Lindsay Harlow
International Society for Autism Research
Research Proposal to Autism Now Foundation
Speech Patterns in ASD Children Research Proposal
August 11, 2023

Executive Summary

August 2, 2023
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Requested Funding Amount: 1,000,000.00
Total Current Organizational Budget: 2,000,000.00
Total Project Budget: 2,200,000.00
International Society for Autism Research Fiscal Year: September 1, 2023- September 1, 2024
The time this funding request will cover: September 1, 2023- September 1, 2024

Purpose

As part of its strategic plan, INSAR aims to ensure that autism research has a broad impact on society, reflected in a strategic initiative to "disseminate science-based knowledge to inform research priorities, policy, professional practice, and public understanding." (International Society for Autism Research, 2023) To this end, INSAR has committed itself to ongoing research in the learning applications and cognitive understanding of autistic individuals. Our objective is to study learning patterns and certain genetic anomalies to better understand the reasoning behind non-verbal speech patterns in autistic children. Analyzing different speech and cognitive patterns is helpful in ASD individuals because it helps guide the way that current therapies and interventions are structured to improve their social communication. The INSAR research fellows plan to follow this proposal. The INSAR is requesting 1,000,000.00 in research grants to achieve this proposal. The INSAR expects to complete this research proposal within this fiscal year of September 1, 2023, to September 1, 2024.

Lindsay Harlow
Senior Fellow
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Organization Background

> "The International Society for Autism Research (INSAR) is a scientific and professional organization devoted to advancing knowledge about Autism. INSAR was formed in 2001 and is governed by an elected, volunteer Board of Directors who oversee all functions of the Society. Various committees assist the Board in carrying out the mission of the Society. INSAR's Strategic Goals are to build identity and promote INSAR as the globally recognized and inclusive society for autism researchers. To represent and serve a diverse and global community. To cultivate interdisciplinary and translational research, public-private partnerships, and relationships within the industry. To foster the next generation for leadership and career development of autism researchers. To foster understanding, communication, and collaboration between autism researchers and people affected by Autism. To disseminate scientific knowledge to inform research priorities, policy, practice, and public understanding. To set the bar for increasing research quality, diversity, and relevance promoted through annual meetings, journals, educational, and other year-round activities." (International Society for Autism Research, 2023).

Our Board of directors is primarily comprised of staff from INSAR that has, at one time or another, each been personally invested in Autism and the research that may come from it. Senior fellow Lindsay Harlow has been passionate about developing and organizing research programs that led to some of the most current understandings in the field of language development in autistic youth. She has two children who are autistic and non-verbal. Her son uses an AAC (Augmentative and Assisted Communication) device. Through this, Lindsay began her journey with IRSAR and understood the reasoning behind communication patterns in autistic youth. She most recently finished her research on "Language Acquisition through Motor Planning (LAMP), a therapeutic approach based on neurological and motor learning principles that give nonverbal or limited verbal abilities a method of independently and spontaneously expressing themselves in any setting." (The Center for AAC & Autism, 2023). These studies have shown increased communication in unique words, enhanced receptive vocabulary, and various communicative functions, to name a few of the improvements.

In January 2020, INSAR appointed its inaugural Autistic Research Committee. While we see that many autistic people and allies have been championing research information, that marked the first time an organization had recognized an effort to directly involve autistic researchers in contributing to the course of autism research. (International Society for Autism Research, 2023). We feel that if the course of the research is going to affect their lives, these individuals should have an investment in the efforts if they choose to do so.

General Support

We are proud to be partnered with Autism Speaks. The Autism Care Network is the only network focused on improving children's health and quality of life. They have invested nearly 215,000,000.00 in scientific grants and projects and 4.2 Billion in federal funding for Autism since 2007. They have graciously agreed to back our research project for 200,000.00 and are providing state-of-the-art facilities and tools to get our research started. (Autism Speaks, 2023).

