



**AUTISM RESEARCH INSTITUTE**  
*Autism is Treatable*

STEPHEN M. EDELSON, PH.D., EXECUTIVE DIRECTOR  
BERNARD RIMLAND, PH.D., 1928-2006, FOUNDER

619-281-7165  
fax: 619-563-6840

## **The Autism Research Institute's Approach to Autism**

We continue to gain insight into the many aspects of autism from research studies and from individuals on the spectrum. The more we know about autism, the more we realize that we need to expand how we think about and treat these individuals. It's been a long-held commitment at the Autism Research Institute (ARI) that, along with identifying what *can* be done, we must also consider with great care what *should* be done to aid those on the autism spectrum. Fifty years ago we were among very few voices seriously talking about autism; today, many more contemplate what it means to treat – or strive to treat – persons with autism, especially as it is now recognized to be a very common condition. But, despite increased interest in research and clinical care, there are great gaps in our knowledge of the causes and care for persons with autism. An understanding of autism and the development and provision of appropriate care for affected individuals and their families is, in our view, one of the central challenges of contemporary medicine.

ARI's nearly fifty-year history of research and advocacy has placed us in a unique position in several important regards: (1) to fund particularly innovative basic and clinical research efforts with the potential for high impact; (2) to support outstanding clinical programs; (3) to develop and make widely available educational materials regarding diverse aspects of autism; and (4) to facilitate communication on all aspects of autism between individuals with autism, families, clinicians, researchers, and policy makers.

### **Who is the leadership of the ARI and what is its central operational philosophy?**

Today ARI is a cohesive and communicative network of researchers, adults on the spectrum, parents, and professionals – all of whom support an all-encompassing approach to understanding autism and promoting high quality education, medical care, and life opportunities for individuals on the spectrum and support for their families. ARI's staff and Board of Directors consist of researchers, individuals on the autism spectrum, parents, and practitioners. Our Scientific Advisory Panel includes researchers and science-oriented clinicians with diverse expertise, including scholars in neurology, medical genetics, biochemistry, nutrition, psychology, and education, all of whom are active in the organization and passionate about our mission. We do not consider that a single perspective will be sufficient to understand and help all, or even the majority, of individuals on the autism spectrum. We therefore embrace inclusive discussion to advance our mission. Our record supports the value of this approach.

## **How does ARI view research on the underlying causes of autism?**

In his seminal book *Infantile Autism*, published in 1964, ARI's founder Dr. Bernard Rimland argued that autism was biologically based; this was a pioneering position at the time. He was also one of the first professionals to propose a possible genetic basis for autism. A few years later, in

1967, he expanded his argument to include environmental insults as possible contributory factors. Over the past fifty years, diverse types of genetic research have indicated that there are different types of genetic contributions to the causation of autism, ranging from some chromosomal causes, to some single gene disorders associated with autism, to forms that have a partial and still poorly understood genetic basis. A growing number of studies, especially in the past ten years, indicate that environmental factors, largely not understood, also contribute significantly to autism causation. Clearly, much more work needs to be done to clarify the underpinnings of autism; while great progress has been made, our understanding of the causes of autism is still quite limited and our understanding of the biology of autism is even more deficient.

## **Can interventions help those with autism?**

ARI was the first organization to argue unequivocally that those on the spectrum can benefit from intervention, coining the phrase "Autism Is Treatable." With enough published peer-reviewed studies, more interventions will soon become evidence-based and be accepted by the autism and medical communities in addition to government agencies and health insurance companies. ARI takes the position that one can live a healthy lifestyle by targeting specific physical problems. Many, if not most, people with autism may need some form of therapy to treat their physical health conditions. These treatments may be neurologically based (e.g., to stop seizure activity), medically based (e.g., to reduce gastroesophageal reflux or severe constipation), nutritionally based (e.g., to normalize a nutritional deficiency), or sensory based (e.g., to reduce hyper-sensitivities). Medical approaches augment educational and behavioral approaches that are often needed and can also be helpful.

Some adults on the spectrum state that it is not necessary to provide them with help or assistance—that they do not need to be "treated." They embrace the diagnosis and are pleased with their overall sense of being. These individuals very much want to be accepted for who they are. ARI's Board of Directors, staff, and those in our network respect the right of those on the spectrum to choose whether or not to access treatment.

## **What is ARI doing with regard to current and future research?**

ARI conducts research, collaborates with other research centers, and awards grants to support "research that makes a difference." (Dr. Rimland's noteworthy slogan). Areas of interest include behavioral analysis, sensory processing, genetics, nutrition, and gastrointestinal, metabolic, neurologic, and immunologic aspects of autism. Both scientific and medical advances have resulted from the research awards that we have provided.

