Evaluating the Impact of a Community-Based Rehabilitation Camp on Caregiver Attitudes of Augmentative and Alternative Communication

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Question/Hypothesis: Children with neurodevelopmental disabilities (**NDs**) often experience significant communication challenges and may benefit from augmentative and alternative communication (**AAC**) to participate in life activities. However, some caregivers are hesitant to adopt AAC, hoping their child will develop spontaneous speech. This study will investigate the impact of *Club chAT*—a summer day camp with integrated speech and physical therapy and caregiver-coaching techniques for families of children who use AAC—on caregiver attitudes and characteristics (self-efficacy, resilience, and openness) to using AAC. These characteristics are essential for long-term AAC adoption and for promoting successful communication. Question: What are the effects of *Club chAT* on caregiver self-efficacy, resilience, and openness toward AAC? Hypothesis: Participation in *Club chAT* will increase caregiver self-efficacy, resilience, and openness to AAC post-intervention compared to pre-intervention, and compared to caregiver controls. We also hypothesize that these characteristics will remain elevated over time in the experimental group.

Innovation/Translation: This project addresses a critical gap by enhancing critical characteristics required, but often missing, to engage long-term AAC use by children with families within a supportive group therapy context. *Club chAT* is a novel community-based intervention that uses evidence-informed direct therapy and caregiver-coaching to empower families to use AAC with their children across settings and partners to reduce barriers to long-term AAC use. As an early-career investigator, this project will foster interdisciplinary collaboration between the PI at CWRU and therapists at UCP to advance targeted communication interventions for young children with NDs.

Feasibility: A pre-post intervention design with a 3-month follow-up will allow comprehensive data collection within the 12-month project period. Caregiver self-efficacy, resilience, and openness to AAC will be assessed with validated surveys at pre-, post-, and follow-up time points. *Club chAT* is offered four times a year at UCP, demonstrating the capacity for strong recruitment and retention potential. An experimental group of six families will be recruited in the first summer session offered. A control group of six matched families of a child who uses AAC, but is not participating in *Club chAT,* will be assessed at approximately the same time points. To address attendance barriers, scholarships will be provided to ease financial strain, while attrition will be minimized through in-session refreshments and post-study compensation for both groups.

Project Milestones	Timeline	Description & Importance
Pre-Intervention Phase	**Q1**: 4 months	**Description:** Recruit and consent participants, complete baseline assessments for experimental and control groups. **Importance:** Establishes a robust sample and baseline data for comparative analysis essential for evaluating outcomes and informing future studies.
Intervention Phase	**Q2**: 2 months	**Description:** Administer intervention as four 90-minute sessions over one month in a group setting at UCP. **Importance:** Core phase for testing intervention efficacy and providing insights for future implementation, modifications, and scaling.
Post-Intervention Phase	**Q2-Q4**: 6 months	**Description**: Complete post-intervention and follow-up assessments for both groups, analyze data, and prepare for dissemination. **Importance**: Synthesizes findings through analysis and readies the project for wider dissemination, laying groundwork for future studies and long-term impact.

Statement of Translation. This project involves a Translation-to-Patients (T2) intervention. *Club chAT* is designed to directly support AAC use in children and their families fostering long-term adoption and "buy-in" among families of children with NDs. This intervention is expected to generate both immediate and sustained impacts on caregiver attitudes toward AAC.

Budget Summary: $50,000 will be allocated to participant scholarships to support family enrollment and travel for equitable service delivery, personnel for staff assisting with research activities, materials for program supplies, purchasing survey tools for validated assessments, and incentives such as refreshments, camp activity prizes, and compensation to promote retention and survey completion throughout the project period.

Human Subjects: This study involves human subjects, and an IRB application will be submitted by January 5, 2025, with approval anticipated by February 5, 2025, to be submitted with the full proposal.

Intellectual Property: This project has not been submitted for Intellectual Property Protection, nor do we plan to file an invention disclosure.

Special Considerations: No foreign components, MOUs, or sub-awards involved with this project.

