



Autism Science Foundation
searching. solving. sharing.

**Request for Applications:
Pilot Studies of Profound Autism
and Severe and Challenging Behaviors**

RFA Released: July 17, 2023

Applications Due: September 15, 2023, 5PM Eastern

Anticipated project start date: February 1, 2024

Introduction:

Past research has established that individuals with autism exhibit a wide range of abilities and disabilities and that those with challenging or problematic behavior, minimal verbal ability, and/or intellectual disability are demonstrably [underrepresented in research](#). Their exclusion prevents generalizability of research discoveries and impedes our understanding of the supports and interventions they require to live fulfilling lives.

The *Lancet* Commission on the Future of Care and Clinical Research in Autism determined that term “profound autism” should be used to describe autistic people who are at least 8 years old, minimally verbal or nonverbal, have IQ below 50, are not able to advocate for themselves, and will likely require 24-hour access to an adult who can care for them for the rest of their lives.

In order to ensure that individuals across the spectrum are included in the research, ASF is interested in supporting projects that will either a) increase the opportunity for people with profound autism to participate in research or will b) identify and characterize the underlying biological mechanisms of profound autism, or will c) develop treatments specifically for those with profound autism.

In addition, this RFA welcomes research broader in scope than the Lancet definition of “profound autism” to include research on severe and challenging

behaviors including self-injury, aggression, and irritability, and research focused on children under age 8.

Investigators must include a letter of support from an advocacy organization involved in profound autism. These organizations can include Patient Advocacy Groups (PAGs) that represent families with idiopathic autism or with rare genetic syndromes that result in a high prevalence of neurodevelopmental disorders, including autism. Many of these groups are represented in the Alliance for Genetic Etiologies in Neurodevelopmental Disorders and Autism ([AGENDA](#)). Investigators may also partner or collaborate with groups like the National Council for Severe Autism ([NCSA](#)) or the [Profound Autism Alliance](#). They may also choose to collaborate with a local organization or another advocacy organization that focuses on the needs of people with profound autism.

Awards:

Autism Science Foundation will award multiple pilot grants determined by available financial resources. The term of the award will be one year and will support up to \$35,000 in costs for one year.

This award cannot be used to cover tuition payments. No portion of these funds shall be used to cover indirect university costs.

Eligibility and Requirements of the Project:

Applicants for this award must hold an M.D., Ph.D., EdD, or ScD, and hold a faculty or postdoctoral position at a university or institution, or an organization with 501c3 status. U.S. citizens enrolled in or employed at universities inside or outside of the United States are eligible to apply. Non-U.S. citizens enrolled in or employed at universities based inside or outside of the U.S. are also eligible to apply.

Awards will only be made to ONE institution and led by the principal investigator. However, subcontracts to other universities are permitted for co-investigators. Subcontracts are to be issued by the sponsoring university. All investigators must be ***named with their research affiliations*** on the title page and biosketches for all co-investigators.

Proposal Preparation:

Proposals must be submitted in 12-point Arial font and should have margins of 0.5 inches or greater with line spacing at 1.5. The applicant's **last name must appear in the header** on every page of the application. **Number the pages.**

A proposal must include the following sections:

1. Title Page

Each proposal must include a title page that includes the **title of the project**, the **sponsoring institution**, and for the principal investigator:

- Full name and highest degree achieved
- Academic title
- Affiliated university or institution
- Current email address
- Permanent, non-university affiliated email address (such as gmail)
- Race/Ethnicity* (**please choose from the following for race:** Black or African origin; Asian; Native American, Alaskan Native or Aboriginal; Native Hawaiian or other Pacific Islander, white/Caucasian; biracial or mixed race; other; prefer not to disclose. **Please choose from the following for ethnicity:** Hispanic; Non-Hispanic; prefer not to disclose)
- ORCID ID
- Include the names, emails and affiliations of any co-investigators on the title page.

** Collecting demographic information helps the Autism Science Foundation assess how effective we are at reaching a broad community of autism researchers. We are committed to reaching applicants from diverse backgrounds and strongly encourage researchers from underrepresented and minority communities to apply.*

Proposals without a title page may be returned without review.

2. Proposal Abstract (Max. 500 words) and Lay Abstract (Max. 250 words)

The proposal abstract should indicate the goals and objectives of the project and clearly state the value of the work toward improving the lives of people with profound autism or severe and challenging behaviors. The lay abstract must be intelligible to a knowledgeable layperson or non-expert. It should not include jargon and should clearly and succinctly state the goals of the project and the expected impact on people with autism and their families.