Problem Statement

"In the United States, 1 out of 59 children will be diagnosed with autism. Studies have shown that up to 50% of these children will be unable to communicate their wants, needs, and thoughts verbally" (The Center for AAC & Autism, 2023). That means that according to the birthrate statistics reported by the CDC, up to 28,000 children are born each year who will be diagnosed with Autism and will remain functionally nonverbal (The Center for AAC & Autism, 2023). When a child has communication issues, it affects their quality of life, education, and ability to develop relationships. This, in turn, leads to frustration, disruptive behaviors, and other challenges. It is imperative for an individual to reach their full potential and that they have the full ability to communicate for the success of their education, employment, and independence.

Understanding why a person with Autism can have anywhere from mild social communication skills to severe cognitive impairments is an important question. Often, apraxia of speech (AOS) is a disorder affecting speech, where a person knows what they would like to say but has difficulty getting their lips, jaw, or tongue to move correctly, which can be the reason behind the communication issue. To speak, our brains send a message to our mouths, making the speech movements complete. AOS keeps this message from getting through correctly. The type of AOS that we plan to look at further in our research is Childhood AOS. This pattern, present at birth, is often caused by genetics and has been found to affect boys more often than girls (Lee, 2022).

While the outlook may seem grim, research on language and communication disorders is positive. Scientists at the Center for Related Disorders in Baltimore looked at information on "535 children ages 8 to 17 diagnosed with Autism and severe language delays at age 4. At age 4, their language delays ranged from not speaking to using single words or phrases without verbs. Researchers found that most of these children did go on to acquire language skills. Nearly half (47%) became fluent speakers, and over two-thirds (70%) could speak in simple phrases" (Autism Speaks, 2023). We feel that through our research into language and communication development, we could find new strategies for understanding why certain children develop language and others never do. We hope to see insight into genetics' role in language and communication development.

Goals and Objectives

This research proposal aims to instrumentally change how language and communication are understood in autistic youth. Helping them with communication issues to reach their full potential in their education, social relationships, employment, and individual freedom. Over the coming year, our objective is to look at the nonverbal human mind to reflect on the breakdown of different cognitive phenotypes in which language is an inherent element. We plan to research various subjects with co-morbidity of verbal and nonverbal cognitive impairment to see if larger patterns can be ascertained.

Strategies

Childhood Apraxia of Speech Intelligibility Therapy for Autism

A current study of minimally verbal autistic children shows signs of having "childhood apraxia of speech" of CAS. If so, will drill-based therapy or therapy embedded in a social, play-based context provide ecologically valid feedback and help children generalize their verbal skills more often? The treatment will consist of 15-hour-long sessions over three weeks. The sessions may take place at our lab or at a child's home or school, and video and audio will be recorded for later analysis. Children between the ages of 5 to 18 will participate. The inclusion criteria are that the child meets the criteria for ASD. Be minimally verbal (produce no more than 20 different words and no multi-word phrases during the language sample). The child must show at least five signs of CAS. The child must be able to repeat at least two syllables correctly. Finally, the child must live in a primarily English-spoken household (Autism Speaks, 2023).