ABSTRACT

Children with neurodevelopmental disabilities often experience significant communication challenges, making it difficult for them to express their needs, participate in daily activities, and engage socially. Many of these children rely on augmentative and alternative communication (AAC), such as speech-generating devices, to communicate. Despite the proven benefits of AAC, many children struggle to use these tools consistently due to barriers in training, support, and caregiver confidence in their ability to support their child's AAC development. Caregivers play a crucial role in supporting their child's AAC use, yet they often face challenges in learning how to use and manage these devices and supporting their child's consistent engagement with AAC. Research shows that caregiver confidence and knowledge directly impact whether a child successfully adopts and continues using AAC. However, many caregivers lack access to structured training and peer support networks which can lead to AAC abandonment. This study evaluates the effectiveness of *Club chAT*, a family-centered, group-based AAC intervention developed and led by speech-language pathologists at the United Cerebral Palsy (UCP) of Greater Cleveland. Unlike most AAC programs that focus on child training, Club chAT integrates caregiver coaching, peer-supported learning, and interactive AAC skill-building. This program provides structured group sessions where children and caregivers practice AAC use together in peer-supported environments. By engaging caregivers in guided coaching and structured activities, the program aims to increase caregiver confidence, AAC integration, and long-term AAC adoption. This study will examine (1) How participation in Club chAT changes caregiver confidence, AAC integration, and family communication dynamics, (2) Whether these changes differ between caregivers of younger vs. older children, and (3) caregiver experiences with, and perceptions of AAC after their participation in Club chAT. To answer these questions, we will conduct a mixed-methods study involving surveys and focus groups. Surveys will assess changes in caregiver self-efficacy and AAC use at three time points: before Club chAT, after Club chAT, and three months later to evaluate lasting effects. Focus groups will give added insights into caregivers' experiences, challenges, and successes with AAC after Club chAT. This research addresses a critical gap in AAC intervention research. While peer-driven and group-based AAC interventions are known to be effective, few studies have focused on caregiver training alongside child AAC use in these settings. Club chAT provides a unique opportunity to study how structured peer engagement can improve AAC use in real-world family environments. The study is conducted in collaboration with UCP of Greater Cleveland and Dr. Sam Bora, a leading expert in neurodevelopmental outcomes at University Hospitals alongside the early career PI at CWRU. Findings from this study will generate critical preliminary data to support future large-scale, NIH-funded research on AAC adoption and caregiver training. By demonstrating Club chAT as a scalable and accessible AAC intervention, this research has the potential to improve communication outcomes for children with disabilities and strengthen family support systems.

RESEARCH PROPOSAL

Background

An estimated 12% of children experience significant communication challenges, placing them at risk for lifelong barriers to education, social participation, and quality of life.[1] Children with neurodevelopmental disabilities such as cerebral palsy and autism frequently experience complex communication needs resulting from physical and language impairments affecting their ability to communicate and participate across settings. These children often require access to augmentative and alternative communication (AAC) modalities, including speech-generating devices (i.e., "AAC devices") to engage effectively with their environment. Despite the potential for AAC to transform communicative independence and social participation, **barriers to the adoption and sustained use of AAC continue to exist**.

Caregivers play a critical role in children's long-term AAC success.[2] Using a socioecological framework, research suggests that a customizable input, context-aware output, and personalized devices enhance AAC effectiveness at the individual level.[3] However, at the interpersonal and community levels, caregiver attitudes, knowledge, and confidence in supporting AAC use are also crucial in ensuring consistent device use, management, and advocacy for AAC use across settings.[4] Caregivers often struggle with misconceptions about AAC impeding speech development, lack of training for use, and isolation from support networks.[2,5,6] Speech-language pathologists (SLPs) identify caregiver buy-in as a major factor influencing AAC success, with caregiver-related barriers contributing to high AAC abandonment rates.[7] Addressing attitudinal challenges is essential for interventions aimed at improving AAC integration and family communication dynamics to promote AAC adoption and long-term success. Interventions that integrate caregiver coaching, peer-mediated learning, and structured AAC skill-building are promising to improve caregiver confidence for AAC integration.[8–10] Studies emphasize the importance of social networks and family-oriented AAC interventions to enhance family communication dynamics involving AAC.[11,12] Yet, there is **limited research on group-based interventions that integrate these evidence-based methods into AAC training**. This gap underscores the need for novel, family-centered interventions that simultaneously support caregiver and child AAC development.

Club chAT is an innovative, community-based AAC intervention designed to address barriers in caregiver engagement, AAC adoption, and sustained use. **Developed and piloted by SLPs at United Cerebral Palsy (UCP) of Greater Cleveland** in 2024, Club chAT provides group-based, family-centered intervention for children who use AAC and their caregivers. The program incorporates adapted games, creative projects, and sensory-friendly activities to enhance accessibility and engagement. By integrating peer-driven learning, AAC skill-building, and structured caregiver coaching, Club chAT aims to increase caregiver confidence, facilitate AAC integration, and promote long-term AAC use. Research suggests that AAC interventions emphasizing "group connectedness" are more likely to be successful.[13] Group-based models provide caregivers with social support, peer mentorship, and shared learning experiences, reinforcing self-efficacy, problem solving, and advocacy. Despite these benefits, existing AAC interventions are largely individualized, focusing on child-directed training without structured caregiver involvement. This gap underscores the need for novel, structured interventions that integrate caregiver coaching with child-directed AAC training. This pilot study will evaluate the impact of Club chAT on caregiver confidence, AAC integration, and family communication dynamics through a mixed-methods approach combining quantitative surveys and qualitative focus groups.

