

**PROPOSAL TITLE: Expanding access to specialty care for autism, PROJECT LEAD: Christie Enjey Lin, EXECUTIVE SPONSOR(S): Bryan King, MD**

**ABSTRACT:** Youth with autism have elevated levels of poor psychological wellbeing and quality of life that stem from their unique developmental needs. They are at higher risk for emotional, behavioral, and mental health challenges. Despite their need for mental healthcare, a major barrier they face is limited access to providers with specialized clinical training to provide tailored, evidence-based therapies to suit their unique needs. This barrier leaves them with potentially worsening wellbeing over time. Difficulties adapting to preferences and routines coupled with emotion-behavior dysregulation are more pronounced in autism than for youth with other psychological conditions. Our goal is to widen accessibility to a treatment that has been uniquely adapted to meet the needs of youth with autism by placing it on an online platform. The goal is to improve access to and maximize the effectiveness of the UCSF healthcare system, particularly a specialized care program developed at our center so we can have a broader reach than we currently do. We developed a program that teaches essential coping skills to better navigate the unique stressors of youth with autism.

**TEAM:** Drs. Christie Enjey Lin and Whitney Ence completed advanced degrees at research-based universities with renowned clinician-scientists specializing in treating youth with autism for their doctoral training in child clinical psychology. They completed advanced training within specialty fellowships for autism as well. provide research-informed care for autism through their outpatient mental health care roles at UCSF. They are involved in or lead research projects and provide clinical teaching to learners at UCSF. These experiences provide the skills to successfully design and carry out this project. Relevant highlights of our expertise are: Dr. Lin has specialty training in modified CBT for youth with autism that she applied to develop this treatment, and she has been involved in conducting randomized clinical trials for various interventions. Dr. Ence has specialty training in behavior treatments for autism and managing large-scale clinical service projects. Dr. King has spear-headed 8 multi-site national pharmacological and psychosocial treatment clinical trials. He is committed to expanding innovative care programs for the division.

**PROBLEM: Limited access to care for autism.** Youth with autism have significant unmet mental health care needs. They have worse outcomes than youth with other psychological conditions and limited access to specific evidence-based therapies. Contributing factors: (1) shortage of specialty-trained providers and (2) demand for care outnumbers availability at specialty clinics (Malik-Soni et al, 2022). For families living in non-metropolitan, remote areas, limited access to care is exacerbated (e.g., nearest provider is more than 1 hour drive away). A result of limited access to care is that youth with autism are 30 times more likely than the general population to seek emergency care (Badgett et al., 2023). The gap to care widens each year with the ever-increasing rate of autism (1 in 39 children; Bethell et al., 2022). Specialized care is needed because therapy must be informed with expert knowledge of autism and effective therapeutic strategies adapted to meet their distinct learning and life needs. Even though there are general child therapists in the community, they defer care for youth with autism because they have not received specialty training. In addition, families who access care from them can experience limited help. Inadequate access to specialized care impacts youth even in metropolitan areas near specialty clinics and is worse for those in remote areas. Therefore, youth with autism face more barriers to access quality care than the general population.

**Lack of treatments teaching coping skills for autism.** A particular vulnerability that youth with autism experience is that they have poor coping skills stemming from impairments in emotion-behavior regulation. Limited coping skills undermines their adaptability to daily life changes related to variations from daily routines and their preferences, referred to as behavior flexibility difficulties. Youth with autism have more intense and frequent episodes of emotional reactivity than children with other mental health conditions that are associated with negative psychological health and quality of life outcomes (Kanne & Bishop, 2021). There are no known evidence-based programs targeting this specific area of need for youth with autism. Behavioral therapies based on the principles of applied behavior analysis (ABA) are often the frontline treatment for autism, but the approach does not adequately address the need for coping skills development.

