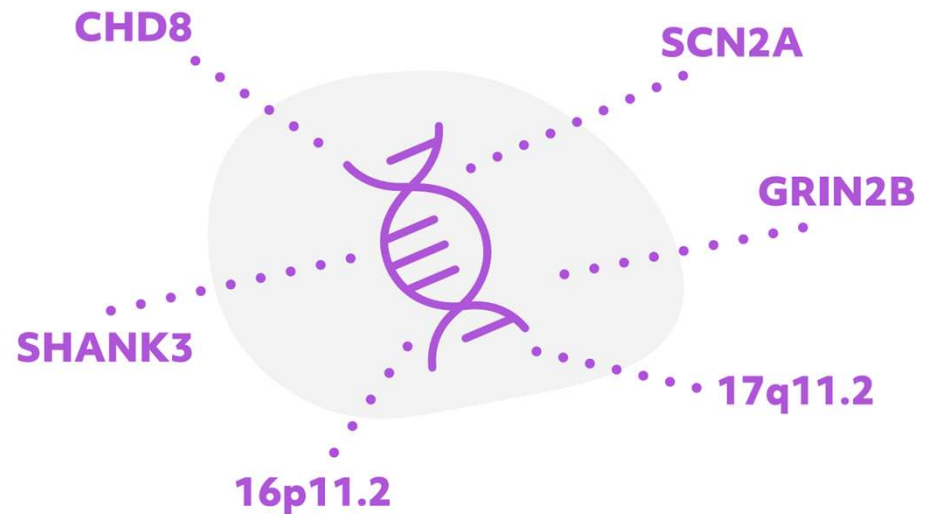
How to get Applied Behavior Analysis (ABA)

- ABA may be covered by private insurance under Ryan's Law
- ABA is also covered by Medicaid
 - Based on medical necessity
 - Beneficiary between 0-21 years of age
 - Healthy Connections Medicaid ID number
 - Comprehensive psychological assessment for an ASD diagnosis
- Contact an ASD provider directly to request authorization for services

Medical Recommendations

Genetics

- Can help identify genes that may be associated with autism and may change how your child's health is monitored
- Offered at:
 - Greenwood Genetics (GGC)
 - MUSC
- To obtain a referral, please discuss with your child's pediatrician
 - If your child is in BabyNet, your EI can also refer to GGC



Audiology

- For children with speech delays, a referral to audiology recommended to rule out hearing loss
- To obtain a referral, please discuss with your child's pediatrician



Family Support Organizations



Empowerment Through Connection: Supporting Families of Children with Disabilities

1 in 5 families face the unique challenges of raising a child with a disability or chronic health condition.

Family Connection provides comprehensive support and resources to families raising children with disabilities, enabling them to navigate through challenges and celebrate every milestone with confidence.

Peer-to-Peer Support

Through our specialized programs, parents receive personalized guidance from others who truly understand, offering insights and resources that transform lives.

"It has been a tremendous blessing. When you feel lost, Family Connection helps you find your way."

- Yokasta, Mom of Ashley

Workshops and Trainings

We offer year-round, accessible workshops covering essential topics for parents, families, and professionals. From understanding rights to exploring therapies, our workshops equip participants with knowledge and confidence.

Outreach and Information

Our initiatives engage families and professionals, creating a network of support. We aim to build collaborative relationships that foster a community of care and understanding.

Every contribution enables us to expand our reach and enrich our programs, ensuring that every family has access to the support they need. With your help, we can empower more families to advocate effectively for their children and make informed decisions to pave the way to a brighter future.

Call our **Support and Information Line**
1.800.578.8750 Para Español: **1.888.808.7462**

www.FamilyConnectionSC.org

Follow us on social media!



Autism Society of South Carolina

- Offers case management services to assist with navigating services
- Parent-School Partnership - Assists with navigating the educational system
- Contact: 803-750-6988 or scas@scautism.org
- Website: <https://scautism.org/>

Lowcountry Autism Foundation (LAF)

- Serves families from Charleston to Hilton Head Island
- Provides free programs to support families from initial concerns for autism through diagnosis, and throughout their lives
- Current Programs:
 - Family support services
 - Parent's day out (Bluffton)
 - LAF AID (collaboration with law enforcement to provide personalized IDs)
 - Swim lessons
 - Music therapy
 - Art Therapy
- Contact: 843-800-7171 or email stacy_littin@lafinc.org

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SOS Care

- Located in Myrtle Beach, Murrells Inlet, and Charleston
- Offers a range of services for individuals with autism and intellectual disability across the lifespan
 - Applied Behavior Analysis
 - Summer camps
 - Recreation clubs
 - Social skills club
 - Respite Care
 - Transitional services
- Contact: 843-449-0554 or info@soscaresc.org



Champion Autism Network (CAN)

- Nonprofit autism awareness organization started in Surfside Beach
- CAN's goal is to create and ensure inclusive communities where all people CAN happily live, work, and play by building a network of autism champions
- Programs:
 - Autism Travel Club/Mobile App (previously CAN Card)
 - \$10/year, identifies autism-friendly businesses and digital card that families can discretely use to identify as a family that has someone with autism
 - Sensory Friendly Events



facebook.com/ChampionAutismNetwork



@ChampionAutismNetwork

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Research Studies



MUSC is partnered with the Simons Foundation Autism Research Initiative (SFARI) to create the nation's largest autism study. *We are a growing community of families, autistic adults, and researchers working together to understand autism and improve lives.*

- Individuals with autism of **all ages**, and their families, are invited to participate.
- Registration is easy and can be done online or in-person with the MUSC SPARK team.
- Participants provide a saliva sample using a kit shipped to their home, complete surveys, and may be invited to participate in other studies that are relevant to them.
- Participants will receive a gift card code valued at up to \$50 once they've completed registration and returned samples. Additional gift cards may be earned by completing surveys or participating in other studies through SPARK Research Match.

