Autism 204 - Supporting the Autism Community in Central and Eastern Washington

Presented by Central and Eastern Washington providers, professionals, parents and advocates.

April 15, 2021, 7-8:30 pm
Our Panel

Jill Bross, MD, FAAP Parkview Medical Group, Grant County

Melissa Brooks, RN, Parent to Parent Coordinator, the Arc of Tri-Cities

Tracie Hoppis, WA State Parent to Parent Network Coordinator, Supervisor for Yakima County Children with Special Health Care Needs Program and Yakima County Parent to Parent, Children’s Village, Yakima

Maria Pulido, Community Health Worker, Parent to Parent and Children with Special Health Care Needs Program- Children’s Village, Yakima
Lori Garcia, MSW, Family Resources Coordinator and Children and Youth with Special Health Care Needs (CYSHCN) Program Coordinator, Children’s Village, Yakima

Sharon Loudon, Regional Autism Education Specialist, Educational Service District (ESD) 105, Yakima

Dana Stevens, ABD, BCBA, LBA, Director, Training and Education and Chief Clinical Advisor Northwest Autism Center, Spokane

John Lemus, UW LEND Program, Vice President – Spokane Chapter of People First of WA, Autistic Self-Advocate
Getting an Evaluation and Diagnosis

What you need to know

Jill A. Dudik Bross, MD

April 15, 2021
Who am I?

General Pediatrician since 1985

Center of Excellence since 2014

Limited focus of practice in 2020 exclusively to Autism and Behavioral Pediatrics

Founder of an ABA Therapy Center in Moses Lake 2017
So What’s the Problems?

All too often parents suspect something is “different” about their child only to be told:
1) Too young to tell
2) He will out grow it
3) Its just a phase
4) It is a speech problem
5) He is just shy

In a recent podcast for the American Academy of Pediatrics, Paul Carbone of Salt Lake City, Utah, discussed how the national average is 600 days from when parents raise the questions to when the diagnosis is made.
So What’s the Problems?

- Our education of primary care providers (PCP) is sadly limited in the amount of time spent on Autism recognition and diagnosis.
- Even when the PCP do recognize and diagnoses, Their resources are also limited.
- Prior to 2013 Insurance companies mostly would not pay for evidence based ABA therapy for Autism
- After the WA State Supreme Court ruling in 2013, mandating the state to cover the cost of ABA therapy the Health Care Authority (HCA) would only pay for therapy if the diagnosis is made and therapy ordered by a Neurologist, Psychiatrist, Psychologist, or Developmental/Behavioral Pediatrician. And there were very few of them available
- As a result, the HCA created Centers of Excellence for the Diagnosis of Autism.
- This expanded the number of physicians and other providers who make the diagnosis and can order therapy
So now what??

Now there are available to the population of the middle of our state, Centers of Excellence for Autism. (COE)

No longer do you need to travel to Seattle, Spokane, or Yakima to have your child evaluated.

There are centers in Walla Walla, Tricities Othello, Moses Lake, Wenatchee, Omak just to name a few.

Recent information from Molina, a major player for Apple Health, reveals that there is NO need for referral from your PCP to be able to access appointments with a COE.

Anyone can refer the child for evaluation, the parents, the schools, the PCP, even the daycare provider.
What does a parent need to do

• Gather information. You know your child best. Share your concerns with your PCP and if they do not see what you are seeing ask for a referral to a COE.

• Advocate for your child. Do not accept “let’s give this time”.

• Check out the WA State HCA website for a list by counties

What does Diagnosis involve?

You should expect to spend a fair with the COE provider who will do your child’s diagnosis.

There will be a ton of questions about now but even more about the past. This process usually is not done all on one or even two days.

Your COE needs time to observe your child and get a good grasp on who your child is and how he/she is interacting with the world.

It is not only “Can” your child do a thing but “Will” your child do it.

