Pseudoscience in Autism Treatment: Recommendations for Parents and Practitioners

Oliver Wendt, Ph.D.
Speech, Language, and Hearing Sciences, & Educational Studies
Purdue University

Sponsored by
University of Florida - Jacksonville
Division of Developmental Pediatrics
Center for Autism and Related Disabilities, June 2015

Dolphin Assisted Therapy (DAT)

“What do you think about the validity of this technique?”

⇒ This is an example of Pseudoscience!

DAT: Is There Evidence?

- Critical reviews show lack of carefully designed studies, lack of efficacy
  - Marino & Lilienfeld (1998; 2007)
- Despite widespread popularity no studies specific to Autism Spectrum Disorders (ASD)
  - Hewitt (2008)

Check out Newsletter for ASHA Division 1 Affiliates

One Newer Review

- Title: Dolphin assisted therapy: Can swimming with dolphins be a suitable treatment?
- Author: Williamson, C.; Whale & Dolphin Conservation Society, UK
- Abstract: Offered as a cure or respite from human illness or disability, proponents of Dolphin Assisted Therapy (DAT) claim it can be used to treat a whole range of physical and psychological conditions, including clinical depression, speech development, Down syndrome, autism, blindness, AIDS, and cancer. Yet there is no ‘industry standard’ to set criteria for what constitutes DAT and there is no official regulation of the practice, such that the market has opened up for DAT programmes and facilities to proliferate across the globe with relative ease. Wild DAT interactions tend to be less structured and consist largely of swimming with dolphins in their natural environment. It is essential that in any Animal Assisted Therapy programme, the health and welfare of both the humans and the animals involved are the primary considerations. We suggest that DAT is not only ineffective as a therapeutic intervention, but could be harmful to both parties. (PsycINFO Database Record © 2009 APA, all rights reserved)
### DAT and Pseudoscience

- All positive reports located in Hewitt review were from one journal (*Anthrozoos*)
- Idea has “cute” factor
- Appeals to idea that animals can provide miraculous experiences
- Theoretical basis is vague
- Prescribed for a huge range of problems

### Diagnoses for which a DAT Center Prescribed Their Therapy

<table>
<thead>
<tr>
<th>Diagnosis</th>
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<tbody>
<tr>
<td>ADHD (Attention Deficit Hyperactivity Disorder)</td>
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<tr>
<td>Agnogenic of corpus Callosum</td>
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<tr>
<td>Angelman Syndrome</td>
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<td>Anechla</td>
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<td>Aphasia</td>
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<td>Autism</td>
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<td>Behavioral Disorder</td>
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<tr>
<td>Cerebral Palsy</td>
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<tr>
<td>Chromosomal Disorder</td>
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<tr>
<td>Congenital Microphthalm</td>
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<td>Crouzen Syndrome</td>
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<tr>
<td>Depression</td>
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<td>Down Syndrome</td>
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<td>Dyspraxia</td>
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<td>Dyslexia</td>
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<td>Dyspepsia</td>
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<tr>
<td>Epilepsy</td>
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<tr>
<td>Focaln Aseia</td>
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<tr>
<td>Gilles de la Tourette Syndrome</td>
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<tr>
<td>Incontinence Pigment</td>
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<td>Krabbelet Disease</td>
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<tr>
<td>Landau-Kleffner Syndrome</td>
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<tr>
<td>Mental Retardation</td>
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<tr>
<td>Mucopolysaccharidosis</td>
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<tr>
<td>Myelodysplastic Syndrome</td>
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<tr>
<td>Optic Atrophy</td>
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<td>Othhlave Syndrome</td>
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<tr>
<td>Paraplegia</td>
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<tr>
<td>Progressive myoklonic Epilepsy</td>
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<tr>
<td>Quatrophage</td>
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<td>Rett Syndrome</td>
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<td>Rett Syndrome</td>
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<td>Ring Chromosome 22</td>
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<td>Schizophrenpy</td>
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<td>Tay-Sachs Syndrome</td>
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<td>Waller Syndrome</td>
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<td>Wahr-Neuhuthen Syndrome</td>
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<tr>
<td>Taur Syndrome</td>
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<tr>
<td>Trisomy 22</td>
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<tr>
<td>Posttraumatic Stress Syndrome</td>
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</tbody>
</table>