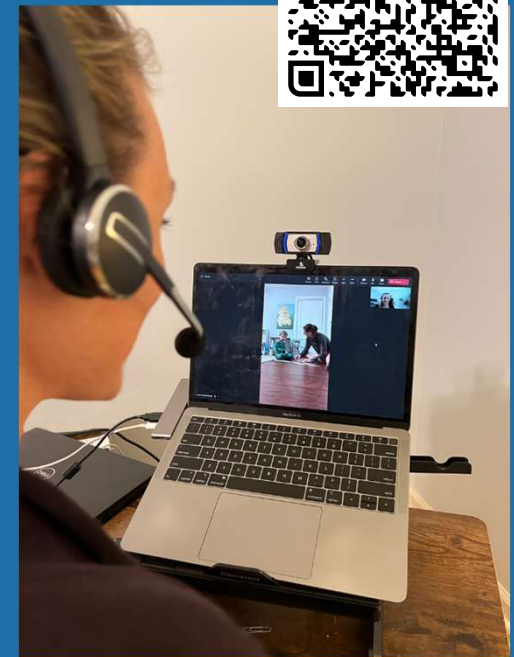
Learn more at: www.SPARKforAutism.org/MUSC

Questions?

Contact our MUSC SPARK Team at sparkautism@musc.edu or 843-714-1352 (call or text)

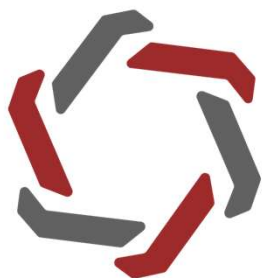
Telehealth Parent-Child Interaction Therapy (Tele-PCIT) Studies at MUSC

- Recommended for children between 2 to 6 years old with challenging behaviors (aggression, tantrums, difficulties following directions)
- PCIT is appropriate for children with some language skills
- PCIT empowers parents by giving them the tools to manage behavior using consistent positive parenting strategies



Questions?

Contact our MUSC Tele-PCIT Team at autismresearch@musc.edu or 843-714-1352 (call or text)



CAROLINA AUTISM & NEURODEVELOPMENT CENTER

- CAN Research Center at the University of South Carolina (USC)
- Variety of studies for all ages
- Families receive compensation for their participation



Scan here to join the registry and be notified about study opportunities!



Autism Parent Support Research Study

FAMILY ELIGIBILITY

- 1 Your child was diagnosed with Autism in the past 12 months and is between 18 months and 8 years old.
- 2 Two parent/caregiver household
- 3 This is your first child diagnosed with Autism

Receive support in understanding your child's diagnosis and navigating services/resources from a trained and experienced parent of a child with autism. All support sessions can be completed from the comfort of your own home via zoom or phone calls.

Receive up to **\$500** for participating

CONTACT ABIGAIL MOJICA, RESEARCH COORDINATOR

OR

(803) 777-1306
mojica@email.sc.edu

SIGN UP HERE!

College of Social Work UNIVERSITY OF SOUTH CAROLINA PennState College of Health and Human Development EDNA BENNETT PIERCE PREVENTION RESEARCH CENTER



Online/National Resources

Online Resources

- Autism Navigator (<https://autismnavigator.com/>)
 - Collection of web-based tools and courses about ASD that may be helpful
- Autism Speaks (<https://www.autismspeaks.org/resource-guide>)
 - Autism Speaks also has a number of “toolkits” and resource guides that may be helpful
 - Autism Response Team (ART: <https://www.autismspeaks.org/autism-response-team-art>)
 - Certified Resource Specialists provide personalized information and resources to families and service providers

Online Parent Training Programs

- Early Start Denver Model (ESDM) (<https://helpisinyourhands.org/>)
 - Play-based, relationship-focused early intervention program for young children with autism
- ADEPT (Autism Distance Education Parent Training) (<https://health.ucdavis.edu/mindinstitute/centers/cedd/adept.html>)
 - 10 Interactive, self-paced learning modules
 - Provides tools and training to teach your child with autism using ABA techniques
- OPT-In-Early (<https://parenttraining.chip.uconn.edu/>)
 - 14 different modules
 - Provides structured learning sessions and how to teach skills during everyday activities
- Vanderbilt Kennedy Center TRIAD Online Learning (<https://triad.vkclearning.org/en-us/>)
 - Brief online training sessions for caregivers and professionals



Questions?

Thank you to all of our collaborators!