Significance. This project addresses a critical gap in AAC intervention research by evaluating changes in caregiver attitudes toward AAC before and after participating in Club chAT. Caregivers play a key role in AAC success, yet barriers such as limited training, misconceptions, and lack of support continue to contribute to high AAC abandonment rates. Club chAT integrates peer-supported learning, AAC skill-building, and structured coaching to equip caregivers with the confidence and skills necessary for long-term AAC use. Unlike traditional AAC interventions that primarily focus on training the child to use AAC, Club chAT equally prioritizes caregiver and child outcomes through peer-mediated learning and structured caregiver coaching. Thus, this study represents a highly **novel approach** to addressing caregiver-related barriers to AAC adoption.

This study aligns with the CTSC mission by fostering interdisciplinary collaboration between CWRU with UCP of Greater Cleveland to advance community-based research. Also, it strengthens research connections between the PI and UH through mentorship from Dr. Samudragupta Bora, an expert in translational research in young children with disabilities. As an **early-career investigator**, the PI will benefit from structured mentorship to ensure methodological rigor and translational impact from Dr. Bora. Findings will inform scalable interventions and provide pilot data for future NIH-funded R01 trials. This study will employ validated survey tools and structured focus groups to ensure rigorous evaluation, generating actionable insights into scalable, caregiver-centered AAC interventions that promote health equity and improved quality of life.

Specific Aims & Hypotheses

1. What are the effects of participation in Club chAT on caregiver attitudes toward AAC, specifically in terms of caregiver confidence, AAC integration, and family dynamics?
    a. Hypothesis: Participation in Club chAT will lead to significant improvements in caregiver self-efficacy, perceptions of AAC integration, and family communication dynamics between pre-intervention and post-intervention, with sustained improvements at the three-month follow-up.
2. Do changes in caregiver attitudes (self-efficacy, integration, and family dynamics) differ between caregivers of younger children (ages 5–12) and older children (ages 13+)?
    a. Hypothesis: Caregivers of younger children will demonstrate greater improvements in caregiver self-efficacy, AAC integration, and family communication dynamics due to higher adaptability and developmental flexibility in this age group, whereas caregivers of older children may exhibit smaller but meaningful improvements.
3. What are the caregivers' qualitative experiences of participating in Club chAT, and how do these experiences shape their perceptions of AAC and its role in their family?
    a. Exploratory Hypothesis: Caregivers will discuss positive experiences, including increased peer support, improved understanding of AAC, and greater confidence in advocating for their child's AAC use across settings, highlighting the unique benefits of peer-driven and group-based interventions like Club chAT.

Preliminary Studies

While no formal research data has been collected on Club chAT, **UCP of Greater Cleveland has successfully implemented this intervention twice in 2024**, demonstrating strong community interest, feasibility, and sustained engagement. Each iteration has provided intimate group therapy for a maximum of six families, fostering peer-supported learning and AAC skill-building in a real-world, clinical setting. Full enrollment and regular participation in these early iterations reinforces the demand for structured, group-based AAC support programs. This pilot study represents the first collaboration between UCP and the PI at CWRU to formally evaluate Club chAT's impact on caregiver attitudes. Adding a research component to an already established and well-received clinical program **ensures feasibility in participant recruitment**, intervention delivery, and data collection. As a primary rehabilitation service provider with an established network of families seeking AAC support in the Cleveland area, **UCP provides a robust recruitment pipeline for this study**. Furthermore, this pilot study will serve as a foundation for ongoing community-engaged research, strengthening long-term partnerships between CWRU and UCP to improve family-centered AAC interventions.

Study Design & Methods

This study will use a **mixed-method design** to evaluate the impact of Club chAT on caregiver self-efficacy, AAC integration, and family communication dynamics. The intervention consists of **four structured sessions**, stratified by child age. UCP is scheduled to offer 2 sessions for children ages 5-12, and 2 for children ages 13-18, in summer 2025. This study will assess pre-post intervention changes in caregiver self-efficacy, AAC integration, and family communication dynamics using validated surveys and structured focus groups.

Participants

A total of **24 caregivers** of children who use AAC will be recruited. Participants must be 1) the primary caregiver of a child aged 5-18 who uses AAC, 2) committed to attending at least three of the four intervention sessions within their summer cohort. Families will self-register for their chosen summer session based on child age and availability for either a June or July session. Research recruitment will be conducted through United Cerebral Palsy (UCP) of Greater Cleveland, leveraging its **established network of families seeking AAC services**. To promote health equity, a portion of the pilot grant budget will provide scholarships for low-income and rural families, ensuring broad accessibility. **Retention strategies** will include direct outreach, automated reminders, and compensation for survey completion.

Intervention

Club chAT is a structured, four-week AAC intervention designed to enhance caregiver confidence and AAC adoption through a combination of SLP-led instruction, peer-mediated learning, and interactive AAC practice. Two sessions are scheduled to be held in June and July each (one 5-12, one 13+ age group), totaling four sessions. Each session is programmed to host six caregiver-child pairs for an intimate group therapy setting.