Most COE’s use a validated tool to diagnose Autism, but it is not mandatory

Diagnosis is based on the DSM-5 Criteria for Autism
7 Symptoms of ASD

3 Social Communication symptoms:
1. Limited *reciprocity*
2. Poor “*nonverbal*” communication
3. Relationship difficulties

4 Behavioral symptoms of ASD
4. *Repetitive* speech, movements, or activities
5. *Inflexibility*
6. Intense *interests*
7. *Sensory* problems
• Symptoms must be present in the early developmental period, but may not become apparent until *social demands exceed limited capacity* or may be *masked by learned strategies later in life*

• Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning

• Individuals with ASD would *not* present with every characteristic/symptom that is listed
Parent and Family Perspective

Melissa Brooks, RN
Parent to Parent Coordinator, the Arc of Tri-Cities

p2p@arcoftricities.com
www.arcoftricities.com
Autism: the positives

Understanding, embracing and celebrating different ways of thinking and doing can release the true power of the autistic mind. Here we look at the positive features of autism.

Absorb and retain facts
- Excellent long term memory
- Superior recall

Visual skills
- Visual learning and recall
- Detail-focussed

Expertise
- In-depth knowledge
- High level of skills

Tenacity and resilience
- Determination
- Challenge opinions

Accepting of difference
- Less likely to judge others
- May question norms

Integrity
- Honesty, loyalty
- Commitment

Attention to detail
- Thoroughness
- Accuracy

Deep focus
- Concentration
- Freedom from distraction

Observational skills
- Listen, look, learn approach
- Fact finding

Methodical approach
- Analytical
- Spotting patterns, repetition

Novel approaches
- Unique thought processes
- Innovative solutions

Creativity
- Distinctive imagination
- Expression of ideas

Remember

Every experience of autism is unique. No one person will identify with every positive feature of autism. We all have individual skills, attributes and characteristics that are as unique as our personalities – this is the power of neurodiversity.

Harriet Cannon
Disability Services, February 2018

UNIVERSITY OF LEEDS
Where and How to Get Family Support Following the Diagnosis

Tracie Hoppis

WA State Parent to Parent Network Coordinator,
Supervisor for Yakima County Children with Special Health Care Needs (CSHCN) Program
Supervisor for Yakima County Parent to Parent, Parent-Children’s Village, Yakima
Washington State Parent to Parent (P2P)

Providing social, emotional and informational support to parents/caregivers raising children with developmental disabilities and/or special health care need.

- Visit: [https://arcwa.org/parent-to-parent/](https://arcwa.org/parent-to-parent/)
- 26 programs serve every County in Washington State
- 13 multi-cultural coordinators serving Spanish speaking families and African American families
- All Coordinator’s are also parents and/or family members of individuals with disabilities
P2P ... by the numbers

2019-2020

- 18,351 parent/caregiver connections for support, information and referral
- 38,797 parents and professionals on mailing lists receiving current information on resources benefitting individuals with disabilities and their families
- 17,162 Social Media ‘followers’
- 831 Trained ‘Helping Parents’
- 618 Helping Parent ‘Matches’
Central/Eastern Washington P2P Programs

- Chelan/Douglas Counties*- based in Wenatchee
- Grant/Adams Counties*- based in Moses Lake
- Kittitas County- Ellensburg
- Yakima County*- based in Yakima
- Benton/Franklin Counties*- based in Richland
- Okanogan/Ferry Counties- based in Omak
- Pend Oreille/Steens Counties- based in Colville
- Spokane County- based in Spokane
- Walla Walla/Columbia/Garfield/Asotin County- based in Walla Walla

*Spanish language Coordinator/programming
Throughout the Pandemic, Parent to Parent programs have offered a variety of virtual social, support and training opportunities for parents and families, including:

- Traditional support group
- Movie and Book Clubs
- Game nights (Bingo, and more)
- Arts and Crafts Class
- Journaling
- Building with LEGO
- Walk-a-thon
- Talent Show
- Costume Party
- Prom
- Zumba
- Cupcake decorating contest
- Pumpkin decorating contest
- Sibshops
- Coffee Chat
- Scavenger Hunts
- Happy Hour
- Show and tell
- Cooking Class
- Training with agencies (OEO, PAVE, DD Ombuds, etc)
- Helping Parent Training
- New Diagnosis Support Group
- Fathers Groups
‘Having the option to still access support groups virtually has been so helpful, now more than ever. As a parent having kiddos home all the time and trying to help with their on-line school is causing huge burnout and I know that I need time for me! Even if it’s just an hour- knowing that’s my time to replenish myself … it is worth it!’
-Danielle-
Children and Youth with Special Health Care Needs (CYSHCN)

- Definition: Children and youth with special health care needs (CSHCN) “have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.”