**Limited bandwidth among specialty providers.** Autism specialty clinics and providers exist in the community, including at UCSF. However, there are not enough providers due to systemic challenges with mental health care, leaving only a small portion of children with autism receiving active mental healthcare. Strategies to manage this bottle neck heightens barriers to care, including managing long waitlists without any active care provided to the families, closing clinic waitlists to artificially “shorten” them, providing parent self-directed learning materials to learn on their own without any feedback from clinicians (e.g., video and reading materials), and offering group-based treatments that may not

be optimal for youth with autism who require more individualized care. For example, of the total potential patients with autism with commercial insurance at UCSF, our clinic only serves about 13%. Other factors that limit available spots for active care are: (1) intervention traditionally requires weekly visits over the course of several months that limits the number of available spots; (2) for children attending school, there are limited therapy spots to offer after school (3 PM or after) and it becomes challenging for families to request early dismissal from school to attend earlier times for weekly visits for prolonged periods of time; and (3) youth with autism need treatment to be personalized more so than the general population, necessitating specialty clinicians to set aside additional time to prepare materials.

**TARGET:** We will develop and provide an online platform of a brief treatment based on cognitive behavior therapy (CBT). **Gains in the number of unique patients served at UCSF.** Given the short-term nature of the program, 6 visits compared to the traditional 16 visit programs, we would increase the capacity of unique patients served from about 108 unique cases per year to 192 per year through this new clinical service line at our clinic. We currently serve about 13% of children with autism within the UCSF healthcare system. Beyond the initial year of this award, in the subsequent years, with a full 12 calendar months of service, we would increase our capacity to 24% of youth with autism in the UCSF healthcare system who have commercial insurance. This would be about a 2-fold increase (based on the data of number of children served in pediatric care at UCSF of 250,000 with commercial insurance, which is 72.6%, and the rate of 4.5% of children diagnosed with autism in California). In the first year of implementing and providing this program for 9 months, we would be able to provide care for about 18% of youth with autism at UCSF that would be about a 1.3-fold increase. Overall, this program will open more doors for youth throughout the broader UCSF service region to receive care, particularly those in remote non-metropolitan areas where there are more limited specialty care providers for autism. The program would move us forward to create equitable access to a research-backed specialty treatment. In addition, it would also increase access to our unique program that targets coping and behavior flexibility skills that is not yet widely available. *We will compare the number of unique patients served through our CBT program at our center for 12 months prior to this project to the number of patients served for the span of year that the program is implemented.* [References for calculations and estimates used above: (1) <https://www.cdc.gov/ncbddd/autism/addm-community-report/california.html>, (2) <https://pediatrics.ucsf.edu/general-pediatrics-patient-care>, and (3) <https://www.kidsdata.org/topic/337/health-insurance-age/table#fmt=393&loc=2,127,1657,331,1761,171,2168,345,357,324,369,362,360,2076,364,356,217,354,1663,339,2169,365,343,367,344,366,368,265,349,361,4,273,59,370,326,341,338,350,2145,359,363,340&tf=124&ch=484,1439,1440,1113,1114,1115,551>]

**Program development timeframe.** To build our program, we will consult with an online therapy platform company that UCSF has an established connection with, WSC Technology (Scalable Care). The funding will be directly used to develop the online platform, deliver it, manage it, and execute it. Dedicated effort for program development is not provided by UCSF given that our positions are funded through direct clinical care. We already have started preliminary work with them. The funding will allow us to concentrate our efforts to accelerate development, to make it available for wider usage sooner. Afterward, we will provide the program in continuity. MONTHS 1-3. Build and finalize online program from our existing treatment materials and add innovative online components, build referral network with UCSF outpatient pediatric and child and adolescent psychiatry clinics, and develop waitlist for initial launch of the online program. MONTHS 3-12. Enroll 4 unique patients each week in the program, over the course of 9 months.