Each 1.5- to 2-hour session will incorporate hands-on AAC modeling, guided peer interactions, and caregiver coaching, ensuring real-world applicability. UCP staff will oversee **program fidelity**, with trained SLPs delivering intervention components. SLPs and research personnel will maintain attendance logs, session participation records, and activity tracking to ensure **implementation fidelity**.

Data Collection

Survey Measures: Caregivers will complete three surveys to assess changes in self-efficacy, AAC integration, and family communication dynamics at pre-intervention, post-intervention, and follow-up time points. In each survey, caregivers will complete two validated self-report rating scales. The Early Intervention Parenting Self-Efficacy Scale (EIPSES)[14] was selected as a highly valid and frequently used self-report measure of caregiver **self-efficacy** in supporting development for children with disabilities (16 items, 7-point Likert scale). The Family Impact of Assistive Technology Scale for AAC (FIATS-AAC38)[15] was selected as a validated clinical self-report measure of **AAC integration** and **family communication dynamics** (38 items, 7-point Likert scale). Both surveys were selected for their strong psychometric properties and conceptual alignment with evaluating caregiver self-efficacy, AAC integration, and family communication dynamics.

Focus Groups: 1-month post-intervention, virtual focus groups will be conducted with caregivers to explore their experiences with AAC integration, peer learning, and long-term sustainability after Club chAT. If participation is lower than expected, 1:1 interviews will be conducted as needed.

Research Time Points: Data will be collected at three key time points. These time points will be **stratified** for June and July cohorts. Pre-surveys will be sent 1-week before the beginning of each Club chAT session. Post-surveys will be sent 1-week after Club chAT has ended. Invitations to focus groups will be provided at the end of the post-survey. Focus groups will be scheduled 1-month after Club chAT has ended for each cohort. Follow-up surveys will be sent 3-months after Club chAT. This multi-timepoint approach allows for the evaluation of both immediate and sustained changes in caregiver attitudes toward AAC between the two age groups to address the research aims.

Aim 1: Effects of Club chAT on Caregiver Attitudes Toward AAC

Data Collection & Analysis: To assess the impact of Club chAT on caregiver attitudes, this study will collect survey data at three time points: pre-intervention, post-intervention, and three-month follow-up. The EIPSES will measure changes in caregiver confidence, while the FIATS will assess AAC integration and family communication dynamics. Survey data will be analyzed using repeated measures ANOVA to examine pre-post differences, with mixed-effects modeling used to account for variability in prior AAC experience.

Anticipated Results: We anticipate significant increases in caregiver confidence, AAC integration, and family communication following intervention participation, with sustained improvements at the three-month follow-up. By evaluating changes in caregiver confidence and AAC integration, this aim will establish proof of concept for Club chAT's effectiveness in promoting long-term AAC adoption.

Potential Challenges: A potential challenge is variability in caregiver AAC familiarity, as caregivers with more prior experience may demonstrate smaller gains. To mitigate this, we will stratify analyses based on prior AAC exposure. Another potential limitation is survey attrition, particularly at follow-up. To maximize retention, we will implement reminder emails, and increased incentives for completing subsequent surveys.

Aim 2: Age-Related Differences in Caregiver Attitude Changes

Data Collection & Analysis: This aim will determine whether caregiver self-efficacy and AAC integration differ based on child age (5-12 vs 13-18 years). Surveys will be analyzed using mixed-effects modeling, controlling for baseline caregiver knowledge and AAC experience.

Anticipated Results: We anticipate that caregivers of younger children (5–12 years) will show greater improvements due to higher adaptability and earlier intervention timing. Caregivers of older children (13–18 years) may demonstrate meaningful but smaller gains, reflecting challenges in modifying established communication routines. Findings from this aim will inform developmentally tailored AAC training programs that address caregiver needs at different stages of AAC adoption.

Potential Challenges: A potential challenge is small effect sizes or weaker-than-expected differences between age groups. If this occurs, qualitative focus group data will be used to explore age-related differences in caregiver learning experiences, AAC implementation challenges, and ongoing support needs. Another challenge is unequal group sizes, which could affect statistical power. If necessary, we will apply mixed-effects modeling techniques to account for sample size differences while preserving analytical rigor.

Aim 3: Caregivers' Qualitative Experiences with Club chAT

Data Collection & Analysis: To explore caregiver experiences with Club chAT, we will conduct structured focus groups one-month post-intervention. Discussions will focus on AAC integration, caregiver confidence, barriers to long-term use, and the role of peer support. Focus group transcripts will undergo thematic analysis, with two independent coders reviewing transcripts to ensure inter-rater reliability. Emerging themes will be triangulated with survey findings to provide a comprehensive understanding of caregiver experiences.

