



Making Sense of Autism Treatment Research

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*Invited Tutorial, Autism Program, Association for
Behavior Analysis Convention, May 2003*

Overview

- Reasons to evaluate claims about autism treatments skeptically and scientifically
 - How to differentiate good science from “voodoo science”
 - Examples in autism treatment
 - Current status of evidence about popular treatments for autism
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Reasons to evaluate claims about autism treatments skeptically and scientifically

- We humans are extraordinarily easy to fool.
 - Hope and the desire to help can make us vulnerable to false or exaggerated claims. (We want to believe).
 - There are a multitude of treatments for autism. All are claimed to be effective by *someone*, many remarkably so. It does not stand to reason that all treatments are comparably effective.
 - Some treatments *appear* to work, especially when viewed through the eyes of wishful beholders.
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Reasons for skepticism and science (cont'd)

- The most tried-and-true way to separate illusions and wishful thinking from real effectiveness is to subject treatments to careful scientific evaluation.
 - The alternative is to base decisions about autism treatments on speculations, beliefs, and superstitions. History has shown this to be extremely costly and harmful.
 - We can't afford to continue wasting time, effort, and money on ineffective, unproved, and implausible treatments.
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Differentiating good science from “voodoo science”

- Science (in a nutshell):
 - Direct, systematic testing of hunches and ideas (hypotheses) using specific tools of quantification, experimentation, logic
 - Independent, public verification of phenomena
 - Self-critical, self-correcting (e.g., through professional peer review)
- “Voodoo science” (Park, 2000)
 - Pseudoscience -- superstitions, beliefs, opinions “dressed up” to resemble science (e.g., with scientific terminology, numbers, graphs), but no objective evidence from sound, peer-reviewed studies
 - Junk science -- “Tortured theories of what could be so, little evidence to prove that it is so”
 - Pathological science -- scientists fool themselves
 - Fraudulent science

Tools for evaluating claims about treatments

- The task: For each claim, determine the quality of the evidence that supports it.
- All research is not created equal; some types of studies produce more credible evidence than others. (Data are only as good as the *methods* used to produce them).
 - Main questions to ask about treatment research: Was there really an effect? If so, was it due to the particular treatment, or something else?
- Some important discriminations:
 - Demonstration
 - Actual direct testing; facts
 - vs.
 - Speculation
 - “I think it works;” opinions, hunches, theories

More discriminations

■ Objective evidence

- Treatment and its effects defined in terms that are specific, observable, measurable (operational definitions)
- Treatment effects measured by instruments or multiple independent observers
- Controls for natural human biases (e.g., independent, “blind” evaluators/observers)

vs.

■ Subjective evidence

- Anecdotes, testimonials, personal accounts, many case reports
- Treatment and effects often described in vague terms
- Subject to bias, inconsistency; notoriously unreliable
- NOTE: “Data” recorded by teachers, tutors, parents, researchers without operational definitions, specific scoring criteria, and periodic checks by independent observers are essentially anecdotal reports

Discriminations (cont'd)

- Direct measurement
 - Effects of treatment measured directly with person(s) receiving treatment (e.g., behavioral observations, medical tests)
 - For claims to be convincing, measures of treatment effects must also be valid (true), accurate (little error), and reliable (consistent)

vs.

- Indirect measurement
 - Third-party reports about perceived effects of treatment (e.g., questionnaires, surveys, interviews completed by persons other than those receiving the treatment)
 - Often unreliable and inaccurate

Discriminations (cont'd)

- Experimental (controlled) research
 - Explicitly and systematically arranges to make potential causal event(s) present and absent (e.g., treatment vs. no treatment) while measuring in both conditions to see if change occurs
 - Allows alternative explanations for apparent treatment effects to be ruled out (e.g., maturation, factors outside experiment, practice, repeated testing), so one can be reasonably confident that effects were produced by the treatment

vs.

