

RAINBOW Study

Assessment and Treatment of Behavior Problems: A Telehealth Approach

Nicole McDonald, PhD

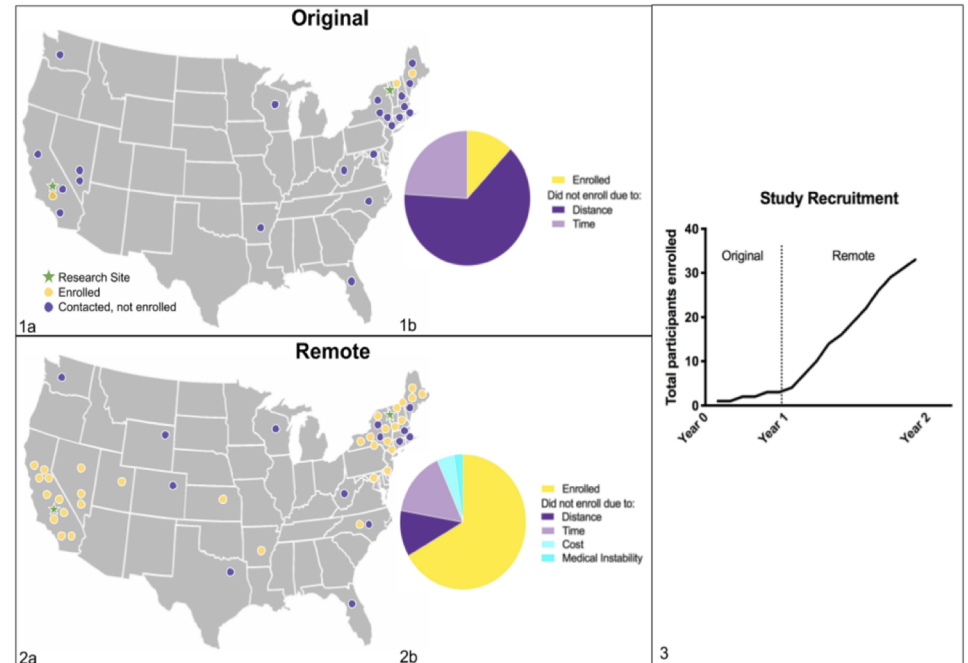
Assistant Clinical Professor, UCLA Semel Institute

May 13, 2024 - TSC Alliance Webinar

Motivation for RAINBOW Study



Switch to hybrid approach



Hyde et al., 2020

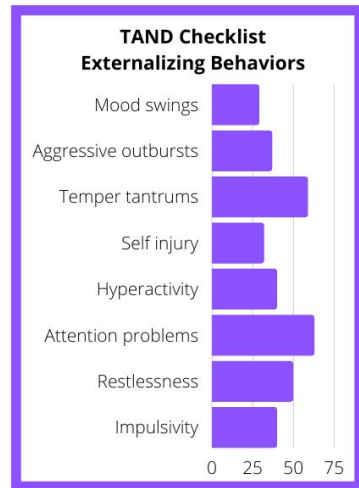


n = 42

83%
TAND Checklist
1+ Externalizing
Behavior

26%
ECBI
Clinically elevated

39%
BRIEF
Clinically elevated



How do we help families of children with TSC and behavior problems?

Parent-Child Interaction Therapy (PCIT) Treatment Targets

Primary target:

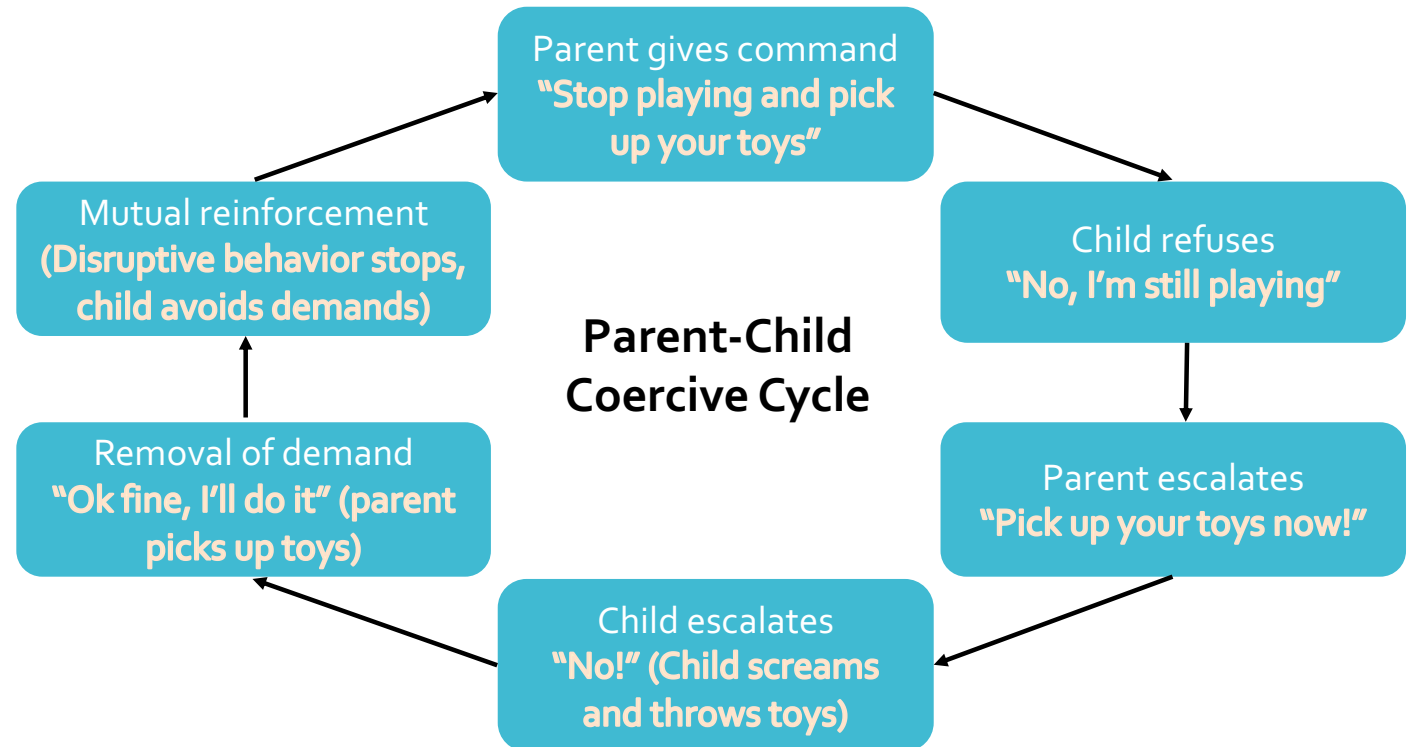
Reduce disruptive behavior (interrupt coercive cycle)

Secondary benefits:

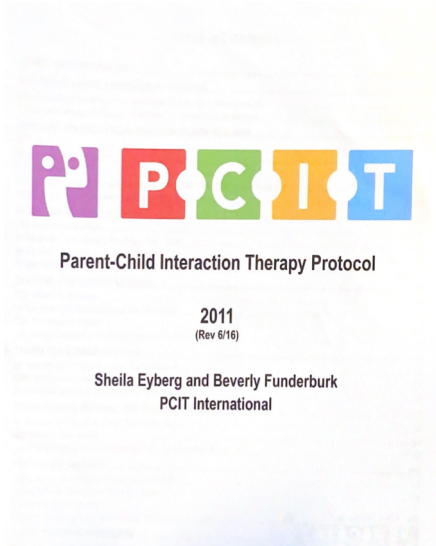
Increase positive parenting skills

Reduce parenting stress

Target age range: 2-7 years old



What Does PCIT Look Like?



Manualized & skills-based



Data tracking & criterion-based



Live coaching via bug-in-ear



Play context

Format of PCIT

First Phase

Child Directed
Interaction
(CDI)

Relationship
Enhancement

Second Phase

Parent Directed
Interaction
(PDI)

Limit Setting

CDI Teach

CDI Coach

PDI Teach

PDI Coach+ & Graduation

What does PCIT Teach?

