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Science, the ARI Way

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Dr. Bernard Rimland established the Autism Research Institute (ARI) in 1967 to conduct and sponsor scientific research on the underlying causes of autism, and on effective treatments for the common co-morbid medical problems. Dr. Rimland's visionary work set forth a clear path for the future to develop a collaborating network of researchers, clinicians, and families.

In the early days of autism, parents were given little or no hope regarding their child's prognosis; the usual recommendation was institutionalization. However, several dedicated people, including Drs. Ivar Lovaas, Eric Schopler, and Ruth Sullivan, along with Rimland, were responsible for building a foundation, based on science, indicating that autism was indeed treatable.

When Dr. Rimland began his 50-year career in the field of autism, he was astounded and dismayed that almost all professionals blamed parents for causing their child's autism even though there was no objective evidence to support this conjecture. Dr. Rimland then wrote a groundbreaking book in 1964 entitled *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior* that moved the thinking about autism toward the direction of science. Concurrently, Carl Ferster at the Indiana University Medical Center was beginning to use behavior modification with children on the spectrum, with positive outcomes. His techniques were later improved and expanded upon by Ivar Lovaas at The University of California at Los Angeles.

I was fortunate to have known Dr. Rimland for over 30 years, and to have worked closely with him for twenty. Because we both received our doctoral degrees in Experimental Psychology, many of our conversations dealt with various aspects of research.

Research Design

Data are information, and there are many forms. The sequence of data collection often, but not always, begins with case histories and then leads to open clinical trials, single subject research, small controlled studies, and large controlled, multi-site studies. All of these approaches are considered useful for scientific investigation and are published in peer-review journals. Over time all of this information is integrated and summarized to determine whether there is enough evidence to show that a finding is valid. Case in point is the research supporting applied behavior analysis (ABA). Most of the evidence supporting ABA comes from case histories, single subject designs, and several small-scale, controlled group studies.

Unfortunately some professionals in the field fail to understand the progression of scientific investigation; sometimes they use the term "pseudo-science" to describe the publications of case histories, open clinical trials, and small controlled studies. These types of published reports and studies are part of the scientific process.

I often hear people argue that the only "accepted" or "gold standard" research design to evaluate an intervention is the double-blind placebo-controlled crossover, and that no other type of research design should be deemed as real evidence. In this type of design, one group receives a treatment, and the second receives a placebo or no treatment. After a certain amount of time, the group who initially received the treatment is given the placebo or the treatment is withdrawn; and the group who initially received the placebo/no treatment is given the treatment. This is a rather simple and straightforward experimental design.

Dr. Rimland and I always felt the double-blind crossover design was often inappropriate to study treatment efficacy in autism. One reason is the heterogeneous nature of the autism population. Basically, this type of design relies on group differences to conclude whether or not an intervention is valid. For example, if 20 individuals receive a treatment and only three or four individuals truly benefit, the results will likely be statistically insignificant.

A second reason is that the crossover portion of the procedure is not suitable for some, possibly many, interventions because participants do not necessarily lose the benefits they gained from the treatment condition. That is, the behavior of the group that receives the treatment first may not deteriorate during the second phase of the study. A prime example would be ABA. In addition, there are ethical concerns regarding the withdrawal of a treatment after it has clearly improved a person's quality of life.

Assessing Treatment Efficacy Using Appropriate Research Designs

There are numerous objective and accepted experimental designs in the field of behavioral science. Prior to his passing, Dr. Ted Carr (a pioneer in behavior modification and functional communication) and I would discuss ways to scientifically document improvement as a result of biomedical intervention. We both agreed that single subject designs were most appropriate because they essentially take into account differences between individuals.

Single subject designs allow individuals to serve as their own controls in research, thus, respecting the heterogeneity of the autistic population. In addition, these designs can be used to measure changes in behavior across various settings to ensure that generalization has occurred and to determine the amount of time that leads to generalization. Single subject designs can also be used to evaluate the impact of different interventions on an individual while providing an objective method for researchers who do not have access to large groups of individuals to study. Finally, the results of a series of single subject designs can be combined with other measures to determine the impact of treatments among a larger group. Single subject designs are robust --- they meet the standards for rigor: internal and external validity, control, replication, causal relationships, and ethical concerns.

Assessment of Treatment Efficacy Using Diagnostic Instruments

For many years researchers relied primarily on diagnostic evaluation tools to determine whether or not a treatment was effective. At one time, Dr. Rimland and I contacted the authors of the popular autism diagnostic tools; all stated that their assessments were valid and reliable for diagnosis, but there was no evidence that they were also valid and reliable to measure treatment efficacy. That is, these diagnostic instruments were not designed to measure treatment effectiveness. Fortunately, just in the past few years I have noticed that researchers have begun using more appropriate methods to evaluate interventions, often using the Aberrant Behavior Checklist, the PDD Behavior Inventory, among others.

Dr. Rimland and I developed a checklist to assess behavioral change, called the Autism Treatment Evaluation Checklist or ATEC. The ATEC evaluates four major areas including Speech/Language, Sociability, Cognitive/Sensory Awareness, and Health/Physical/Behavior. Many professionals, including researchers, physicians, and therapists, as well as parents, use the ATEC to monitor progress. Split-half reliability tests on the ATEC are very encouraging, and several published studies have shown the ATEC to be effective in assessing behavioral change. However, more research is needed to evaluate both the ATEC's validity and reliability.

Comment on New Interventions

The Internet and support groups, where new treatments are often shared and discussed, are seen as valuable resources for families and even clinicians. Due to the fact that they are new treatments, in most cases there is little or no research to support them. Some families choose to try the intervention because there is an urgent need to help their children. They also know that there is no guarantee that the treatment will actually help. Some professionals take the perspective that no one on the autism spectrum should receive any treatment, no matter how harmless, until there is enough research evidence to show that the treatment is effective. Unfortunately, this process can take many years, and, given the heterogeneity of the population and how impact is measured, outcomes will likely be mixed.

ARI has always taken the approach that parents should receive complete information on the potential risks and benefits of all interventions, whether or not they are considered evidence-based. It is not appropriate to overstate to parents and family members the benefits of treatments that are not evidence-based. Similarly, professionals should not report that an intervention is successful when studies provide, at most, indirect support. On the other hand, severe side-effects of evidence-based, FDA-approved treatments, such as Risperdal, are often not shared with parents, nor are they made public.

We need to take Dr. Rimland's lead. He would often say "Just tell them the truth."

Note: ARI has established a webpage to inform parents of possible side effects, including seizures, associated with drugs. You can find the link on ARI's homepage, www.autism.com.

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