Telemedicine-aided therapy helps parents of children with developmental disorders, including autism

Parents and therapists collaborate to customize therapy to advance social skills

UCLA Health

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UCLA's Semel Institute for Neurodevelopment and Human Behavior

NEWS PACKAGE	
SUGGESTED TEASE	CUTTING EDGE THERAPY IS HELPING YOUNG CHILDREN CLOSE DEVELOPMENTAL GAPS EARLY IN LIFE. COMING UP, LEARN HOW FAMILIES OF CHILDREN WITH DEVELOPMENTAL NEEDS CAN GAIN ACCESS TO CUTTING-EDGE TREATMENT.
(PACKAGE START) CG: Courtesy: UCLA Health: 00 -: 03 Shots of Mary playing with John Michael	EXPERTS SAY SIGNS OF DEVELOPMENTAL DELAYS CAN OFTEN BE IDENTIFIED IN THE FIRST YEAR OF LIFE, YET EVOLVING THERAPIES THAT HELP PARENTS ACT EARLY AND CLOSE THOSE GAPS ARE OFTEN NOT AVAILABLE LOCALLY. NOW, A NEW CLINICAL TRIAL IS INVESTIGATING A UNIQUE APPROACH TO REMOTE TREATMENT, STARTING WITH CHILDREN WHO NEED IT MOST. TUBEROUS SCLEROSIS IS A GENETIC DISORDER THAT COMES WITH A HIGH-RISK FOR AUTISM, BUT ALSO SEVERAL OTHER MEDICAL CONDITIONS THAT MAKE IT DIFFICULT FOR THESE FAMILIES TO TRAVEL TO FIND THE BEST CARE. ANIETRA HAMPER HAS THE DETAILS. (Nats - Sound) :02 AT SEVEN MONTHS OLD, JOHN-MICHAEL CRAWFORD WAS DIAGNOSED WITH TUBEROUS SCLEROSIS, A GENETIC DISORDER THAT OFTEN CAUSES DEVELOPMENTAL ISSUES, INCLUDING AUTISM. SO WHEN HIS PARENTS BEGAN TO NOTICE DELAYS, THEY WEREN'T SURE WHERE TO TURN. :12
CG: Mary Crawford Mom of child with tuberous sclerosis	"It hurts, because as a momma you want to be able to do and do and do, but you got to know it takes a village." :06

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Shots of Dr. Jeste reviewing video with family

Shots of Mary and John Michael recording session

THE CRAWFORDS, WHO LIVE IN ARKANSAS, EXPANDED THEIR VILLAGE TO INCLUDE EXPERTS MORE THAN FIFTEEN-HUNDRED MILES AWAY AT U-C-L-A'S SEMEL INSTITUTE IN LOS ANGELES, WHERE SCIENTISTS ARE EXPLORING AN INNOVATIVE APPROACH USING TECHNOLOGY TO BRING CUTTING EDGE TREATMENTS TO PATIENTS THOUSANDS OF MILES AWAY. :11

Nats of Mary and John Michael recording session :02

CG: Shafali Jeste, MD
UCLA's Semel Institute for Neuroscience
and Human Behavior

"Every week, they practice with their baby. They upload their videos to a trained interventionist who's at the sites." :11

CG: Brandon Crawford Dad of child with tuberous sclerosis

Shots of family's recorded sessions

Shots of therapist working with family

"The remote sessions are really the only reason we were able to participate in the program. We could do it on our schedule. We could do it in a space that he was familiar with, with his toys." :10

THE THERAPY – CALLED JASPER – IS A SCIENCE-BACKED METHOD DEVELOPED AT U-C-L-A THAT USES PLAY TO ENHANCE CHILDREN'S DEVELOPMENT AND BEHAVIOR.

THE THERAPY CAN BE IMPLEMENTED IN INFANCY

– LONG BEFORE TREATMENT WOULD NORMALLY
BEGIN.

SCIENTISTS FOUND EARLY SIGNS OF AUTISM IN THIS GROUP OF INFANTS WHO, UNTIL NOW, WOULD NEVER HAVE RECEIVED CRUCIAL EARLY INTERVENTION. :18

"The earlier you can intervene, the earlier you can enrich that environment, the more likely you are to actually exact

Dr. Jeste (CG'd earlier)

Shots of John Michael in assessment

Shots of therapist working with the Crawford's in play therapy

session

AFTER A THOROUGH ASSESSMENT OF THE CHILD. :03

change in brain development.":08

(Nats) Therapist "Whats this?" John Michael: "A leg." Therapist: "A leg.":02

THERAPISTS TRAIN PARENTS TO USE THE JASPER METHOD IN EVERYDAY PLAY...:03

(Nats) Therapist: "So that's why every time he's speaking to me I'm responding to him." :02

Shots of Mary and John Michael

ALLOWING THEM TO IMPROVE EVERY DAY AND

recording session

REPORT BACK ON THEIR PROGRESS VIA TELEMEDICINE.

