

Telehealth Advances for Autism Spectrum Disorder

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- Grant funding from NIH, DOD, Simons Foundation, and Autism Speaks
- Consultant for Jaguar Therapeutics and Forge Therapeutics
- Board Member of the National Fragile X Foundation
- Creator and Trainer of Regulating Together

Overview

Treatment

Diagnostics

Family Experience

Reimbursement

Provider Accessibility

Research Needs

A recent set of recommendations for removing ableist language from autism research (Bottema-Beutel et al., 2021) will inform my terminology use throughout this presentation.

“In regard to neurodevelopmental psychiatry, it is possible to manage medications on video with yearly in person visits for labs, vital signs, and physician exam.

I started telemedicine 15 years ago and the only thing that has changed, in a good way, is acceptance of telemedicine. It has always been feasible”

- Craig Erickson, MD

Director of the Cincinnati Fragile X Center

Treatment: Does it Work

- Very Promising Evidence!
 - Adapted and New Programs
- Example Programs
 - Regulating Together for ASD Experience
 - Fragile X Telehealth Program



“Telehealth assessment is feasible and accepted among clinicians and families. Children who have more impairment and higher ASD concern appear to be an ideal group for telehealth diagnostics and primary care screening can be used to triage patients into the right diagnostic setting.

The biggest barrier has been insurance company recognition of diagnoses from telehealth. Unfortunately, we have had to spend significant time educating insurance companies.”

- Debra Reisinger, PhD
Riley Hospital for Children

Diagnostics: Is it Possible?



- Early Positive Evidence!
- Comparable outcomes (80-95%)
- Provides More Naturalistic Information
- New Measure Development
- Must identify best candidates
- New collaborative models of diagnosis

“An in-person 30-60 minute appointment at our clinic is an entire day activity. Every aspect of the day has to be considered. From leaving the house early in case you have traffic delays, to planning for food throughout the day , to having a “reward” at the end of the day, etc. And that does not include all the hours of planning done ahead of time for that day, from scheduling the appointment at a time that will minimize traffic delays, to taking care of all the home parts (time off work, other children, etc).

You have to think of everything, because if one thing goes wrong..... It takes a lot of time and emotional energy. Plus you have to plan for the actual appointment. Summarize what has been going on with your child, write down your questions....

With telehealth, you only need to think about the actual appointment. Easy-peasy.

When possible, telehealth visits are a wonderful option.”

- Caregiver

What Do Families Think?

- Overall Positive Feedback!
- High rates of satisfaction during the pandemic
- Decreased caregiver and child burden
- Hybrid preference when possible
- Do we have a complete picture?
 - Need more diverse perspectives
 - Need more involvement of self-advocates



“It would be an incredible disservice to families of children with developmental disabilities to limit an evidenced- based service just because it is provided via Telehealth, especially when we have emerging research data to suggest comparable efficacy of telehealth services.”

- Sarah Greenwell, PsyD
Cincinnati Children's Hospital

Are We Being Reimbursed?

- Mostly Yes... But Not for Everything...
- The Treatment Gaps
 - Employer Opt-In
 - Family Therapy
 - Multi-family Group Therapy
- Diagnostics Impact
 - Recognition and future coverage



For our family, telehealth has significantly improved access to professionals and clinicians. We are two hours from the closest FX clinic making our regular visits a full day endeavor when in-person. Through telehealth we can have both boys seen in about 30-45 minutes without the expense of traveling.

Telehealth takes away so many barriers and provides access without the added stress/anxiety/etc. just by allowing us to be in a familiar setting.