Language Outcomes in Minimally Verbal Children with Autism Spectrum Disorder

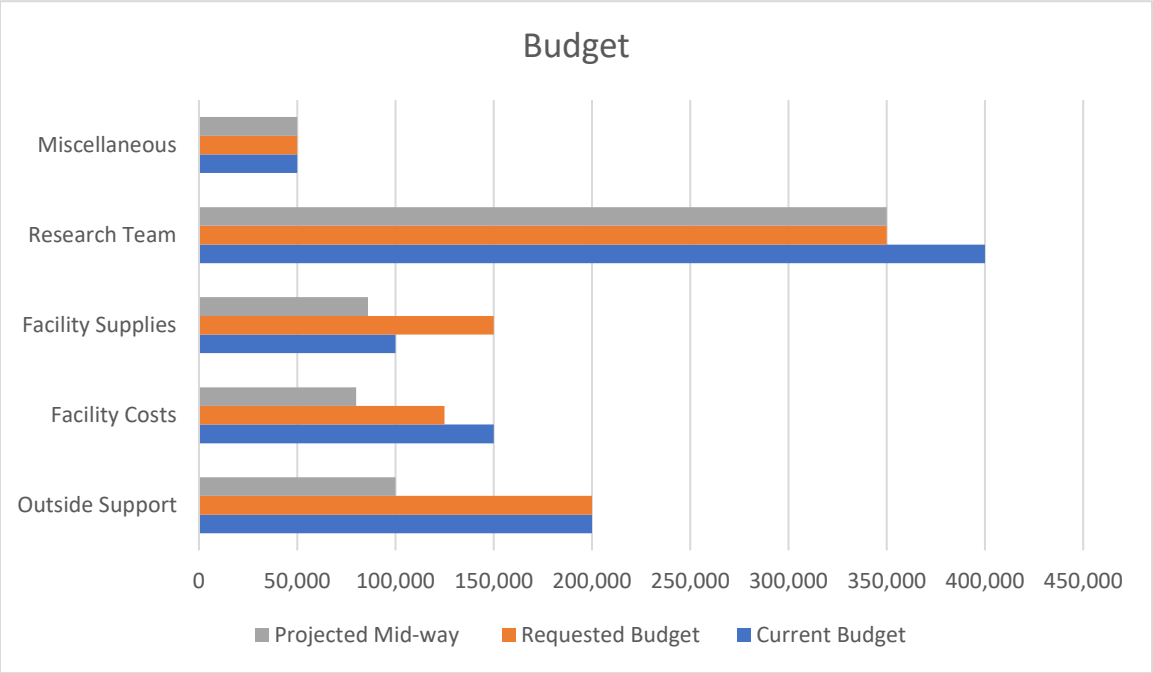
In want to know how motor skills and brain responses to sounds and speech and how they can be related to different patterns within language development in minimally verbal and nonverbal children with autism spectrum disorder. This study will include play-based behavioral assessments, non-invasive brain imaging (EEG), motor assessments, parent interviews, and surveys. The criteria for this study will be children between the ages of three and six years old. Children from English-speaking homes and children with Autism have language difficulties. The exclusion criteria are that we will not accept any typically developing children or children with neurodevelopmental disorders (Autism Speaks, 2023).

Speech and Motor Assessment Remote Trial (SMART)

This project compares how a child performs on a series of speech, language, and motor assessments in our lab, remotely, and at home. Children with neurodevelopmental or genetic

diagnoses between the ages of 2 to 18 are asked to participate. Children will be assessed in a series of motor and spoken-language assessments. Motor assessments will include walking back and forth and recording each of their footsteps. Spoken language assessments are to include watching a preferred video where children's facial movements are recorded. Children will also be asked to repeat a set of 8 syllables, do a picture-naming task, and try some tongue twisters. The specific spoken-language tasks for each child will be selected based on their verbal ability, so everyone has the challenge adequate for the child. The in-person and remote assessments will be audio and videotaped for later analysis (Autism Speaks, 2023).[1]

Financials



Here, we see the budget for the previous year, the projected budget, and where we plan to be for the mid-way point during the research proposal. The items listed above are the Facility cost, the cost for the Research team, the facility's supplies, and any miscellaneous expenses that might be incurred. This is a factor for any food for volunteers and any travel incurred. It also covers any other unseen costs that might be incurred. This graph also shows where we have outside contributions coming in from. It would also be disclosed at any time that the program received any other endowments that would further the research.

We expect to receive a certain amount of donations and free service during the research program. Many volunteers and trial participants are doing so at no charge. In most cases, there is no reimbursement of any kind being made other than their want to help. Other services we generally

[1] All of the above mentioned Research Studies are actual studies being done by Autism Speaks at present.

see donated are food, printing, marketing, accounting, equipment, vehicles, and other miscellaneous tangible items used for the program.

As always, there is a certain amount of indirect costs that would be applied to the budget, otherwise known as overhead. These are utilities, technology support, legal, administrative support, etcetera. This number is the equivalent of about 20% of the total budget.

Evaluations

Our evaluations aim not to judge individual workers or researchers but to consider the entire program and what does and does not work. To this end, we plan to implement formative evaluations that will help us assess the feedback of the research results we receive and how those results impact the ASD community. These evaluations will allow us to see if the correct services are being researched, how well they are being researched and implemented, and whether they could be done more efficiently. These evaluations will also help us understand if the participants' lives are positively impacted.