### Other Pseudoscientific Aspects

- Lots of for profit centers
  - Some capture wild dolphins for this purpose
  - Marine mammal experts oppose DAT for this reason

### Other Pseudoscientific Aspects (Cont.)

- Exaggerated claims based on testimonials:
  - *The benefits of Dolphin Therapy*
    - Swimming with dolphins creates an effect that gives joy and peace of mind, enhances the immune system, improves awareness, attention and self-control and develops feelings of compassion and self-confidence. As the interest and curiosity for the outside world expands, the capacity to benefit from interpersonal relations improves radically.
    - Consequently, patients who receive ergotherapy, logopedy or physiotherapy will benefit from these treatments much faster and more thoroughly.
    - After the dolphin therapy, disabled children build a capacity to learn faster; in one or two months, they can acquire the knowledge and physical skills that will normally take them a year to learn. Dolphin therapy accelerates the learning process two to ten times the normal rate, and this improvement will be effective from six months up to a year.
    - It has been observed that a six-year-old autistic child went through the dolphin therapy and received special tutoring and therapies for a year; he got rid of all autistic symptoms and when he came back for the dolphin therapy the following year, no autistic traits were observed.* [http://www.dolphintherapy.eu/en/](http://www.dolphintherapy.eu/en/)

### Pseudoscience

“A pretended or spurious science; a collection of related beliefs about the world mistakenly regarded as being based on scientific method or as having the status that scientific truths now have” (Simpson & Weiner, 1989, p. 1)

- Pseudoscientific treatment claims
  - Appear to be, but are not, objective, empirically based, and rooted in the larger methods of science
  - Antithetical to the purposes of a true evidence-based clinical service discipline such as speech-language pathology
  - Deserve careful scrutiny

### Autism and Pseudoscience

- Autism: ripe ground for unsubstantiated claims
  - No obvious physical differences
  - Developmental trajectory very individual
  - A child could make spontaneous large gains for no known reason
Characteristics of Science and Pseudoscience

**Objective**
- Based on systematic methods that involve hypothesis testing, systematic observations, and verification

**Subjective**
- Often scientific (i.e., uses terms that make events appear scientific but there is in fact no evidence)

**Productive**
- Evolving process
- Progress depends on an accumulated growth of knowledge over time, during which useful features are retained and non-useful features are discarded

**Not Productive**
- Knowledge does not change
- Moribund state of knowledge based on age-old traditions

Why Can Pseudoscience Be Harmful?

Three major ways in which pseudoscientific treatments can be problematic:

1. Treatment harmful per se, e.g., 10-year-old Colorado girl smothered to death by rebirthing therapy (Mercer, Sarner, & Rosa, 2003).
2. Treatments that themselves are innocuous can indirectly produce harm by depriving individuals of scarce time, financial resources or both.
3. Use of unsubstantiated treatments undermines scientific foundations of the profession. (Lilienfeld, Lynn, & Lohr, 2003)

Characteristics of Science

- Hypothesis generation and testing
- (Usually) slow accumulation of evidence
  - Rarely "proof"
- Often studies produce conflicting results
  - Why?
    - Design
    - Interpretation
    - Variability of phenomenon
  - (Rarely, we hope) scientific fraud

Key Aspects of Science

- For science:
  - Importance of theory
  - Trustworthy methods
    - For domain of study
  - Systematicity
    - See: Some Notes on the Nature of Science
  - For research:
    - Inquiry itself is research
    - Becomes scientific by the nature of the research carried out

Distinguishing Between Science and Pseudoscience

- Clinicians must differentiate between scientific and pseudoscientific claims to treatment efficacy
- Look for warning signs
  - Untestable
  - Unchanged
  - Confirming evidence
  - Anecdotal evidence
  - Inadequate evidence
  - Avoiding peer review
- Disconnected
  - New terms
  - Grandiose outcomes
  - Holistic

(Finn, Bothe, & Bramlett, 2005)
Is the Treatment Unable To Be Tested Or Disproved?

- Pseudoscientific approaches may be vague or circumspect, making it difficult to think of a method to test them.
- If no tests can be made, a treatment’s credibility relies on the developer’s assertions.
- Proponents may ignore findings that raise doubts about the treatment or ad hoc hypotheses may be derived to deflect concerns.
  - “One size does not fit all” claim.

Does Tx Remain Unchanged Even In the Face of Contradiction?