- Caregiver

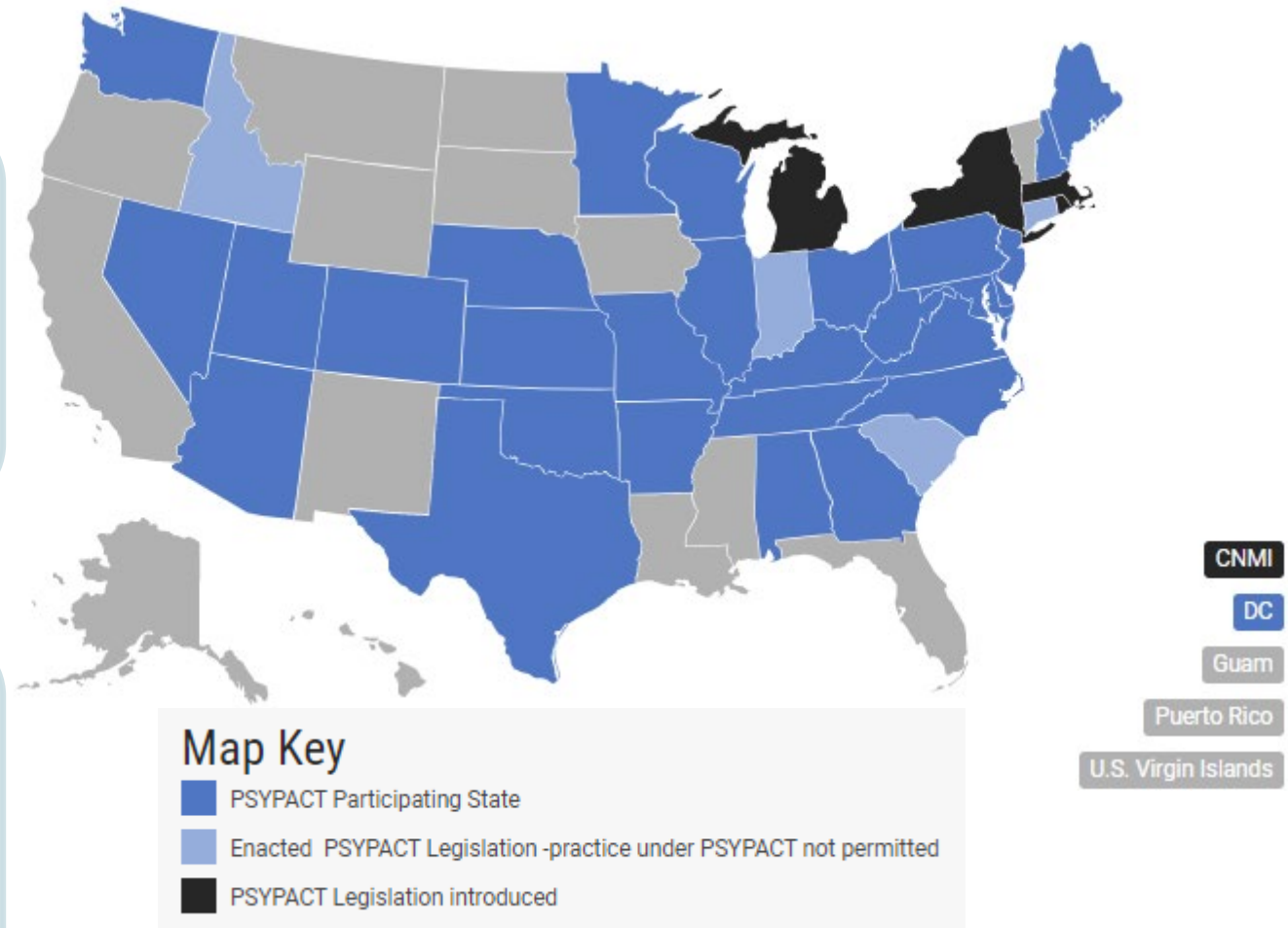
Are Providers Accessible?

PsyPACT

- Psychology Leading the Way!

Fragile X

- Only 31 Centers Across the US
- Telehealth Opens Care



Where are the Research Needs?



ClinicalTrials.gov

- 28 open trials
 - Only 3 Diagnostic Related
 - Adult Assessment
 - Disparity focused
 - Outcomes for Families
 - Treatment Related
 - Primarily Caregiver Training
 - Very few examining direct intervention

Gaps

- Comparison Trials of Diagnostic Tools
- Diverse and Self-Advocate Involvement
- Direct Intervention Trials with Autistic Individuals
- Examination of Disparities and Access
- Interventions for Profound Autism

Future Focus



Thank You

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- National Fragile X Foundation Staff and Board
- Contributors to the JADD Special Issue about Telehealth Advances

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