- Nearly 20% (or one in five) of U.S. children under age 18 years of age have a special health care need.

- Children and youth with special health care needs and their families often need services from multiple systems – health care, public health, education, mental health, and social services.
In Washington State, the Children and Youth with Special Health Care Needs (CYSHCN) program is located at the Department of Health (DOH), and serves:

Infants, children and youth up to age 18 years who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions and require health and related services of a type or amount beyond what is generally needed.

For more information, visit: https://www.doh.wa.gov/YouandYourFamily/InfantsandChildren/HealthandSafety/ChildrenwithSpecialHealthCareNeeds
At the local level, the CYSHCN program supports contractors to help families with resources and linkages to community services including family support, care coordination, and health information. Guiding principles for our activities are reflected in the National Standards for Systems of Care for Children and Youth with Special Health Care Needs: http://cyshcnstandards.amchp.org/app-national-standards/#/

Find a CYSHCN Coordinator near you: https://www.doh.wa.gov/Portals/1/Documents/Pubs/970-141-CoordinatorList.pdf
Getting Started

Call the Help Me Grow Washington Hotline at 1-800-322-2588

We can help you understand and apply for a variety of food and health resources in Washington state, including:

- WIC (Women, Infants & Children Nutrition Program)
- Basic Food (Food Stamps)
- Health Insurance for children, pregnant women and adults
- Birth control through the Take Charge Program
- Health and family planning clinics
- Developmental screenings
- Pregnancy and baby supplies

211

2-1-1 is a free confidential community service and your one-stop connection to the local services you need, from utility assistance, food, housing, health, child care, after school programs, elder care, crisis intervention and much more. 2-1-1 is always ready to assist you in finding the help you need. Dial the three digit number 2-1-1 on your phone or Find Help here. If you are outside of Washington or have a problem dialing the number 2-1-1, please dial 1-877-211-9274.

Llame a la Línea de Family Health 1-800-322-2588

¡Estamos aquí para ayudarle! Si usted llama a la línea de Family Health, el personal con experiencia que contesta la línea le ayudaran a proyectar y asistirlo para que pueda solicitar para los diferentes programas estatales, incluyendo:

- WIC (Programa de Nutrición para Mujeres, Infantes y Niños)
- Comida Básica (Estampillas de Comida)
- Cobertura médica para niños y mujeres embarazadas
- Anti-conceptivos a través del Programa de Take Charge (Tomar a Cargo)
- Clínicas de Salud
- Artículos para el embarazo y el bebé
- Apoyo de amamantamiento
- Bancos de comida
- Y mucho más...

El personal está disponible de lunes a jueves de 8:00 a 5:30pm y viernes de 8:00 a 5:00pm

- El personal bilingüe habla español
- Para otros lenguajes se utilizan los intérpretes de la línea de lenguajes de AT&T
- No hay cuotas ni límites de tiempo con respecto al tiempo que pasamos hablando, tomamos todo el tiempo necesario para ayudarle a conectar con los servicios que busca
- Por teléfono hacemos evaluaciones de elegibilidad y le ayudamos con su solicitud o también le proporcionamos información y una referencia rápida- ¡usted decide!
Barriers and considerations for Hispanic families:
Tips for getting what you need

Maria Pulido
Community Health Worker, Parent to Parent and Children with Special Health Care Needs Program- Children’s Village, Yakima
Am I Eligible?

Your child with special needs may be eligible for programs and services that help him or her and your family.