3. Research and Analytic Plan (*Maximum 7 single spaced pages*)

The plan should describe the specific project, including the rationale and background, relevance to understanding those with profound autism or severe and challenging behaviors, any preliminary data, specific aims, methodology, participant characterization and recruitment, expected results and how they will be shared, and the timeline for completion. Please note that for animal studies, ASF strongly encourages applicants to [follow this guidance](#).

4. Bibliography (*maximum 2 single spaced pages*)

Include complete literature citations, including titles and all authors.

5. Budget, Timeline and Budget Justification (*maximum 1 single spaced page*)

The budget should include a breakdown of all the expenses, where the funding will go and to whom/what for the full funding amount. Each item should include a justification. A table listing the type of expense, the justification, and the amount is sufficient. Salaries and fringe can be used to support the project, but should not exceed \$20,000 total.

6. Biosketch

Please include a biosketch for the PI and anyone receiving salary support, at all career levels.

7. Support letter from Patient Advocacy Group

Each application is required to work with an advocacy group, either locally or nationally, on the overall goals of the project. That advocacy group should write a 1-2 page letter describing their enthusiasm for the project and how they will be involved in the execution of the goals stated in the application, if applicable.

These letters should be **submitted directly by the PAG** by the due date of the rest of the materials to grants@autismsciencefoundation.org. Please instruct the group to include the PI last name on the file or on the subject line when sending in the letter. If you have questions about what groups are appropriate to provide these letters, please email: ahalladay@autismsciencefoundation.org

Revisions:

Proposals reviewed during the 2022 cycle may be resubmitted for consideration. If from an earlier cycle, it would be considered a new submission. In addition to the proposal, the applicant should provide a one page, single spaced letter addressing the changes made in response to the reviewers' comments. The one page, single spaced letter will not be included in the proposal page limit, but it should only contain information relevant to the reviewers' previous comments and suggestions. It should be placed before the research plan. The revised proposal should be submitted without track changes or other editing notation. You may not request reviewer feedback on a previous submission at this point.

Submission of Proposals

Proposals must be submitted as a single PDF document with all materials bundled together. Submit the PDF by email to grants@autismsciencefoundation.org. Be sure to have the PAG email their letter of support by the due date as well.

Proposals are due on or before September 15, 2023 5:00 PM ET. Proposals will not be accepted after the due date unless prior permission is obtained, and only for exceptional circumstances. Please note the time zone when applying. Technical issues will not suffice as an excuse for a late submission.

Autism Science Foundation reserves the right to return any proposal without review. This includes proposals not in compliance with the conditions prescribed in the RFA, proposals that are not responsive to ASF's research goals, and proposals that exceed the stated funding levels. ASF also reserves the right to return any proposal from applicants whose mentors or grant officers have a previous history of submitting reports late or from universities whose ASF-funded students have, in the past, submitted late or incomplete final reports.

Award notifications are expected to be made in December 2023. Awarded projects must be started between February 1, 2024, and March 1, 2024.

Payment of Awards

Awards will be paid in two installments; the first within 30 days of the start date and the second at the six-month point, provided we receive a satisfactory progress report from the applicant. Payment will be contingent upon acceptance (by an official authorized to act for the institution receiving the award) of the Autism Science Foundation award

terms and conditions **without amendment** (provided at the time of the award) and receipt by ASF of all required certifications.

An award cannot be transferred to another investigator, laboratory, or sponsoring institution without prior written approval from the Autism Science Foundation.

Review Process and Evaluation Criteria

Proposals will be reviewed by members of the Autism Science Foundation's Scientific Advisory Board, as well as by active and experienced investigators recruited from the scientific community for their expertise in the research areas of the proposals. Proposals may also be reviewed by a panel of experienced laypersons (parents, individuals with autism, other advocates) who will provide input to the Scientific Advisory Board.

Additional questions about proposal submission, proposal content and review, or applicant eligibility should be addressed to Dr. Alycia Halladay, Autism Science Foundation's Chief Science Officer, ahalladay@autismsciencefoundation.org.

A question-and-answer session will be held on August 17th at 12 p.m. ET to review the goals of the RFA and will include tips on writing a strong application. Please register here: https://us06web.zoom.us/meeting/register/tZwkcu6prT0uEtxKfUW_j6aY0ug3yW5ab-Bg