Having access to tissues is crucial to many types of biomedical research. We financially support a brain-tissue bank at the University of Maryland, as well as another tissue repository at the pediatric gastroenterology section of the Massachusetts General Hospital.

One of the reasons for the slow progress in finding solutions is the disconnect among researchers in the various disciplines mentioned above. At ARI we continually work to develop productive lines of communication among researchers within and between various fields by inviting them to participate on our Scientific Advisory Panel. We sponsor regular conference call meetings with these committee members and invite other scientists to join in on the conversation. In addition, we organize multidisciplinary national and regional Think Tanks each year and publish a science review newsletter summarizing these discussions and other advances.

### **How does ARI help those with autism and their families?**

Our efforts at ARI are also focused on disseminating relevant information about autism to those on the spectrum and their families. We do this by providing assessment forms as well as informative articles and videos on our popular website, [autism.com](http://autism.com). We also broadcast live presentations on the Internet on an almost weekly basis. In addition, we publish three different e-newsletters on a regular basis, post relevant information daily on social media, and manage a toll-free information call center.

ARI is active in distributing information to families throughout the world. ARI is one of a handful of autism-related NGO members at the United Nations. Many of our evaluation forms and articles are translated into other languages. We co-sponsor an international three-day conference in Moscow each year, and we helped send representatives to present talks in various parts of the world, including Colombia, Ghana, India, the Philippines, and Ukraine.

### **What is ARI doing with respect to adults with autism?**

More than a decade ago, ARI started to expand its efforts to include adults on the spectrum. In 2007, we organized and edited a book with Jessica Kingsley Publishers on adult-related issues. We also offered lectures on adult-related issues at our past conferences, and currently in our live webinars. Some of these presentations are uploaded to YouTube.

A few years ago we formalized an adult program within ARI called the Autistic Global Initiative (AGI), and we employ adults on the spectrum to run it. They provide self-advocacy mentorship to young adults, publish a quarterly e-newsletter, produce film documentaries (trauma, sensory sensitivities), and develop trainings (residential care, employment). At their 50th anniversary conference this year, the Autism Society of America honored ARI's AGI program for "the advancement, effective transition, and meaningful employment of people with autism." We are proud of our record of advocacy for adults with autism.

### **What is ARI's position on the possibility of recovery from autism?**

We hear reports by parents and professionals regarding recovery in some individuals on the spectrum based on many of the interventions mentioned earlier. There are many ways to interpret the word "recovery," and we view recovery in the same way as the medical community—that is, as a managed state, similar to recovery from addiction or cancer. Individuals receiving appropriate treatment and support will retain their unique and wonderful personality, but they will be better able to manage life and feel physically well. Although there may still be some residual "autistic" traits, many of these individuals have a positive prognosis to live independently, be fully employed, develop personal relationships, and live a fulfilling life. Over the years, we have conducted surveys on these unique individuals, produced documentaries and a book describing cases, and even assisted NIMH in recruiting participants for a study on those who make unusual progress beyond their initial prognosis.

## **What is ARI doing to support clinicians who care for persons with autism?**

To expedite the use of evidence-based treatments, ARI also disseminates science-based information directly to healthcare professionals. We work jointly with the Cleveland Clinic Center for Continuing Education and offer free online CME films for providers on diverse aspects of autism. We also distribute a bimonthly e-newsletter to inform more than 6,000 physicians, nurses, obstetricians, and parents on the latest medical advances. Recently, ARI has continued its efforts in support of education of health professionals through a new initiative: the development of a new scholarly work, to be published by Jessica Kingsley Publisher, on understanding and treating self-injurious behaviors, an often devastating phenotype that has heretofore received inadequate attention.

## **What's next for the ARI?**

In the year to come we plan to continue developing more innovative ways to support the autism community through networking, supporting research, and disseminating relevant information at a global level. We also plan to maintain our current programs and projects. To learn more about ARI, please read our list of accomplishments in 2015 at: [www.ARIaccomplishments.com](http://www.ARIaccomplishments.com). Lists of accomplishments in previous years can be found on our website.


## **How can you help?**

Most of our financial support comes directly from the autism community, especially from parents of children of all ages and their relatives. Unlike most autism organizations, we are independent of outside influence. We do not accept grants from government agencies or donations from big Pharma or insurance companies. In addition, we do not accept contributions from providers or promote autism-related products and services.

If you agree with our approach to autism and value the work that we've done, I urge you to support our continued efforts by making a contribution to ARI *and* by sharing our information with those on the spectrum, parents, and professionals.

*Please consider supporting our efforts.*

Respectfully yours,



Stephen M. Edelson, Ph.D.  
Executive Director

ARI is a 501(c)(3) organization - Fed ID No. 95-2548452