Advocacy - Organizations can help you advocate for your child (0-21) within the state’s educational system:
- PAVE: (877) 821-4113  www.wapave.org
- Washington State Office of the Education Ombuds: (866) 297-2597  www.governor.wa.gov/education

Developmental Disability Ombuds - The DD Ombuds is a private, independent office focused on improving the lives of persons with developmental disabilities in Washington State:
- (800) 727-8900  https://ddombuds.org

Children with Special Health Care Needs Program - Care Coordinators help families with linkages to needed services and supports. This program serves children with special needs, age birth to age 18, and their families.
- Children with Special Health Care Needs Program at Children’s Village: (509) 574-3200

Crisis Line – 24-hour confidential mental health and substance use crisis line through Comprehensive Healthcare: (509) 575-4240 or (800) 572-8122

Developmental Disabilities Administration (DDA) - State and federal benefits may be available to eligible children and individuals with intellectual and developmental disabilities:
- DDA: (509) 225-4620 or (800) 822-7840  www.dhs.wa.gov/dda

Informing Families - An excellent website with up-to-date information about services and supports for children with special needs and their families:
- www.informingfamilies.org

Family Support
- Yakima County Parent to Parent - Family support and activities including family events, parent and sibling groups, a social/recreation program and resources and referral: (509) 574-3200 or (800) 745-1077


School Services - Special services are available to eligible children per the Individuals with Disabilities Education Act:  https://sites.ed.gov/idea/
- 0-8 Program - for infants and toddlers with developmental delays and disabilities - contact Children’s Village (509) 574-3200 or (800) 745-1077
- Developmental preschool - free preschool program in school districts for eligible children - contact local school district
- School services for eligible children and youth age 3-21 - contact local school district

Supplemental Security Income (SSI) - Federal benefits are available to eligible children with special needs. Eligibility includes child’s level of delay or disability and family income.
- 866-345-8552  www.ssa.gov/sdi

Transportation - If your child has Medicaid, you should be eligible for transportation assistance.
- People for People: (509) 248-6793 or (800) 233-1624  www.p4p.org/pts/pts/home.aspx

“Yakima County”

This document was developed by the Yakima County Children with Special Health Care Needs (CSHCN) team at Children’s Village. For questions about resources or care coordination, please call a member of the CSHCN team or Parent to Parent.
Supports Available from the Early Support for Infants and Toddlers (ESIT ) Program and Public Health CSHCN Programs

Lori Garcia

Family Resources Coordinator and Children and Youth with Special Health Care Needs (CYSHCN) Program Coordinator, Children’s Village, Yakima
Transition

At age 18, an individual’s status changes with Supplemental Security Income (SSI). Parent/family income is no longer considered so individuals who didn’t qualify prior to age 18 may qualify. SSI provides Medicaid and each benefit to eligible individuals.

Social Security Administration
http://www.ssa.gov
(800)772-1213

Washington State ID Card - An individual can obtain an ID card before or after age 18 with proof of residence and identity. Visit a local Department of Licensing office to apply. Cost is $84.00. This is good for 6 years.

Department of Licensing
http://www.dvl.wa.gov/drivierlicensing/gettinganidcard.html
(866)510-4365

Apply for Durable Power of Attorney or Guardianship for your child, if necessary. This is management of the affairs of a person who has been judged unable to manage his or her own affairs. It is the transfer of legal rights and decision making to another individual through a legal process.

For more information, contact:
Washington Law Help
http://www.washingtonlawhelp.org/WA/index.cfm/index.cfm
(click on “Aging and Elder Law”)
ARC of Washington State
http://www.arcw.org

Primary Medical Care: By age 18, talk with the Primary Care Provider about transfer of medical care if necessary.

Transition time line for students with disabilities age 16-21. Created by the Yakima County Children with Special Health Care Needs Team at: Children’s Village
(800)746-1077 (509)574-3290

Students on IEP’s can attend school through the age of 21. The student whose twenty-first birthday occurs after August 31, shall continue to be eligible for special education for the remainder of the school year.

Apply to adult service provider agencies - Developmental Disabilities Administration (DDA) and Division of Vocational Rehabilitation (DVR).

DDA
http://www.dda.wa.gov/dda/index.html
(800)223-4365 Region 2 (509)223-7970
DVR
(800)637-6627 Yakima office (509)218-4455

Additional Resources:
Washington State Adolescent Health Transition Project
http://depts.washington.edu/healthtr/ (206)845-7701 (Center on Human Development and Disability)
Washington State Office of the Superintendent of Public Instruction
http://www.k12.wa.us/specialed/ARCofWashington--AdvocatesfortheRightsofPeoplewithDevelopmentalDisabilities
http://www.arcw.org
(888)754-8798
Informing Families:
http://informingfamilies.org/
Mental/Behavioral Health Resources for Individuals and Families living in Yakima County