CDI

Follow child's lead

PRIDE skills

Selective attention

Daily special time

PDI

Effective commands

Time out procedure

Home practice

House rules

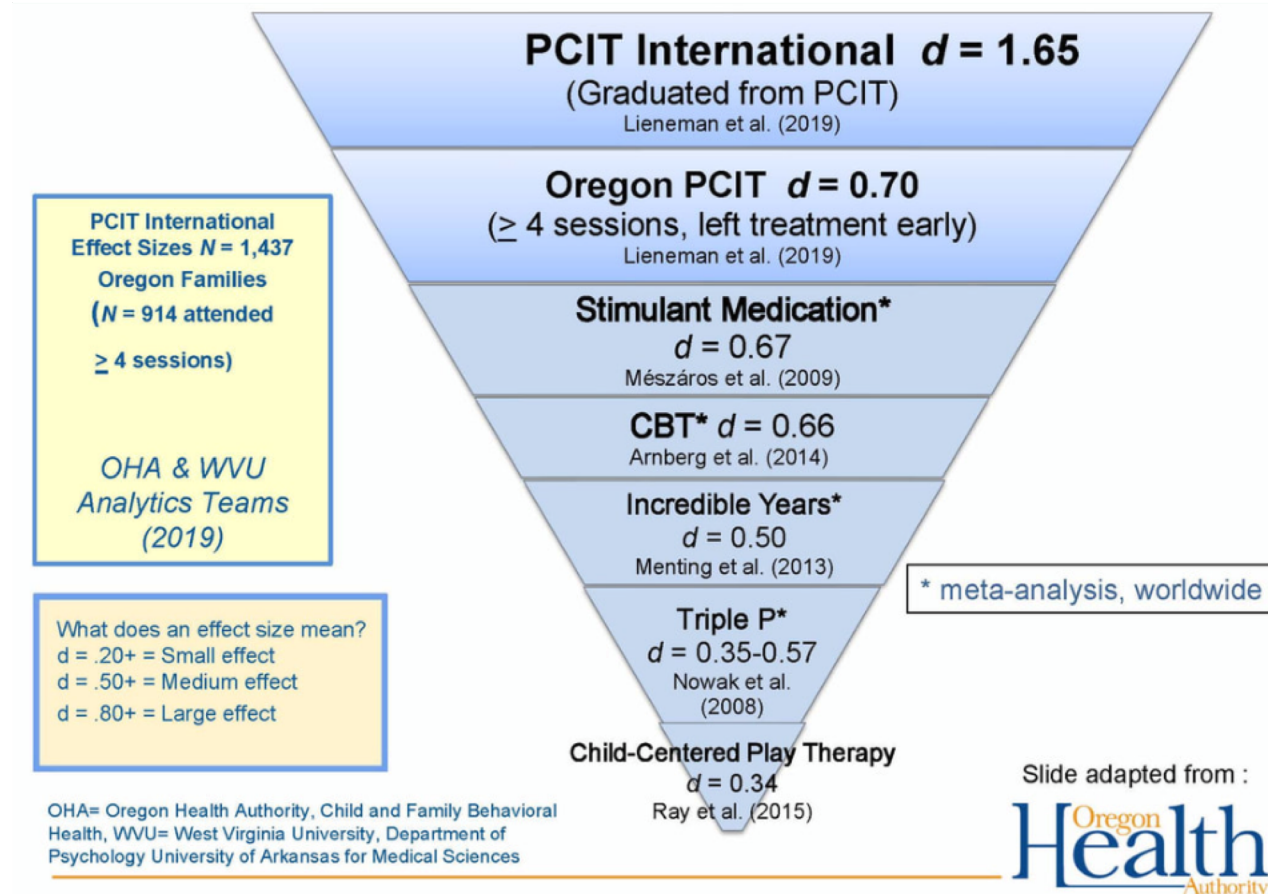
Generalization

Research Base

Large effect for disruptive behavior disorders

Has been tested across countries & languages

Effective in many community settings



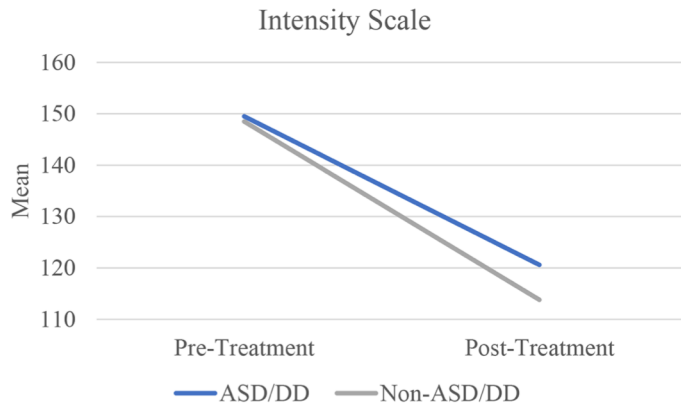
PCIT in Neurodevelopmental Disabilities (NDDs)

Journal of Autism and Developmental Disorders
<https://doi.org/10.1007/s10803-022-05755-0>

ORIGINAL PAPER

Community-based Agency Delivery of Parent-Child Interaction Therapy: Comparing Outcomes for Children with and Without Autism Spectrum Disorder and/or Developmental Delays

Lauren B. Quetsch¹ · Rebecca S Bradley¹ · Laurie Theodorou² · Kathleen Newton² · Cheryl B. McNeil^{3,4}