- Descriptive (uncontrolled) research
 - Paints a picture of what is (or appears to be) occurring
 - Starting point of all research, but no controls for alternative explanations, so cannot conclude that treatment was responsible for apparent effects
 - Observational studies, qualitative research, much developmental research, clinical case studies

Example: Facilitated Communication (FC)

- Claims: “Breakthrough” communication method that enables scores of people with severe communication impairments to reveal previously hidden communication, literacy, and other skills
 - Based on
 - uncontrolled observations, anecdotes, testimonials, qualitative studies
 - *speculation* that autism and related disorders are primarily neuromotor disorders (“apraxia,” “dyspraxia”); contradicts numerous facts about autism and behavior
 - Some alternative explanations:
 - Facilitators, not people with disabilities, control the spelling
 - Facilitators interpret strings of letters as words, phrases, sentences (observer bias)
 - People with disabilities had some reading and spelling skills before FC

FC: Some scientific testing methods

- Prevent facilitators from seeing letter display
 - Provide different information to facilitators and their partners, then ask for “facilitated” responses to questions
 - Measure reading, spelling, and typing skills without FC
 - Establish criteria in advance for determining if strings of letters are words, and if they are accurate responses to questions; have independent observers (not facilitators) evaluate responses
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Example: Sensorimotor therapies (sensory integration, patterning, etc.)

■ Claims:

- Special types of stimulation are required to help brain “integrate” sensory input
- Engaging in sensorimotor activities fixes faulty brain wiring, produces improvements in social, communication, academic, and other skills as well as reductions in aberrant behavior
 - Based on
 - uncontrolled clinical observations, uncontrolled or poorly controlled studies
 - *speculations* about how the brain works that contradict facts about brain function, and about behavior

Sensorimotor therapies (cont'd)

- Some alternative explanations:
 - Behavioral improvements do not actually occur (observer bias)
 - Improvements (if real) are due to individual attention, absence of demands, pleasurable activities rather than the “therapy” per se
 - Improvements (if real) are actually due to other ongoing interventions
 - Some scientific testing methods:
 - Define behaviors operationally, measure them objectively over course of treatment (especially outside of therapy sessions)
 - Measure effects of 1-to-1 attention, no demands, activities per se
 - Compare effects of therapy alone with no treatment, other types of treatment
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Example: Secretin

- Claims: Injections of hormone that stimulates pancreas produce improvements in gastrointestinal functioning as well as social, communication, academic, and toileting skills in children with autism
 - Based on
 - 3 uncontrolled case studies (initially), clinical observations, anecdotes, testimonials
 - *speculations* about “gut-brain” connection (GI problems cause abnormal brain development/functioning)
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Secretin (cont'd)

- Some alternative explanations:
 - Children in initial case studies did not actually have autism, GI problems
 - Improvements did not actually occur
 - Improvements, if real, were due to other interventions children were experiencing (e.g., intensive ABA)
 - Some scientific testing methods:
 - Define alleged behavioral and physiological effects operationally, measure them objectively before and after secretin injections
 - Compare effects of secretin with placebo (sugar pill), using double-blind procedures
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Example: Withholding vaccinations

- Claims: There is an “epidemic” of autism, caused largely by the MMR and other vaccines
 - Based on
 - Methodologically weak clinical reports from Wakefield and colleagues in UK of children said to have “PDDs” and gastrointestinal problems, plus anecdotes and testimonials
 - Methodologically weak studies reporting large increases in numbers of cases of autism in recent years
 - *Speculation* that MMR vaccine causes GI problems, which in turn cause a regressive variant of autism; contradicts strong scientific evidence of *no link* between vaccines and autism

Vaccines (cont'd)