Anticipated Results: We expect caregivers to describe increased confidence in using AAC, improved communication with their child, and a stronger understanding of AAC strategies. Many will highlight the benefits of learning from peers, practicing AAC in a supportive environment, and gaining practical skills for AAC implementation at home. Findings from this aim will provide important insights into how caregivers perceive AAC interventions and identify specific support needs for sustaining long-term AAC use.

Potential Challenges: A potential challenge is participant variability in focus group engagement. To ensure balanced participation, we will use structured facilitation techniques, such as directed prompts and rotating discussion leads. Another challenge is recall or social desirability bias, which could lead caregivers to provide overly positive responses. To address this, we will use open-ended, non-leading questions and offer anonymous feedback options to supplement qualitative findings.

Expected Timeline

Project Activity	**Q1:** May – Jul 2025	**Q2:** Aug – Oct 2025	**Q3:** Nov– Jan 2026	**Q4:** Feb – Apr 2026
Aim 1: Effects of Club chAT on Caregiver Attitudes toward AAC				
Scholarships offered to registrants; survey recruitment begins	X			
Pre-surveys sent 1-week before Club Chat	X			
Club chAT Intervention (June/July cohorts)	X			
Post-surveys sent 1-week after Club Chat	X	X		
Follow-up surveys sent 3-months after Club Chat		X	X	
Data analysis for Aim 1			X	
Aim 2: Age-Related Differences in Caregiver Attitude Changes				
Pre-survey stratified by child age		X		
Post-survey stratified by child age		X		
Follow-up survey stratified by child age			X	
Data analysis for Aim 2			X	
Manuscript 1 preparation for Aim 1 & 2			X	X
Aim 3: Caregivers' Qualitative Experiences with Club chAT				
Recruitment for focus groups from post-survey responses	X	X		
Focus Groups held	X	X		
Thematic analysis of Focus Groups		X	X	X
Manuscript 2 preparation for Aim 3			X	X
Dissemination				
Conference presentation for Aims 1 & 2 preliminary findings			X	
Submit CTSC progress report with preliminary data from all Aims				X
Submit Manuscript 1 (through post-project period)				X
Submit Manuscript 2 (through post-project period)				X

Feasibility

UCP's prior experience **successfully implementing Club chAT** (two sessions with maximal enrollment in 2024) demonstrates community interest and feasibility. The existing pipeline of interested families, structured recruitment plan, and research infrastructure **ensure robust participation**. UCP staff will assist with survey distribution, attendance tracking, and focus group facilitation, ensuring **seamless data collection**. Caregiver time constraints may pose challenges to full participation in surveys and focus groups. To reduce attrition, **retention strategies** will include automated email reminders at each survey time point. Focus groups will be conducted in small (up to 6 caregivers per group), flexible, and virtual formats. Dr. Bora will provide **expertise in mixed-effects modeling** and **longitudinal caregiver outcome analysis**, ensuring that findings are robust and statistically sound. His contributions will support modeling caregiver engagement trajectories over time and refining methodologies for future large-scale NIH-funded trials. Given the strong **demand for AAC service**

models like this program and established community partnerships, the study is well-positioned for successful execution within the one-year funding period.

Relevance and Future Directions

Relevance to the CTSC: This project aligns with the CTSC mission by fostering interdisciplinary, community-based research that advances health equity in Northern Ohio. Club chAT addresses a critical gap in AAC adoption by evaluating how structured, group-based interventions impact caregiver self-efficacy, AAC integration, and family communication dynamics. Despite research support for group interventions, their effect on caregiver engagement and long-term AAC adoption has not been rigorously studied. This study will generate preliminary data to establish **proof of concept** for scalable AAC interventions. This project strengthens collaboration between CWRU and UCP, creating a pipeline for future studies on intervention effectiveness and caregiver needs. The involvement of Dr. Bora (UH) integrates neurodevelopmental expertise for methodological rigor. Findings will provide essential pilot data for an NIH R21/R01, evaluating long-term efficacy using an RCT design. Additionally, pilot funding will provide scholarships to low-income and rural families, ensuring access to AAC access during summer months when therapy services may be limited.

Benefit to Translational Research: This study bridges the gap between evidence-based AAC practices and their real-world implementation in community settings. Club chAT represents a **T2 translational intervention**, directly supporting caregiver adoption of AAC strategies. By evaluating caregiver self-efficacy and AAC integration, this study will generate findings that inform clinical guidelines, refine intervention models, and optimize caregiver training strategies. The study's interdisciplinary approach integrates clinical research collaboration across CWRU, UCP, and UH to promote health outcomes. The mixed-methods design strengthens real-world evaluation, making findings applicable across clinical, educational, and home settings. This research directly aligns with **NIDCD's funding priorities**, specifically Theme 4, which emphasizes translating scientific discoveries into assistive technologies and interventions that improve the well-being of individuals with communication disorders. By targeting caregiver attitudes and buy-in, this project addresses a key barrier to AAC adoption at the family and community levels.

