Request for Applications:
Focused Research to Support Pilot Studies of Profound Autism and Severe and Challenging Behaviors

RFA Released: July 18, 2022
Applications Due: September 16, 2022
Anticipated project start date: February 1, 2023

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 stalls our understanding of the supports and interventions they require to live fulfilling lives.

In recognition of the differing support needs of those who are minimally verbal or have an intellectual disability, and to encourage both the clinical and research communities to prioritize the needs of this underserved community, The Lancet Commission on the Future of Care and Clinical Research in Autism called for the use of the term “profound autism.” “Profound autism” describes 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.

To ensure that individuals across the spectrum are included in research, ASF is releasing a focused RFA to support projects that will improve, expand, or make possible the inclusion of those with “profound autism.” These include studies of those with an intellectual disability or impaired cognitive ability (IQ measured below 50)
and minimal verbal ability. In addition, the RFA welcomes research broader in scope than The Lancet’s 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.

Novel ideas and approaches in this area are welcomed. We recognize that research in this area should be multidisciplinary and we hope to support projects across many disciplines of research. These pilot grants should focus on inclusivity in research, including, but not limited to developing and validating methods or tools that will facilitate or enhance scientific studies to improve the quality of life of these families; translational models that include assessment of verbal ability and cognition; novel uses of technologies and supports; and improved understanding of neurobiological and/or genetic profiles of those who will require lifelong supports.

Investigators are strongly encouraged to reach out to 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). Studies that do not include a rare genetic syndrome should partner or collaborate with groups including the National Council for Severe Autism (NCSA). They may also choose to collaborate with a local organization or another advocacy organization that focuses on the needs of people with higher support needs. A support letter from such an organization is welcomed.

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., Ed.D., or Sc.D., and hold a faculty or postdoctoral position at a university or institution, or an organization with 501c3 status.
U.S. citizens enrolled in universities inside or outside of the United States are eligible to apply.

Non-U.S. citizens enrolled in universities based inside or outside of the U.S. are also eligible to apply.

**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.** In order to provide continuity to reviewers, if pages are not used, the words “page intentionally left blank” must appear as a watermark on that page. For example, if the research plan only requires 5 pages, page 6 should be numbered and watermarked with “page intentionally left blank.”

A proposal must include the following sections:

- **Page 1: Title Page**
  Each proposal must include a title page with the applicant’s name and full contact information (including a permanent, non-university affiliated email address), applicant’s ORCID ID, title of the project, and name of the sponsoring institution. **Proposals without a title page may be returned without review.**

- **Page 2: Proposal Abstract (Max. 500 words) and Lay Abstract (Max. 250 words)**
  The 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.

- **Pages 3-8: Research and Analytic Plan (Maximum 6 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.

- **Pages 9-10: Bibliography**
  Include complete literature citations, including titles and all authors.

- **Page 11: Budget, Timeline and Budget Justification**
  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.

- **Pages 12-15: Biosketch**
  Please include a biosketch for the PI and anyone receiving salary support, at all career levels.

- **Page 16: Support letter from Patient Advocacy Group (optional)**
  Applications that include a support letter will be given preference.

**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.

**Proposals are due on or before September 16, 2022 5:00 PM ET.** Proposals will not be accepted after the due date unless prior permission is obtained, and only for exceptional circumstances.

**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 will be made in December 2022. Awarded projects must be started between January 1, 2023, and March 1, 2023.

**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, at ahalladay@autismsciencefoundation.org.

A question-and-answer session will be held on August 19th at 12 p.m. ET to review the goals of the RFA and will include tips on writing a strong application. Please [register here](#):