At the beginning of the research program, we plan to give each participant's parent a survey to fill out. We will also observe the participants in a poll taken at different intervals. Annual budget reviews will also be conducted to ensure the program stays within its cost constraints.

We also plan to use summative evaluations to measure the research plans' outcomes, effectiveness, and impact on speech patterns in people with ASD. By implementing these evaluations, we will be able to see if target goals have been met and if unanticipated results have occurred. How cost-effective has the research program been, and what factors have contributed to all of these? These evaluations will occur with a measure at the start, a mid-way portion of the process, and then at the end of the research study. These will also involve measures of participants' attitudes and behaviors. Questionnaires, surveys, observations, and systematic collection will be implemented to collect the data from these various sources.

Sustainability

The overwhelming support that our research has had from Autism Speaks has been instrumental in the sustainability of the success of this program. The community's involvement has also been a significant motivator in getting our research off the ground. We believe that the commitment of INSAR and its partners will bring great success to the future of autism research.

Conclusion

Lindsay Harlow and INSAR are grateful for this opportunity to seek support from the Autism Now Foundation. We hope you will consider a general support research grant of 1,000,000.00 for the one year of September 1, 2023, to September 1, 2024. Thank you for your time and consideration.

References

Autism Speaks. (2023). www.autismspeaks.org: https://www.autismspeaks.org/science-news/nonverbal-child-autism-language-delays

Columbia University Irving Medical Center. (2019, May 24). Do you hear what I hear? Infants with autism risk may be less able to distinguish between familiar and unfamiliar speech patterns, study suggests. *ScienceDaily*. www.sciencedaily.com/releases/2019/05/190524113533.htm

Fagan, B. (2023, April 11). *www.pandadoc.com*. https://www.pandadoc.com/blog/grant-proposal/

International Society for Autism Research. (2023). *INSAR*. www.autism-insar.org: https://www.autism-insar.org/

Karsh, E., & Fox, A. S. (2019). *The Only Grant-Writing Book You'll Ever Need* (5th ed.). New York: Basic Books.

Kolin, P. C. (2023). *Successful Writing at Work* (12th ed.). Boston, MA: Cengage.

Kuo, H.-Y., Chen, S.-Y., Huang, R.-C., Takahashi,, H., Lee, Y.-H., Pan, H.-Y., . . . Liu., F.-C. (2023). Speech- and language-linked FOXP2 mutation targets protein motors in striatal neurons. *Brain*. 10.1093/brain/awad090

Lee, S. W. (2022, March 28). *Health Line*. https://www.healthline.com/health/apraxia-of-speech

Oliu, W. E., Brusaw, C. T., & Alred, G. J. (2020). *Writing That Works* (13th ed.). Boston, MA: Bedford.

O'Neil-McElrath, T., Kanter, L., & English, L. (2019). *Winning Grants Step by Step* (5th ed.). Hoboken, New Jersey: John Wiley & Sons, Inc.

Peirce, K., Wen, T., Zahiri, J., Andreason, C., Courchesne, E., Barnes, C., . . . Cheng, A. (2023). Level of Attention to Motherese Speech as an Early Marker of Autism Spectrum

Disorder. *JAMA Network Open, 6*(2). https://www.sciencedaily.com/releases/2023/02/230208125050.htm

Pereira-Smith, S., Boan, A., Carpenter, A. L., Macias, M., & LaRosa, A. (2019). Preventing elopement in children with autism spectrum disorder. *Autism Research, 12*(7), 1139-1146. https://doi.org/10.1002/aur.2114

Schultz, S. L. (2015, June). *National Library of Medicine: National Center for Biotechnology Information*. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4442745/

The Center for AAC & Autism. (2023, August). *The Center for AAC & Autism*. www.aacandautism.com: https://www.aacandautism.com/lamp

USA.gov. (2023). *www.usa.gov*. https://www.usa.gov/government-grants-and-loans

www.grants.gov. (2023). *www.grants.gov*. https://www.grants.gov/applicants/apply-for-grants.html