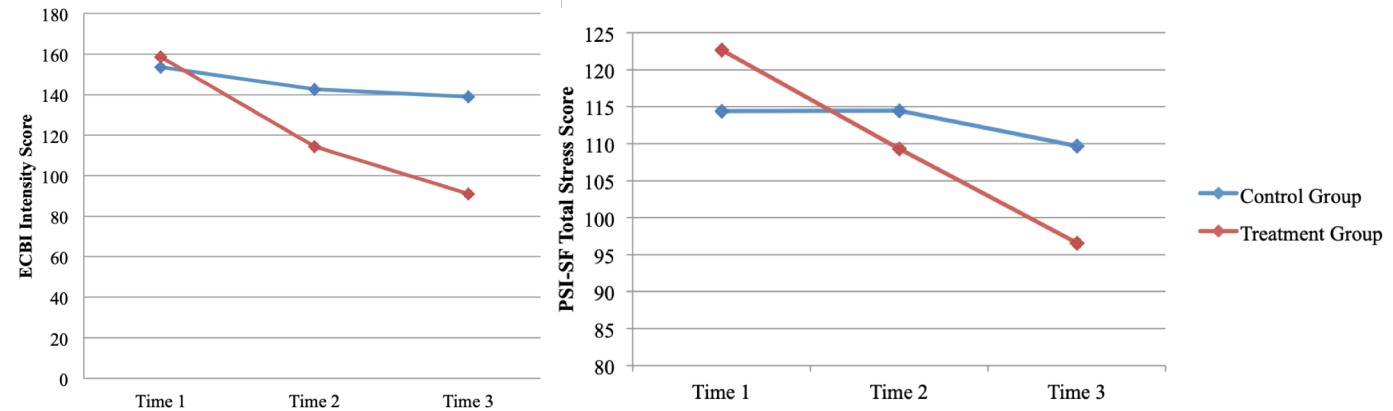


Journal of Autism and Developmental Disorders
<https://doi.org/10.1007/s10803-022-05428-y>

ORIGINAL PAPER

Parent-Child Interaction Therapy for Children with Disruptive Behaviors and Autism: A Randomized Clinical Trial

Korrie Allen¹ · John Harrington^{2,3} · Lauren B. Quetsch⁴ · Joshua Masse^{5,6} · Cathy Cooke³ · James F. Paulson⁷



Autism: Similar reductions in disruptive behavior and parenting stress, some evidence of secondary effects on autism behaviors and adaptive skills

Intellectual/developmental disabilities: Very limited data, evidence of efficacy but possibly higher drop out rate

No studies in TSC or other specific neurogenetic conditions

Allen et al., 2022; Bagner & Eyberg, 2007; Parlade et al., 2020; Quetsch et al., 2022; Zlomke et al., 2017; 2020

Internet-delivered PCIT (I-PCIT)