- The goal of science is to determine what is true.
  - Disconfirming evidence should be used to correct mistakes, reduce errors, and eliminate ineffective treatments.
- Pseudoscientific approaches are rarely tested.
  - Errors are not self-corrected.
  - New findings are not incorporated.
  - Approach remains founded on conviction and trust in theories, not facts.

Is the Rationale for the Tx Based Only on Confirming Evidence?

- Supporting evidence increases the credibility of a claim especially when replicated by different researchers.
- However, truth is only demonstrated by eliminating the possibility that the claim is false.
- Pseudoscience is usually based on confirming evidence alone because negative evidence is ignored, discredited, or difficult to find.

Does Supporting Evidence Rely on Personal Experience or Anecdotes?

- Case studies can be a source of new hypotheses and provide a basis for developing therapy techniques, but that basis is weak.
  - Highly selective.
  - Susceptible to bias.
  - Lack of experimental controls.
- A scientific approach requires that change be documented with objective measures, experimental controls, and replication of findings.
- Pseudoscience depends primarily on case studies, testimonials, and personal experience.

Are Claims Incommensurate With the Level of Evidence Needed?

- Scientists must provide evidence to support their claims.
  - Scientific demonstrations should follow a phased model with each level addressing a different question.
  - Credibility should be based on the findings from each level of evidence.
- Pseudoscientists may not provide sufficient evidence for their claims, and insist that it is the role of their critics to prove them wrong.
  - May require others to believe them on the basis of their personal authority.

Is the Tx Unsupported by Evidence that Has Undergone Scrutiny?

- Scientists submit their research to peer-reviewed journals.
  - Peer review involves critical examination of pertinence, importance, clarity, and scientific credibility by experts in the field.
  - This process helps to ensure the integrity of scientific literature.
- Pseudoscientists disseminate information in other ways.
  - Direct presentation to the public.
Is the Tx Approach Disconnected from Established Scientific Models?
- Scientific claims are usually consistent with current treatment paradigms for a given disorder
  - Differences typically involve improvements or changes to current models, not entirely new approaches
- Pseudoscientific claims are usually not consistent with established paradigms and have little evidence to support them
  - These new paradigms may appear exciting, revolutionary, and more compelling

Is the Tx Described by Terms that Only Appear Scientific?
- Scientific terms are precisely defined, operationalized, and linked to observable, measurable events
  - These terms may be tested by anyone who can carry out the same procedures
  - Some scientific terms are similar to words used in everyday language, while others appear obtuse
- Pseudoscientific terms lack consistent operationalization and are not easily observable or measurable
  - They may appear obtuse to avoid careful scrutiny and to hide their lack of meaning

Is the Tx Approach Based on Grand Claims or Unspecified Outcomes?
- Scientists carefully specify the conditions under which a treatment can be studied
  - Predictions are based on groups, likelihoods, or probabilities with the remaining uncertainty always acknowledged
- Pseudoscientists are less likely to recognize limitations in their predictions
  - Claims are often designed to appeal to emotions and to raise false hopes

Is the Tx Claimed to Be Holistic in Nature?
- Scientists are precise and search for the reasons for a treatment's effectiveness
  - This leads to a more thorough examination of characteristics of the disorder or components of the treatment, and it may appear that they have lost sight of the bigger picture
- Pseudoscience claims that a disorder can only be understood in a larger context
  - Such a claim may appease the general public, but results in a vague approach to the problem and unspecified interactions between biological, behavioral, and social systems

Exercise: Facilitated Communication
- Watch video clip and apply the ten criteria of pseudoscience!

Which Criteria Are Fulfilled?
1. Untestable: YES
2. Unchanged: YES
3. Only Confirming Evidence: YES
4. Mostly Anecdotal Evidence: YES
5. Inadequate Evidence: YES
6. Avoiding Peer Review: NO
7. Disconnected: YES
8. New Terms: NO
9. Grandiose Outcome: YES
10. Holistic: YES
Pseudoscience Criteria Applied to Facilitated Communication

TABLE 3. Pseudoscience criteria at issue in existing controversy about facilitated communication, by consensus among three judges.