Anticipated Results and Funding Potential: This study will provide preliminary evidence on Club chAT's impact on caregiver self-efficacy, AAC integration, and family communication dynamics establishing feasibility, effect sizes, and intervention refinement for a future NIH-funded randomized controlled trial (RCT). This pilot is a critical step in developing a scalable, evidence-based intervention model. Future research will expand on this pilot by: 1) assessing age groups, (<5 years) to assess early intervention benefits, 2) evaluating key intervention components, including the incorporation of interdisciplinary SLP/PT/OT services, 3) examining long-term caregiver support needs and the relationship between AAC adoption and caregiver mental health outcomes, and 4) conducting a multi-site RCT comparing Club chAT's effectiveness to 1:1 AAC interventions. Findings will serve as a **foundation for NIH R21/R01 applications**, supporting the optimization of AAC intervention strategies, caregiver well-being, and communication outcomes for children with neurodevelopmental disabilities. This research also has direct clinical implications, shaping best practices in AAC intervention models for community organizations, early intervention programs, and healthcare providers.

Request for Early Timeline: To ensure equitable provision of scholarships across all Club chAT sessions, pilot funding is necessary prior to the estimated project start date, as early as April 2025 but as late as May 2025. This will allow for timely distribution of **scholarships**, ensuring that families registering for June and July sessions have equal financial support. Additionally, early access to funds is critical for ensuring timely **pre-intervention survey invitations**, allowing for adequate participant engagement prior to the start of each cohort. Without sufficient lead time, June sessions may experience disparities in participant recruitment and data collection consistency. The **IRB** for this project is under review, and all community engaged researchers are completing the *CIRTification Program for Community Partners*, with approval anticipated by March 2025.

Summary

This project directly aligns with the CTSC's mission to support interdisciplinary research, particularly for **early career investigators**, that improves health outcomes for underserved families and expands research connections between clinicians and scientists in Northern Ohio. By evaluating a **real-world AAC intervention**, this study bridges the gap between research and clinical practice, generating critical data to prevent AAC abandonment and rejection. Findings will lay the foundation for large-scale trials and support the translation of research into scalable, equitable interventions that enhance AAC access, caregiver confidence, and child communication success through group-based interventions that build structured support networks.

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BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors.
Follow this format for each person. DO NOT EXCEED FIVE PAGES.

NAME: Long, Helen L.

eRA COMMONS USERNAME (credential, e.g., agency login): HLONG1

POSITION TITLE: Assistant Professor

EDUCATION/TRAINING *(Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.)*

INSTITUTION AND LOCATION	DEGREE	END DATE	FIELD OF STUDY
Indiana University, Bloomington, IN	BA	05/2010	Speech Language & Hearing Sciences; Slavic & Eastern European Languages & Cultures
Florida State University, Tallahassee, FL	MS	08/2012	Speech-Language Pathology
University of Memphis, Memphis, TN	PhD	12/2020	Communication Sciences & Disorders
University of Wisconsin, Madison, WI	Postdoctoral Fellow	07/2024	Intellectual & Developmental Disabilities; Clinical & Translational Research Methods

A. Personal Statement

I am an early-career investigator with a research focus on advancing early identification and intervention for communication impairments in children with cerebral palsy (CP) and other neurodevelopmental disabilities. My work integrates clinical expertise in speech-language pathology (SLP) with research on early speech and communication development in populations with complex communication needs, including autism and cerebral palsy. As a certified and licensed SLP, my clinical and research experiences have shaped my approach to studying early vocal and speech development to incorporate considerations about caregiver involvement in AAC adoption to prevent AAC abandonment, as well as interdisciplinary strategies for enhancing communication outcomes.

My doctoral training provided a strong foundation in vocal and speech development research, focusing on both typical development and infants at risk for neurodevelopmental disabilities. During my postdoctoral training, I expanded this work by examining early predictors of speech motor impairments in children with CP, integrating naturalistic observation coding of parent speech and child vocalizations, and standardized and dynamic assessments with longitudinal data collection methods. These experiences equipped me with the necessary expertise in clinical translational research, behavioral observation methods, and caregiver-focused intervention strategies, which are essential for the successful execution of this project.

As an Assistant Professor at Case Western Reserve University (CWRU), I am now focused on expanding my research to consider aspects of early intervention for communication support needs of children with disabilities. Building a network of local community research connections is an integral part of establishing this research in the Cleveland, OH region. The first aim of this extension of my work seeks to evaluate how caregiver engagement and peer-mediated interventions impact AAC adoption and long-term communication outcomes. The proposed project, which investigates the effects of Club chAT—an intervention program developed by the SLPs at the United Cerebral Palsy of Greater Cleveland—aligns with my broader research goals by targeting caregiver self-efficacy, AAC integration, and family dynamics in children with complex communication needs to prevent AAC abandonment. My prior work has highlighted the importance of early caregiver involvement for positive communication outcomes, and this study will provide critical data to inform scalable, community-based interventions.