Format well suited to telehealth

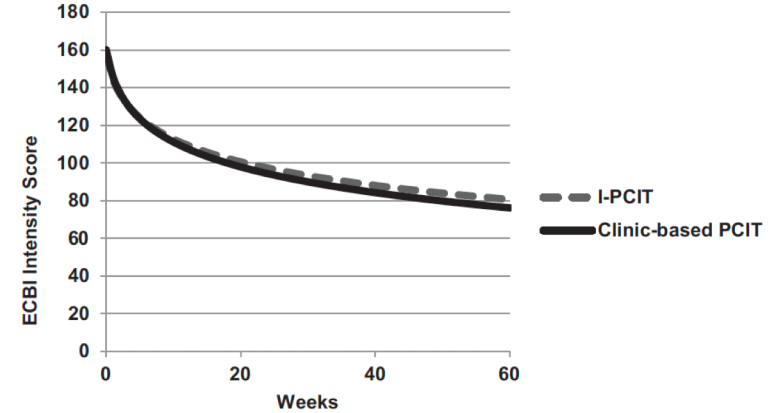
COVID-19 led to more rapid implementation of I-PCIT

Similar reductions in child disruptive behavior

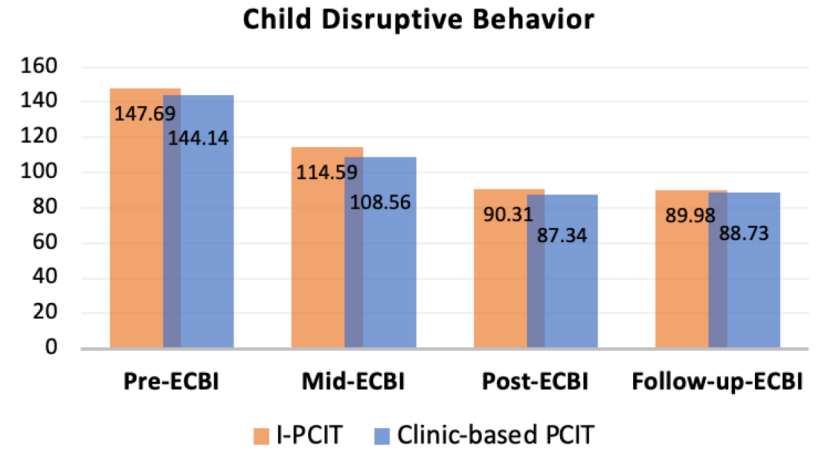
Reduced barriers to treatment



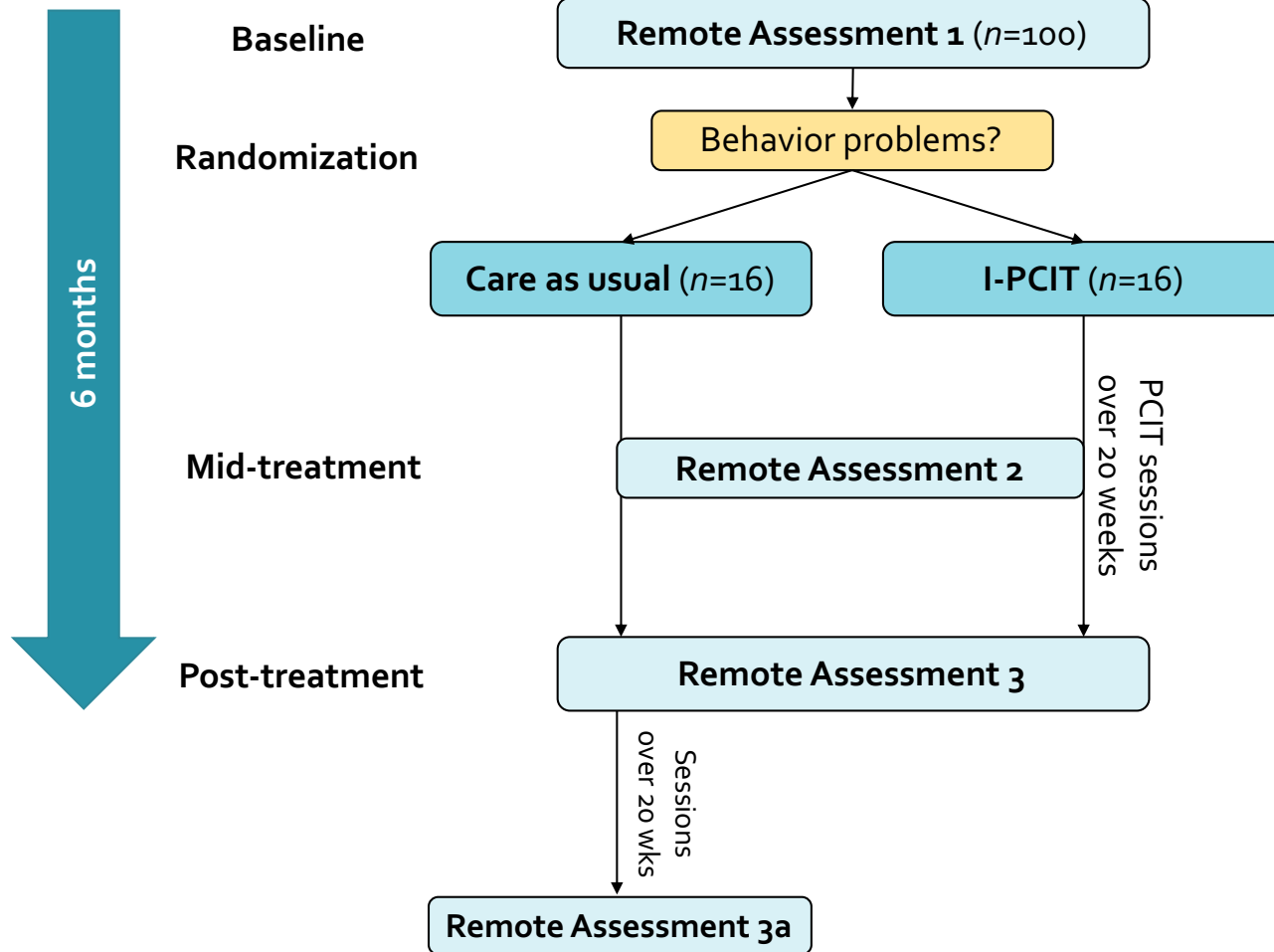
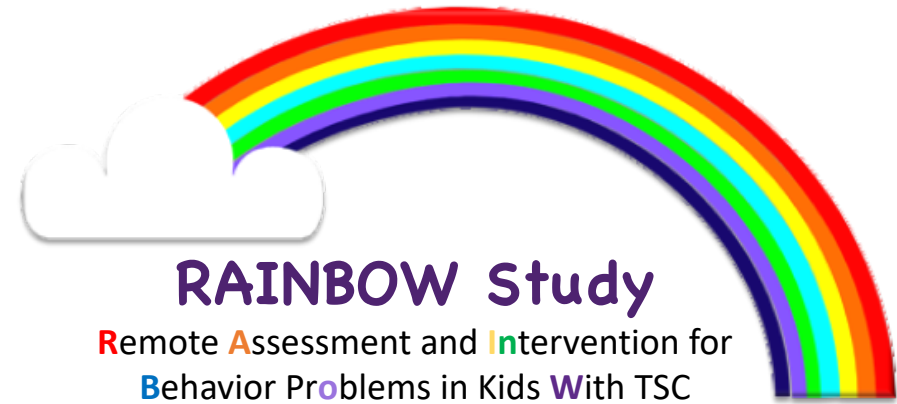
(Courtesy of Kurtz Psychology)



Comer et al., 2017



Peskin et al., accepted



Recruiting English- & Spanish- speaking TSC families now (ages 3-6 years old)!

Aim 1: How common are behavior problems in preschool-aged kids with TSC? How can we assess remotely?

Aim 2: Is I-PCIT doable and acceptable in families of children with TSC and behavior problems?

Aim 3: Does I-PCIT seem to work in children with TSC and behavior problems?

Aim 4: Who responds best to I-PCIT treatment?

What does I-PCIT look like?



Study Progress to Date



Who has signed up so far?