JOHN MICHAEL'S PARENTS HAVE NOTICED IMPROVEMENTS, AND ARE GRATEFUL FOR EFFECTIVE THERAPY SO EARLY IN LIFE. :10

Mary Crawford (CG'd earlier)

"If we close the gaps now, it'll just be helpful later in all kinds of areas." :07

Brandon Crawford (CG'd earlier)

"He's had pretty drastic improvements that we've noticed, not just on paper, but just interacting with him. He's grown leaps and bounds." :10

Shots of John Michael and Mary playing

AT UCLA'S SEMEL INSTITUTE FOR
NEUROSCIENCE AND HUMAN BEHAVIOR, THIS IS
ANIETRA HAMPER REPORTING. :05

(PACKAGE END) -----

EXPERTS THIS PROCESS MAY BE USED IN THE FUTURE TO OFFER THE LATEST THERAPIES TO FAMILIES AND CHILDREN FACING DEVELOPMENTAL CHALLENGES NO MATTER WHERE THEY LIVE, AS WELL AS TO TRAIN THERAPISTS IS EVERY CORNER OF THE COUNTRY SO THAT MORE CHILDREN CAN BENEFIT FROM THE LATEST DEVELOPMENTAL RESEARCH AND INTERVENTIONS.

ANCHOR TAG

SOCIAL MEDIA

Share it! Suggested tweet:

Therapy developed at <u>@UCLASemel</u> may help close developmental gaps in babies. And a unique approach to telemedicine is helping families benefit from the research no matter where they live. http://bit.ly/2NsokdW.

Suggested post:

A novel play-based therapy developed by researchers at <u>UCLA's Semel Institute for Neuroscience and Human Behavior</u> can improve symptoms of developmental delays early in life, before a child is diagnosed. And thanks to a unique telemedicine approach, families can benefit from this research no matter where they live.

http://bit.ly/2NsokdW.

EXTRA BITES

CG: Shafali Jeste, MD
UCLA Health Semel Institute for
Neuroscience and Human Behavior

Jeste says developmental delays are present before an autism diagnosis:

"We know that autism is very common and we usually diagnose autism around age four and later, even though we know that there are symptoms of autism that start really early in development. We also know that early intervention is effective." :11

CG: Shafali Jeste, MD
UCLA's Semel Institute for Neuroscience
and Human Behavior

Jeste says parents who see delays often don't have a course of action:

"Parents were concerned about their children. They knew that there were some red flags like lack of eye contact or not responding to their name or delays in language, and they were not able to access any services that would target and try to modify the social and communication skills.":18

Jeste says the study may lead to early intervention for more children:

"If we can show that the intervention is helpful, then that might help over time change policy so that these infants are, across the board, receiving early interventions for autism symptoms." :13

Kasari says remote therapy allows families anywhere to participate:

"There are a lot of families that live very far away, or they hear about different therapies and they just can't get the therapy because there's nobody trained locally. One way to close that gap is to actually deliver the treatment remotely.":16

Kasari explains how each child is carefully assessed: "We do a very careful assessment of where children are, developmentally, in these different skills, like what did they do with play or with toys, what does their social communication skill look like, do they engage in joint attention or eye contact or sharing?" :16

CG: Connie Kasari, PhD
UCLA's Semel Institute for Neuroscience
and Human Behavior

Kasari says JASPER helps parents build their child's development:

"Sometimes as a parent you need help in knowing like what the play level is, what kind of toys would be appropriate, how I try to get the child to attend to me and to the toys, and how to sort of develop some of those early communication skills.":19

Kasari says remote delivery can help parents and therapists: "If you can help parents in sort of normal everyday life with strategies to help their child, that's one thing, but you could also train therapists in that child's local environment.":13

CG: Mary Crawford Mom of child with tuberous sclerosis Mary explains the training they received from the therapist: "As we were in the room with her, she would say, 'And I'm doing this because,' 'Oh, and the reason why we're doing this is because,' or 'I'm going to redirect him over here because.'" :08

CG: Mary Crawford Mom of child with tuberous sclerosis Mary says research behind the therapy gave her confidence: "Knowing that there's all this research behind it, and knowing that there's cases that show a kid was here and they're going to be here was uplifting and enlightening to know that — with just intentional play." :14

Mary says learning the therapy methods was empowering: "It made us feel confident, like we are trying, we are there for him. Although we can't help with what's inside, we can help the advancements cognitively or physically or even through language and things like that.":12

CG: Brandon Crawford Dad of child with tuberous sclerosis Brandon explains how the trial was conducted: "We watched them do the first JASPER session, but after that it was us reading the materials, and then recording a session, uploading the session. And then, we would have sort of a feedback session where they would give us feedback on how the methods were working and what we

Brandon explains how the developmental therapy progressed: "They sort of show you how to identify specific toys that can be used to sort of gradually step up, play methods that are associated with different levels of development." :17

References

could improve on.":20

¹Data & Statistics on Autism Spectrum Disorder, **Centers for Disease Control and Prevention**, **2019**. Online: https://www.cdc.gov/ncbddd/autism/data.html

²Autism Fact and Figures, **Autism Speaks, 2019.** Online:

https://www.autismspeaks.org/autism-facts-and-figures?gclid=EAlalQobChMlm-KnpZeZ4wlVzUwNCh1UMACSEAAYASAAEglw3_D_BwE

³JASPER Early Intervention for Tuberous Sclerosis (JETS), Clinicaltrials.gov, Feb. 2018.

https://clinicaltrials.gov/ct2/show/NCT03422367?term=JETS&cond=Tuberous+Sclerosis&rank =1

For viewer information on this story, contact: UCLA Health

Produced by:



1800 West 5th Ave. Columbus, Ohio 43212

Phone: (614) 932-9950 Fax: (614) 932-9920

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Video content provided by: UCLA Health Media Relations:

David Olmos, UCLA Health
DOlmos@mednet.ucla.edu / (310) 267-8276