If you or a loved one is experiencing distress and needs support, call:
- National Parent Helpline 1-855-4 A PARENT or 1-855-427-2736
- Info Children /Parent Helpline 1-778-782-3548
- National Suicide Prevention 1-800-273-8255
- Crisis Text Line by texting TALK to 741741

Local Crisis Line for Yakima County:
- Comprehensive Healthcare Crisis Line- 509-575-4200
- NAMI 509-453-8229 (available 24/7)

If you or a loved one have mental health concerns, or behavioral challenges, and would like to make a referral, call the following for ongoing services (additional local mental health counselors may also be available):
- Behavioral Health Services (Yakima Valley Farmworkers Clinic) - 509-453-1344
- Comprehensive Healthcare-509-575-0484
- Catholic Charities Services- 509-965-7100
- Medicaid / Manage Care Organizations offer Case Coordination Support
- Private Insurance companies will direct you to authorized service providers

Please remember to take care of yourself during this stressful time, including:
- Taking breaks- go for a walk outside, play outside with your children/family
- Don’t watch the news 24/7
- Take time for fun! Do a craft activity with your child, watch a funny movie, and be silly
- Reach out to a friend by phone or Face Time- talk about things other than the virus
- Eat healthy as much as possible
- Get enough sleep
- Try to maintain a daily routine- for you and your children!
- Keep in mind, this will pass- focus on positives as much as possible
- Separate what is in your control from what is not

10 Ways to Feel Less Isolated as a Parent While Social Distancing

1. Post heartwarming memories on social media.
2. Open up about how you’re organizing your time.
3. Cook with friends and loved ones virtually.
4. Create a thoughtful craft.
5. Post pictures that make you and...
How Schools Can Help: the ESD 105 Model

Sharon Grandy Loudon
Regional Autism Education Specialist, Educational Service District 105, Yakima
Autism Services Through ESD 105: How did we create support for smaller districts in a large geographical area?

- 10 School Districts came together in 2005 to create an Autism Cadre within ESD 105. (Easton to Grandview)
- School Districts pay into the cadre to access Autism Support Services
  - Cost per school district is based upon the size of the district as well as the allotted days they would like to purchase.
  - School districts can add additional days into their contract with the Autism Cadre at any time during the school year.
Services Offered Through ESD 105 Autism Cadre:

- School District Trainings
- Grade Level Trainings
- Student Observations
- Transitional Support Moving Between Classrooms/Programs
- Functional Behavioral Assessments
- Hands on Teacher Support (Model and Practice)
- Teacher Support in the Creation of Meaningful IEP Goals (Individual Educational Plans)
- Creation of Tools to Increase Student Success
  - Visual Schedules
  - First/Then Boards
  - Token Economies
  - Social Stories
Services Offered Through ESD 105 Autism Cadre Continued:

- Home Visits to Support Generalization of Skills
- Social Skills Groups (In person and Online Groups)
- Social Skills Training and Supportive Curriculum Development for Teachers
- Problem Solving Difficult Patterns of Behavior with Community Providers
  - Linking Students Back to Medical Home/Primary Care
  - Support in Accessing Specialty Services (Counseling, Medical Management)
Small Can Equal Powerful:

- Our smaller school districts have pooled resources together to access ongoing autism support within their school districts.
- Our ESD Autism Education Specialist is linked to community resources to create the success for individual families.
- Through our service model, families and children can be supported from the time of diagnosis as they work to navigate their child’s special educational and medical needs.
Questions?

Feel free to contact Sharon Grandy Loudon at ESD 105.

sharon.loudon@esd105.org

509-895-4491
What’s Applied Behavioral Analysis (ABA) Therapy and What to Do While Waiting for it

Dana Stevens, ABD, BCBA, LBA
Director, Training and Education and Chief Clinical Advisor Northwest Autism Center, Spokane
Mission:

BUILDING A STRONG NETWORK OF SUPPORT
Northwest Autism Center exists to support, facilitate, and build accessible and comprehensive community based approaches for helping children and adults with autism spectrum disorder and other developmental disabilities in the Inland Northwest.