**Assessing therapeutic gains from the service:** Data from caregivers will be obtained at pre- and post-treatment. Ratings for their top three primary areas of concern will be collected at every visit. We will track the severity of behavior flexibility impairments, child psychological wellness, family quality of life, and program satisfaction. In line with preliminary findings from a pilot of our original treatment, we expect to see positive changes in these areas (we observed about a 30% improvement from pre-to post-treatment that is comparable to gains made in clinical medication and non-medication treatment trials among youth with autism). We will examine: **BEHAVIOR FLEXIBILITY:** (1) Behavior Inflexibility Scale- Captures the degree of difficulty youth demonstrate adapting to daily demands. (2) Autism Impact Measure- Assesses the frequency and impact of autism symptoms (e.g., repetitive behaviors). (3) Youth Top Problems- Tracks caregivers' severity ratings of their primary areas of concern. (4) Behavior Flexibility Interview- Guides therapy planning and tracks changes across common behavioral categories in which neurodiverse youth demonstrate behavior flexibility difficulties. **WELLNESS:** (1) Emotion Dysregulation Inventory- Captures severity and frequency of emotion reactivity and dysphoria. (2) Parent-Rated Anxiety Scale-ASD- Assesses behavioral expression of anxiety in youth with

autism. **QUALITY OF LIFE:** Family Adaptability and Cohesion Evaluation System- Assesses family characteristics and satisfaction with family life. **SATISFACTION:** (1) Therapy Attitude Inventory- Measures satisfaction with treatment. (2) Treatment Experiences Interview- Obtains caregiver program experiences via brief interview.

**Benefit of the program for youth with autism.** This is the first evidence-based program to directly target coping skills related to behavior flexibility—a specific need for these youth that is not widely available. It will be the first program of this type to be scaled up via an online platform. Unique program features will include: (1) custom-made program for families based on their primary concerns, (2) personalized caregiver ratings to more sensitively track goals, (3) electronic tools to remind caregivers to practice skills between visits, (4) families will learn from interactive online lessons at a time optimal for them, (5) families will have live coaching visits with therapists to practice and refine skills, (6) caregivers will have regular intervals of brief touchpoints with therapists for timely problem-solving and maintain momentum with skills, and (7) the child, caregiver and other relevant family members can actively learn and practice skills from their home.

**GAPS: Limited access to mental healthcare.** Youth with autism face more barriers to access care than children with other psychiatric conditions that poses a serious risk to worsening and prolonging the challenges they and their families experience (Jones et al., 2017). Although creative solutions to access care have become more available for neurotypical youth, such as the CalHope program for children in California to access free mental healthcare via an online platform, it is unclear how effective these programs are for youth with autism.

**Lack of specialized treatment targeting coping skills.** There are no treatments to directly target coping skills for youth with autism to adapt to daily life change; therefore, our program is unique and not available elsewhere to address this need.

**Potential available visit spots are underutilized.** Autism specialty providers need to create materials to engage and support the child during visits to meet their unique learning needs (e.g., self-directedness). At least one hour per day is needed to develop materials for sessions that is different from the time needed to prepare materials for the general population.

**INTERVENTION: Proposed program.** We developed a brief behavior flexibility program delivered in a traditional manner: clinician meeting with the child and caregiver in person and telehealth: 6 visits for families only on our treatment waitlist. Preliminary findings show up to an average of 30% improvement in youths' adaptability, emotion regulation, and family functioning. 30% of children who completed the brief program no longer needed full treatment because they showed reduced severity levels on standardized parent questionnaires. We will innovate this program by placing it on an online platform. It will feature both synchronous (i.e., live coaching) and asynchronous care aspects (e.g., family-directed learning of online lessons), send electronic reminders for caregivers to support skill use, and provide regular touchpoints with families. Treatment will be provided to children 4-12 years old, with commercial insurance, who have an established diagnosis of autism in the UCSF healthcare system, and with language at their age-level. Children with physical aggression at severe levels will not be eligible: aggression to the point of causing injury to people and the family is not able to adequately manage aggression.

**Potential of brief treatment models.** Brief active treatment models via an online platform can be a solution for children with autism. The benefit of brief treatment allows families to attend visits more than a weekly 16-visit programs. The online nature of treatment also reduces the burden of travel for families. Some existing strategies to provide online care includes caregiver self-guided learning programs, such as online reading materials (McGarry et al., 2020). However, self-guided learning alone has been associated with less behavior gains compared to active models of care (Gentile et al., 2022). In the general population, a brief model that has growing emerging efficacy is the single session consultation model (Schleider et al., 2022). For children with autism, a similar mechanism has been examined (Ryan & O'Connor, 2017). A strength of these models is direct interface with a clinician to learn skills that seems ideal over self-guided programs to meet the complex needs of children with autism. However, a single session consultation model may be too brief to make a meaningful impact.