- Assessment visit: **62** participants enrolled (goal=100)
- Intervention study: **21** participants enrolled (goal=32)
- 47.3% girls/52.7% boys
- Almost all had history of seizures, 66% controlled
- 44.4% had elevated behavior problems at baseline

Baseline Data	Age (years)	Vineland-3 score	ECBI score
Range	3.0 – 7.0	34.0-97.0	59-203
Mean (SD)	4.61 (1.27)	66.98 (14.76)	127.89 (30.24)

What is involved?

Remote assessment only:

- 3-4 hour time commitment
- Video-recorded play & parent interviews over Zoom
- Parent questionnaires
- \$100 compensation & clinical feedback

If eligible and interested, remote intervention:

- Weekly 1 hr sessions over Zoom (45-60 mins) for up to 20 weeks
- Daily 5-min practice & response to quick text
- 2-3 follow up assessments of ~1-2 hours each
- \$50-\$100 per assessment & free toy bin



Interested in participating?

Contact: Viviana Rodriguez
(vivianarodriguez@mednet.ucla.edu)

or Nicole McDonald
(nmcdonald@mednet.ucla.edu)

Thank you!

RAINBOW Study Team



Cami Ferrario



Viviana Rodriguez



Carly Hyde



Corinna Klein



Jason Jent



Karol Grotkowski

Thank you to all of the families who have participated so far!



Questions?





For more information

RAINBOW Study

Remote Assessment and Intervention for Behavior Problems in Kids With TSC

We are seeking to learn more about behavior problems in young children with Tuberous Sclerosis Complex (TSC)

You can participate in this study from home!

This study is being led by **Nicole McDonald, PhD at UCLA**

Your family may be eligible for this study if your child has a **diagnosis of Tuberous Sclerosis Complex (TSC)**, and:

- Is 3-6 years old
- English or Spanish is the primary language spoken in your home
- You live anywhere in the United States



This study involves **one virtual visit** which will include:

- Play interactions between you and your child
- Parent interviews
- Questionnaires

Your family will receive:

- Feedback on your child's behavior and development from a clinician
- \$100 gift card upon completing virtual visit

Potential opportunity to receive free internet-delivered behavioral treatment!

For more information, please contact Viviana Rodriguez: vivianarodriguez@mednet.ucla.edu or (424)326-3118





Para obtener más información

RAINBOW Study

Remote Assessment and Intervention for Behavior Problems in Kids With TSC

Nos gustaría aprender más sobre los problemas de comportamiento en niños pequeños con Complejo de Esclerosis Tuberosa (CET)

¡Puedes participar en este estudio desde casa!

Este estudio está siendo dirigido por la **Dra. Nicole McDonald en UCLA**

Su familia puede ser elegible para este estudio si su hijo tiene un diagnóstico de **Complejo de Esclerosis Tuberosa (CET)**, y:

- Tiene 3-6 años
- Inglés o Español es el idioma principal que se habla en su hogar
- Ustedes viven en cualquier parte de los Estados Unidos



Este estudio implica **una visita virtual** que incluirá:

- Evaluaciones de desarrollo basadas en el juego
- Interacciones grabadas entre usted y su hijo
- Entrevista con los padres y cuestionarios

Su familia recibirá:

- Comentarios sobre el comportamiento y el desarrollo de su hijo
- \$100 al completar la visita virtual

¡Existe también la oportunidad de participar en un tratamiento conductual gratuito administrado por Internet!

Para obtener más información, comuníquese con Viviana Rodriguez: vivianarodriguez@mednet.ucla.edu o (424)326-3118

REMOTE intervention study for children with TSC!

TRAIN

TSC Remote Assessment & Intervention

You and your child may be eligible to participate if:

- Your child has a clinical TSC diagnosis
- Your child is between 12-36 months of age
- English is the primary language spoken at home
- Parent is available twice weekly for remote video conference calls

Participants will receive:

- Free assessments of communication, cognition, and play
- Free evidence-based intervention
- \$150 for study completion

For more information, email: JASPERforTSC@gmail.com or text/call: (323) 451-1485



UCLA Jasper

Protocol ID:IRB#20-00010 UCLA IRB Approved Approval Date: 11/18/2021 Committee: Medical IRB 3