Vision:

PROMOTING THE WORTH OF EVERY INDIVIDUAL
Each individual with autism spectrum disorder and other developmental disabilities living in the Inland Northwest will have access to early diagnosis and treatment; best practices in public education and healthcare; and the social supports necessary for optimal personal growth and the fullest level of participation within family and community.
Improving community support and connection through partnerships, education and awareness.

Providing evidence-based direct treatment services for individuals and families.

Contributing key values, ideas and information to local, state, and national debates on caring for individuals with autism and other developmental disabilities.

Providing learning opportunities across disciplines for university students, faculty, and practicing professionals to improve collaboration and quality of care.
Applied Behavior Analysis (ABA) Treatment

- Scientifically validated Evidence-Based Treatment

- Insurance Reform: ABA must be covered as a *medical necessity* treatment for ASD and other developmental disabilities for which ABA has been proven effective

- 2012: Health Care Authority (HCA) settled lawsuit related to EPSDT (Early and Periodic Screening, Diagnostic and Treatment)

- Since 2014, all private carriers in Washington State must cover ABA
What is ABA?

• ABA involves the **systematic application** of scientifically validated **principles of human behavior** not only to change “**inappropriate**” behaviors but teach **SKILLS**!

• ABA uses **scientific methods** to reliably demonstrate that behavioral changes are caused by the prescribed evidence-based interventions

• ABA's focus on **social significance** promotes a family-centered and whole-life approach to intervention
Purpose of ABA

Applied behavior analysis (ABA) assists individuals and their families to improve the core symptoms associated with autism spectrum disorders (ASD) or other developmental disabilities for which there is evidence ABA is effective.

ABA services support learning, skill development, and assistance in any of the following areas or domains: Social, behavior, adaptive, motor, vocational, or cognitive.
ABA Delivery Methods and Settings

Emergency rules in WSR 21-04-111, effective 2/1/2021
ABA cannot have a cap on age and can be prescribed throughout the lifespan!

• Appropriate staffing ratio to accomplish individual client’s goals, for example:
  – 1:1
  – Group setting

• Appropriate setting to accomplish individual client’s goals, for example:
  – Home-based
  – Clinic/Center-based
  – Community-based
  – Early Intensive Day Treatment Program (Medicaid Specific Short-term benefit for young children)

Can be a combination
Applied Behavior Analysis (ABA) Service

• Direct Treatment
• Coordination of Care
• Family (Caregiver) Training

• Service Providers
  • Health Care Authority (HCA) website for list of ABA providers
    https://www.hca.wa.gov/assets/billers-and-providers/medicaid-enrolled-aba-providers.pdf
  • Northwest Autism Center (NAC) maintains a list of local ABA providers
Caregiver Training Only

• Eligible while child is on waitlist for services or cannot access services

• Covered by private and Apple Health

• 1:1 or group settings

• Copy of Center Of Excellence (COE) evaluation and ABA prescription/order

• ABA provider completes assessment to:
  • Confirm medical necessity and readiness for treatment
  • Completes treatment plan with only caregiver treatment goals related to child’s assessment

• Can be delivered via telemedicine/telehealth
Services while waiting for ABA Treatment

- Family Training and Education
- School Services
- Speech and Language Services
- Occupational / Physical Therapy (OT/PT)
- Medical Providers
- Mental Health Providers
- Support Groups
Websites and Resources

WA State Medical Home Partnership Project
This website brings together practical and current tools, strategies, and information designed to help physicians and other health care providers in Washington State care for children and youth with special health care needs and their families.

Current list of Centers of Excellence (COEs) by County
Note: Can contact NAC for updated list of COE providers in Spokane County

Current list of ABA Providers by County
Note: Can contact NAC for updated list of ABA providers in Spokane County

Current Healthcare Authority (HCA) ABA Billing Guide
This guide provides instructions for COEs and ABA providers but may also be helpful to providers who want to assist clients and their families in accessing ABA services and navigating the pathway to care.

Chapter 182-531A WAC Applied Behavioral Analysis
This link states regulations (Washington Administrative Codes) around ABA access and treatment in the state of WA.
Contact NW Autism Center for Spokane ABA Provider List


Contact Information

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www.nwautism.org
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An Autistic Perspective: What’s Important for Parents and Providers to Understand About the Lived Autistic Experience and How to Support Autistic Individuals

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