



## Autism Research COVID-19 Call for Resources

*We believe there is a timely and high-impact opportunity for the autism research community to redirect our collective expertise, creativity and capacity to help meet the needs of those with autism, their families, and frontline professionals in this public health crisis. Therefore, we are requesting the research community to submit and share useful tools and resources that may help families and individuals with autism weather the coming weeks and months. Working together, we can help speed dissemination of useful tools and resources into the hands of people with autism and their families to help meet their most pressing needs now and going forward.*

### Background

COVID-19 is a once in a generation public health crisis. Since many individuals in the autism community live with pre-existing medical conditions, they are at increased risk for more severe outcomes. In addition, drastic but necessary public health measures being taken by governments to contain or mitigate spread employment.

Many of the resources available at the CDC, WHO, and other leading health agencies do not speak directly to the often unique and complex daily challenges facing the autism community.

For example, a recent survey of over 9,000 parents of children and dependent adults with ASD by SFARI found that most report severe disruptions to school- and community-based services, and that only a minority of these families have received any virtual or adapted services.

In addition, many families are struggling to navigate a growing flood of information and options to find feasible and effective resources that are relevant to their specific circumstances.

### Aim

1. Leverage the collective expertise of the autism researcher community to deliver evidence-based tools and resources to help meet the needs of those with autism, their families, and professionals during this public health crisis.
2. Curate a collection of evidence-informed resources to support families and service provider in times of public health emergencies and humanitarian crisis.
3. Disseminate resources globally.

### Collaborators

Autism Speaks and Autism Science Foundation working with SFARI and INSAR.

## Use Case

We recognize autism is a spectrum across all ages and cultures, and people with autism and their families have diverse needs. The use case below illustrates one of those needs that currently is being highlighted by many families in our community. Accordingly, different user vignettes will accompany future calls focusing on additional community priorities.

*Mary is a young single mother living in a two-bedroom apartment in a suburb of New York City, where she has reliable internet. Her 6-year-old daughter, Alma, is on the autism spectrum and usually receives school-based services in her public school as a first grader while Mary works as an administrative assistant at a law firm. She also has a typically developing son, Joseph, who is 9.*

*After the law firm asked its employees to work from home due to the COVID-19 crisis, Mary has been trying to develop a routine at home that would allow her to work while looking after Alma and dividing her time between Alma and Joseph.*

*Alma's school is working to move some of the educational activities online, but they will be mostly academics and activities for her entire classroom. The in-class supports she received will no longer exist. Also, the previous schedule of school-based supports and private supports is no longer in place.*

*Mary realizes that she still needs to find resources or other activities for about 3 hours per day to help Alma maintain her skills, stay happy, and avoid crisis situations.*

### **How can we help Mary and Alma and other families in similar situations?**

Examples of what may be helpful to Mary and her family:

- Online and offline activities and programs for a variety of skills and support needs (sensory, social, daily living, behavioral management, etc.)
- Adaptive educational programs to supplement district opportunities
- Visual aids or communication supports
- Mental and physical health resources for family members (parents and siblings)
- Videos
- Games
- Tools, tips and strategies to establish and maintain a daily routine for children and include them in family/home routines.

### **Criteria for Resources**

1. Relevance to the identified needs
2. Ease of use (feasibility) for the intended audience
3. Not proprietary/Adaptability for different settings (e.g., languages, cultures, accessibility/no Internet)
4. Implementation readiness
5. Level of evidence
6. Available to users at no cost.

## Submitting a Resource

Resources will be collected by submitting applications in the [Autism Speaks Science Grants System](#).

1. Login or register in the [system](#). For registrations, choose Investigator when prompted.
2. Choose 'Applications' from the profile page, then "Start a new application", and then "Choose Proposal Type".
3. Choose "Submit a Resource 2020" from the list and then "Start new application for Submit a Resource 2020".
4. The application has two webpages – the basic page and the application form page.
  - a. Basic page – only entry is a title. Be brief (100 character limit, including spaces).
  - b. Application Form page
    - i. Enter a description of your resource
    - ii. Choose one answer in each of the following:
      1. **Audience** – families or providers
      2. **Target Age group** -Select all that apply
        - a. Infant/Toddler
        - b. Pre school
        - c. K-5th grade
        - d. 6th-8th grades
        - e. 9th-12th grades
        - f. Post high school
        - g. Adults
      3. **Topic**: Education, Medical issues, Behavior issues, Mental Health, Telehealth issues
      4. **Type**: Teaching story, PDF, Link to video, Link to website
    - iii. Upload a document and/or provide a URL
    - iv. Provide a short list of references which speak to your resource.
    - v. Briefly describe how a family or provide would utilize this resource
5. At any time, the application can be saved as draft and be returned to later.
6. When all is complete, click 'Submit Application' at the bottom of the application form page.
7. The system will send a submission confirmation email.
8. Please contact Joan New, [jnew@autismspeaks.org](mailto:jnew@autismspeaks.org), (609) 228-7313, for assistance with the system.

The image contains three screenshots of the Autism Speaks Science Grants System interface. The first screenshot shows a button labeled "> Start a new application". The second screenshot shows a dropdown menu for "Proposal Type" with "Post A Study 2020" selected, and "Submit a Resource 2020" is circled in red. The third screenshot shows a dropdown menu for "Proposal Type" with "Submit a Resource 2020" selected, and a button labeled "> Start new application for Submit a Resource 2020" is circled in red.

## Notifications

Submitters will be notified by email whether or not the submitted resource is chosen to be disseminated. Submitters may also be contacted with questions or suggestions for alterations prior to a final decision.

## Questions about this call for resources can be directed to:

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