- Some alternative explanations:
 - Wakefield's samples did not actually have "regressive" autism (i.e., if they had autism, characteristics were present *before* they received MMR vaccine), were not representative of autistic population
 - GI problems, if real, are not strongly associated with either vaccination or autism
 - Reported increases in # of cases of autism are attributable to broadening of diagnostic criteria, diagnostic and reporting practices, earlier identification, increased public awareness, methodological problems in studies, political and social pressures rather than actual increase in the disorder

Vaccines/"epidemic:" Some scientific testing methods (Fombonne, 2000,2002, 2003)

- Examine incidence rates (proportion of cases) of GI problems and autism before and after widespread immunization, or in vaccinated vs. unvaccinated children
 - Measure GI problems, onset and nature of autistic characteristics directly and objectively (rather than using retrospective record reviews, anecdotal reports, clinical impressions)
 - Measure incidence of autism over time in studies that
 - Use standard, consistent case-finding methods (not referral statistics, e.g., children referred for public services)
 - Use large and representative samples
 - Take into account changes in underlying population and in diagnostic and reporting practices (affecting autism as well as other disorders, such as MR)
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Vaccines: Final remarks

- Effects of withholding vaccinations are well-documented and serious, they include deaths and developmental problems
- Several large, well-controlled studies have found *no associations* among MMR vaccine, GI problems, and autism
- The MMR-autism controversy has consumed enormous resources, created major public health problem
- “It is now hoped that more attention will be given by reviewers, editors, and researchers to basic methodological flaws in the articles that allowed the MMR-autism controversy to expand” (Fombonne & Cook, 2003)
- “Although claims about an epidemic of autism and about its putative causes have the most weak empirical support, the subsequent controversy has put autism on the public agenda...what has triggered substantial social policy changes in autism appears to have little connection with the state of the science” (Fombonne, 2003).

The quality of the current evidence about autism treatments

- *Little or no scientific testing:* special diets, Vitamin A, cod liver oil, chelation therapy, detoxification, Options, Whole Life Therapy (Higashi), touch therapy, deep pressure therapy, music therapy, animal therapy, holding therapy, water therapy, visual integration therapy, Irlen lenses, Rhythmic Entrainment Intervention, craniosacral manipulation, play therapy, “Floor Time,” Giant Steps, Gentle Teaching, Fast ForWord, “rapid prompting,” most OT techniques, antifungal medications, hormones, many psychotropic medications, neurosurgery
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Evidence about autism treatments (cont'd)

- *Found ineffective in scientific studies:* Vitamin B, DMG, patterning (Doman-Delacato), sensory integration therapy, secretin, typical early intervention/special education
 - *Found harmful in scientific studies:* Facilitated Communication, auditory integration training, intravenous immune globulin, withholding vaccinations
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Evidence about autism treatments (cont'd)

- *Limited scientific testing/limited effectiveness:* TEACCH, developmental approaches, nonintensive and “naturalistic” behavior analytic models, some drugs for specific aberrant behaviors (e.g., risperidone)
 - *Substantial scientific evidence of effectiveness:* Applied behavior analysis (specific procedures for developing specific skills and reducing specific aberrant behaviors, as well as comprehensive “packages”)
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Summary and recommendations

- “Voodoo science” is not benign; it is costly and harmful.
- It pays to apply the tools of skepticism and critical thinking to *all* claims about autism treatments (including those made by behavior analysts).
- Remember two maxims:
 - “If it sounds too good to be true, it probably is.”
 - “Extraordinary claims require extraordinary evidence.”
- No less than people with other disorders, people with autism deserve effective, scientifically validated treatment. That will occur only if consumers as well as professionals demand good science and reject “voodoo science.”

Some Web sources of scientifically sound info about autism treatments:

- Cambridge Center for Behavioral Studies --
www.behavior.org/autism
 - NY Dept. of Health Early Intervention Program --
www.health.state.ny.us/nysdoh/eip/index.htm
 - Autism Biomedical Information Network --
[www. autism-biomed.org](http://www.autism-biomed.org)
 - Association for Science in Autism Treatment --
www.asatonline.org
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