<table>
<thead>
<tr>
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<th>At issue</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Untestable</td>
<td>Yes</td>
</tr>
<tr>
<td>2. Unchanged</td>
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</tr>
<tr>
<td>3. Confirming evidence</td>
<td>Yes</td>
</tr>
<tr>
<td>4. Anecdotal evidence</td>
<td>Yes</td>
</tr>
<tr>
<td>5. Inadequate evidence</td>
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</tr>
<tr>
<td>6. Avoiding peer review</td>
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<td>10. Holistic</td>
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And You Thought FC Was Gone …?

Some (not all!) current FC movements:
- FC-loving Nancy Lurie Marks Foundation gave $29 Mio. to FC-promoter Margaret Bauman’s outfit at Massachusetts General Hospital.
- The Syracuse “Inclusion Institutes,” which includes the FC Institute just received $1 million.
- U.S. Department of Justice in its manual for interviewing victims with communication disabilities/cognitive disorders endorses FC.
- Recently a Michigan man spent 80 days in jail, his whole family falsely accused of rape through FC (Todd, 2009)
- “There have been many more imprisonments due to false facilitated allegations of rape than there have been objective demonstrations of successful FC”  
  (Todd, 2009, personal communication)

FC Continues to Grow …

- Bill being proposed in Massachusetts mandating FC training  
  http://www.metrowestdailynews.com/state/x42388429/Bill-would-make-it-easier-on-students-who-cannot-hear
- State of CO sponsors FC training through its Developmental Disabilities Council, see  
  http://www.wowcolorado.org/
- Intellectual and Developmental Disabilities published non-experimental Pro-FC article in 2009, without questioning (Tuzzi, 2009)

FC Continues to Grow … (Cont.)

- FC in disguise:  
  http://savedbytyping.com
  “How supported typing has helped our family”
  “Participants will learn to recognize the brain-body disconnect experienced by many individuals on the autism spectrum and the neurologic music therapy techniques that can and do make a difference.”
  ⇒ Only a few of current ongoing activities!

Find Recent Evidence

- Special Issue on FC by Evidence-Based Communication Assessment and Intervention Journal, Vol. 6, Issue 1, 2012  
- For example:
  - Boynton, J. “Facilitated Communication – what harm can it do: Confessions of a former facilitator”  
  - Palfreman, J. “The dark legacy of FC”  
  - Mostert, M. “Facilitated Communication: The empirical imperative to prevent further professional malpractice”  
  - International Society for Augmentative and Alternative Communication (ISAAC) – Position Statement  

Exercise: Rapid Prompting Method

Watch video clip and apply the ten criteria of pseudoscience!
Rapid Prompting Method (RPM) Summary

- Aka “Informative Pointing”
- Promoted through the media and workshops as a "revolutionary" new intervention for establishing pointing- and writing-based communication in people who are otherwise non-verbal.
- Putative communicator is taught to respond directly to subtle non-physical prompts and matching cues provided by the facilitator rather than being manually guided.
- Authorship validation, ongoing data collection, and other controls are vigorously avoided and discouraged. But, because the students' responses are typically made without physical contact with the facilitator, they appear to be more genuinely independent than the manually guided responses of FC.

Methodological shortcomings

Introductory textbook-level conceptual foundations

Complete lack of empirical support


Which Criteria Are Fulfilled?

1. Untestable | YES
2. Unchanged | YES
3. Only Confirming Evidence | YES
4. Mostly Anecdotal Evidence | YES
5. Inadequate Evidence | YES
6. Avoiding Peer Review | YES
7. Disconnected | ☒ NO
8. New Terms | ☒ NO
9. Grandiose Outcome | YES
10. Holistic | ☒ NO

Pseudoscience Criteria Applied to Rapid Prompting

Lesson learned:

- Distinguishing science from pseudoscience is not a dichotomous decision and involves a continuum, that is, the difference is in degree rather than in kind (Herbert, Sharp, & Gaudiano, 2002)

Recent Conclusions on Rapid Prompting

- “…participants receiving RPM become dependent on facilitator prompts and therefore only seem to communicate. In other words, RPM facilitators generate and subsequently prompt participants to convey messages that may not represent the individual’s genuine desires, thoughts, or emotions.”
  Lang, Tostanoski, Travers, & Todd, 2014

Another Pseudoscience Example: Fast ForWord

Gillam et al., 2008 Study

- Conclusion: Fast ForWord Language, the intervention that provided modified speech to address a hypothesized underlying auditory processing deficit, was not more effective at improving general language skills or temporal processing skills than a nonspecific comparison treatment (AE) or specific language intervention comparison treatments (CALI and ILI) that did not contain modified speech stimuli.
Pseudoscience Criteria Applied to Fast ForWord

TABLE 2. Pseudoscience criteria at issue in existing controversy about Fast ForWord, by consensus among three judges.