I am well-equipped to lead this project, drawing on my expertise in longitudinal research design, postdoctoral training in both intellectual & developmental disabilities and clinical and translational research, interdisciplinary collaboration, and caregiver-focused intervention research. Additionally, my collaboration with Dr. Sam Bora (University Hospitals) will further strengthen the translational impact of this study, leveraging mentorship in research methodology and health services research. Findings from this project will lay the groundwork for future NIH-funded research on AAC interventions and communication outcomes for children with neurodevelopmental disabilities.

Relevant publications:

1. **Long HL**, Ramsay G, Bene E, Su P, Yoo H, Klaiman C, Pulver S, Richardson S, Pileggi M, Brane N, Oller D. Canonical babbling trajectories across the first year of life in autism and typical development. Autism. 2024 May 17; DOI: 10.1177/13623613241253908
2. **Long HL**, Christensen L, Hayes S, Hustad KC. Vocal Characteristics of Infants at Risk for Speech Motor Involvement: A Scoping Review. J Speech Lang Hear Res. 2023 Nov 9;66(11):4432-4460. PubMed Central PMCID: PMC10715844.
3. **Long HL**, Hustad KC. Marginal and Canonical Babbling in 10 Infants at Risk for Cerebral Palsy. Am J Speech Lang Pathol. 2023 Aug 17;32(4S):1835-1849. PubMed Central PMCID: PMC10561958.
4. **Long HL**, Mahr TJ, Natzke P, Rathouz PJ, Hustad KC. Longitudinal change in speech classification between 4 and 10 years in children with cerebral palsy. Dev Med Child Neurol. 2022 Sep;64(9):1096-1105. PubMed Central PMCID: PMC9339470.

B. Positions, Scientific Appointments and Honors

Positions and Scientific Appointments

2024 -	Assistant Professor, Case Western Reserve University, Cleveland, OH
2023 - 2024	NCATS TL1 Postdoctoral Fellow, Institute of Clinical and Translational Research, University of Wisconsin-Madison, Madison, WI
2021 - 2023	NICHD T32 Postdoctoral Fellow, Waisman Center, University of Wisconsin-Madison, Madison, WI
2014 - 2021	Speech-Language Pathologist, Shelby County Schools, Progressus Therapy, Memphis, TN
2012 - 2014	Speech-Language Pathologist, Easter Seals Massachusetts, Worcester, MA

Honors

2025	WP Jones Presidential Faculty Development Fund, College of Arts & Sciences, Case Western Reserve University
2022 - 2024	Morse Society Scholar, Waisman Center, University of Wisconsin-Madison
2022 - 2024	Loan Repayment Award, NIDCD
2022 - 2023	New Investigators Research Grant, ASHFoundation
2023	Lessons for Success Fellow, American Speech-Language-Hearing Association (ASHA)
2021	Pathways Program Fellow, American Speech-Language-Hearing Association (ASHA)
2020	OrthoPediatrics Scholarship, American Academy for Cerebral Palsy & Developmental Medicine (AACPDM)
2019	S.P. Wong Award for Best Presentation in Statistical Application, Department of Mathematics, University of Memphis

C. Contributions to Science

1. **Vocal Predictors of Speech Impairments in Cerebral Palsy:** My primary line of research studies the early identification of speech impairments in children with cerebral palsy (CP). One longitudinal study of clinical speech classification showed that early speech performance predicts later abilities, highlighting the need for early detection and intervention. This line of work suggests that children with greater speech motor impairments in early childhood may produce less developmentally advanced babbling patterns in infancy. Our scoping review on this topic identified a need for the use of more technological advanced methods of measuring vocal development, standardized methodologies, and larger sample sizes in this research. These studies demonstrate a critical need for additional research examining vocal predictors of speech motor impairments to support early diagnosis and intervention.

    a. **Long HL**, Hayes S, Hustad KC. A pilot investigation on the relationship between infant vocal characteristics at twelve months and speech motor impairment at four to five years. J Speech Lang Hear Res. *In Press*.

b. **Long HL**, Christensen L, Hayes S, Hustad KC. Vocal Characteristics of Infants at Risk for Speech Motor Involvement: A Scoping Review. J Speech Lang Hear Res. 2023 Nov 9;66(11):4432-4460. PubMed Central PMCID: PMC10715844.

c. **Long HL**, Hustad KC. Marginal and Canonical Babbling in 10 Infants at Risk for Cerebral Palsy. Am J Speech Lang Pathol. 2023 Aug 17;32(4S):1835-1849. PubMed Central PMCID: PMC10561958.

d. **Long HL**, Mahr TJ, Natzke P, Rathouz PJ, Hustad KC. Longitudinal change in speech classification between 4 and 10 years in children with cerebral palsy. Dev Med Child Neurol. 2022 Sep;64(9):1096-1105. PubMed Central PMCID: PMC9339470.