**Integrating and optimizing technology for individualized care.** An online platform can alleviate provider time to develop individualized treatment materials. Families also would readily have access to materials on their own devices providing ease and portability of treatment materials to use in their daily lives.

**Potential concerns.** Families will need to have internet and technological devices to access care over telehealth. For children who develop more severe behavioral concerns during the program, they will be referred to more specialized care through the UCSF healthcare system, such as crisis care. Families will be provided with follow-up care following completion of the program should they seek out ongoing guidance for skills learned through the program.

**PROPOSED EHR MODIFICATIONS:** None

**RETURN ON INVESTMENT:** The estimated combined cost savings/revenue enhancement for the implementation of this service line = \$254,106.72.

**Revenue enhancement.** The program provides 6 visits over the period of 3 months (2 visits per month for one patient = 1 family visit with patient and 1 family visit without patient). The set-up would be a total of: (A) 3 family visits with patient (50 min) = CPT90847 @ Reimbursement rate of \$100.53 = \$301.59. (B) 3 family visits without patient (parent-only check-in visits 30 mins) = CPT90846 @ Reimbursement rate of \$95.54 = \$286.62. 1 completed patient (6 visits total) = \$588.21. The reimbursement rates are based on the national payment amount from Medicare in 2024. They reflect the *minimum* amount UCSF would be reimbursed given that commercial insurance reimbursement rates would be higher. Our department only accepts commercial insurance at this time and reimbursement rates vary depending on the contracts negotiated between UCSF and insurance companies. Source for 2024 reimbursement rates: <https://therathink.com/cpt-code-90847/>

For first year of this program, with a rate of 4 unique patients seen each week for 9 months the program is in service, the revenue generated would be = \$84,702.24. In one year, revenue generated for 12 months would be = \$112,936.32 given that we would not need the 3-month period to develop the online platform. As mentioned above, these estimated revenue projections are the *minimum* amount given the reimbursement rates would likely be higher with commercial insurance.

**Cost Savings.** There are two sources of lost revenue that will be addressed by this project. Total revenue lost that we would save each year = \$169,404.48. (1) *Waitlists.* About 15 patients are on the waitlist each month at our center for CBT services. This is an underestimate of the actual demand for services because our clinic stops accepting referrals and adding patients to the waitlist when we have reached a cap due to concerns about limited care. For 12 months with 15 patients not served, estimated lost revenue = \$105,877.8 (2) *Underutilized visit spots for active patient care.* At least one potential patient care visit is used for clinicians to develop personalized, visual support materials that takes away a spot that could be used for patient care. For 12 months, one potential patient visit lost to material preparation for 108 patients (our estimate of unique patients our clinic provides CBT for in 1 year) = \$63,526.68

**SUSTAINABILITY:** An online version of our brief program will allow us to scale up services for youth with autism in the broader UCSF community. The program will immediately increase access to our specialty clinicians beyond our current reach. In addition, we would be able to take more referrals from across the outpatient clinics at UCSF who serve youth with autism that we have not been able to support. We have trainees who rotate through our clinic: psychiatry fellows, pediatric fellows, and clinical psychology trainees who can be supervised and participate in this program (4 each year who rotate with us). We also have 5, full-time behavioral health clinicians at our center that are available to provide care in this program.

**BUDGET:** The total funding being requested is \$50,000: (1) Enjey Lin at 13% time for 12 months with projected salary in the upcoming year at 200,000 = \$25,000. To develop online platform with existing protocol and materials with Scalable Care, manage the project, and provide supervision and training for trainees and clinicians. (2) Whitney Ence at 8% time for 12 months with projected salary in the upcoming year at 200,000 = \$15,000. To develop connection with UCSF outpatient clinics that serve children with autism to start and maintain recruitment flow and provider education about this new service line and develop processes and service flow for this as an ongoing clinical service. (3) One-time consultation fee to Scalable Care = \$10,000.