2. **Vocal Predictors of Language Differences in Neurodevelopmental Disorders:** This line of research investigated early vocal predictors of language differences in infants with neurodevelopmental disorders, specifically tuberous sclerosis and autism. These studies analyzed human-coding of infant vocal types produced during laboratory and home recordings and showed delayed canonical babbling onset and reduced volubility across these clinical groups compared to typically developing infants. These findings highlight the potential of early vocalizations as indicators of later social language differences to aid in early diagnosis and intervention for these populations.

a. **Long HL**, Ramsay G, Bene E, Su P, Yoo H, Klaiman C, Pulver S, Richardson S, Pileggi M, Brane N, Oller D. Canonical babbling trajectories across the first year of life in autism and typical development. Autism. 2024 May 17; DOI: 10.1177/13623613241253908

b. Oller DK, Bene ER, Yoo H, Su PL, **Long H,** Klaiman C, Pulver SL, Richardson S, Pileggi ML, Brane N, Ramsay G. Acoustic features of vocalizations in typically developing and autistic infants in the first year. Res Dev Disabil. 2024 Nov;154:104849. doi: 10.1016/j.ridd.2024.104849. Epub 2024 Oct 16. PMID: 39413560; PMCID: PMC11560582.

c. Su PL, Yoo H, Ramsay G, **Long HL**, Bene ER, Klaiman C, Pulver SL, Richardson S, Pileggi ML, Brane N, Oller DK. Foundations of Vocal Category Development in Autistic Infants. J Autism Dev Disord. 2024 Feb 25. doi: 10.1007/s10803-024-06267-9. Epub ahead of print. PMID: 38403868.

d. Gipson TT, Ramsay G, Ellison EE, Bene ER, **Long HL**, Oller DK. Early Vocal Development in Tuberous Sclerosis Complex. Pediatr Neurol. 2021 Dec;125:48-52. PubMed Central PMCID: PMC8557126.

3. **Origins of Speech and Development of Infant Vocalizations:** My doctoral dissertation investigated the role of nonsocial and social factors in the emergence of speech to understand how infants signal developmental progress through vocalizations. Using human coding of laboratory and home recordings of infant vocalizations, we found that infant vocal imitation is rare but salient, nonsocial vocalizations occur more frequently than social ones, and advanced vocalizations occur more frequently during interactions with caregivers than during independent vocal play. These findings underscore the dual motivations behind vocal development, highlighting the importance of both self-driven vocal exploration and social engagement in speech development.

a. **Long HL**, Ramsay G, Griebel U, Bene ER, Bowman DD, Burkhardt-Reed MM, Oller DK. Perspectives on the origin of language: Infants vocalize most during independent vocal play but produce their most speech-like vocalizations during turn taking. PLoS One. 2022;17(12):e0279395. PubMed Central PMCID: PMC9803194.

b. Yoo H, Su PL, Ramsay G, **Long HL,** Bene ER, Kimbrough Oller D. Infant vocal category exploration as a foundation for speech development. PLoS One. 2024 May 29;19(5):e0299140. doi: 10.1371/journal.pone.0299140. eCollection 2024. PMID: 38809807

c. **Long HL**, Bowman DD, Yoo H, Burkhardt-Reed MM, Bene ER, Oller DK. Social and endogenous infant vocalizations. PLoS One. 2020;15(8):e0224956. PubMed Central PMCID: PMC7406057.

d. **Long HL**, Oller DK, Bowman DA. Reliability of Listener Judgments of Infant Vocal Imitation. Front Psychol. 2019;10:1340. PubMed Central PMCID: PMC6579846.

4. **Open Science Practices in Communication Sciences and Disorders:** A secondary research area I have supported has studied the adoption and barriers of open science practices in the discipline of communication sciences and disorders. One survey study identified low levels of knowledge and

implementation of open science practices such as preregistration and open data. Yet we found a strong desire among researchers to learn more and engage in these practices. Additionally, a separate study showed that fully open access articles receive significantly more citations and online attention than paywalled articles. These findings highlight the importance of promoting open science practices to enhance clinical research reproducibility, transparency, and accessibility.

a. El Amin M, Borders JC, **Long HL**, Keller MA, Kearney E. Open Science Practices in Communication Sciences and Disorders: A Survey. J Speech Lang Hear Res. 2023 Jun 20;66(6):1928-1947. PubMed Central PMCID: PMC10554559.
b. **Long HL**, Drown L, El Amin M. The Effect of Open Access on Scholarly and Societal Metrics of Impact in the ASHA Journals. J Speech Lang Hear Res. 2023 Jun 20;66(6):1948-1957. PubMed Central PMCID: PMC10465153.

Complete List of Published Work in My Bibliography:
https://www.ncbi.nlm.nih.gov/myncbi/helen.long.1/bibliography/public/