<table>
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</tr>
<tr>
<td>3. Confirming evidence</td>
<td>Yes</td>
</tr>
<tr>
<td>4. Unreliable evidence</td>
<td>Yes</td>
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<tr>
<td>5. Inadequate evidence</td>
<td>Yes</td>
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<tr>
<td>6. Avoiding peer review</td>
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<td>7. Disconnected</td>
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Pseudoscience versus Evidence-based Practice

- Information about the nature and treatment of disorders should be developed through research and other empirically based activities
- Not through other possible ways of knowing (e.g., faith, authority, or introspection)
- Conclusions about communication processes should be derived from and supported by scientific evidence
- Assessment and treatment methods should be evaluated by empirical methods
- Emphasis on research or evidence-based practice (EBP)

Evidence-based Practice (Overview)

- Emphasis on data-based decision making
- Grounded in solid treatment efficacy research
- Practitioners need to evaluate the research evidence
- Differentiate high from low quality research

A Schematic of the EBP Process

1. Developing a well-built question
2. Selecting evidence sources and executing the search strategy
3. Examining and synthesizing the evidence
   - Discard pseudoscientific reports, sort out low quality from high quality research
4. Applying the evidence
5. Evaluating the application of the evidence
6. Disseminating the findings

Assessing the Evidence: Individual Studies (ASHA, 2005)

- Publication of a study in a peer-review scientific journal is not a guarantee of quality.
- Assess along two dimensions: level of evidence and study quality. Level of evidence refers to the establishment of a hierarchy of study designs based on the ability of the design to protect against bias.
- No one universally accepted hierarchy, randomized controlled trials (RCTs) are considered to be the design least susceptible to bias, and various hierarchies follow from there through observational studies and non-experimental designs. The following are examples of hierarchies of levels of evidence:

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
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<tbody>
<tr>
<td>Ia</td>
<td>Well-designed meta-analysis of &gt; 1 randomized controlled trial</td>
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<tr>
<td>Ib</td>
<td>Well-designed randomized controlled study</td>
</tr>
<tr>
<td>IIA</td>
<td>Well-designed controlled study without randomization</td>
</tr>
<tr>
<td>IIb</td>
<td>Well-designed quasi-experimental study</td>
</tr>
<tr>
<td>III</td>
<td>Well-designed non-experimental studies, i.e., correlational and case studies</td>
</tr>
<tr>
<td>IV</td>
<td>Expert committee report, consensus conference, clinical experience of respected authorities</td>
</tr>
</tbody>
</table>
Hierarchy of Levels of Evidence
Augmentative & Alternative Comm.

1. Meta-analysis of (a) single-subject experimental designs, (b) non RCTs
2a. One well-designed non RCT
2b. One single-subject experimental design – one intervention
2c. One single-subject experimental design – multiple interventions
3. Quantitative reviews that are non meta-analytic
4. Narrative reviews
5. Pre-experimental group designs and single-case studies
6. Respectable opinion

adapted from Schlosser, 2003

Value of Systematic Reviews

- Clinicians can save considerable time and rely on someone else’s expertise when they are provided with access to pre-filtered evidence.
- Pre-filtered evidence is established when someone with expertise in a substantive area has reviewed and presented the methodologically strongest data in the field (Guyatt & Rennie, 2002).
- Systematic reviews are considered one source that provides pre-filtered evidence.

Current Treatment Evidence Base in Autism Spectrum Disorders

- Lots of anecdotes and speculations, little or no scientific data: special diets, Vitamin A, cod liver oil, chelation, detoxification, Gold Salts, marijuana, Options, Whole Life Therapy (Higashi), touch therapy, deep pressure therapy, music therapy, art therapy, animal therapy, holding therapy, water therapy, visual integration therapy, metronome therapy, Irin lenses, Rhythmic Entrainment Intervention, craniosacral manipulation, play therapy, “Floor Time” (DIR), Giant Steps, Gentle Teaching, Fast ForWord, “rapid prompting,” Relationship Development Intervention, SCERTS, many OT techniques, antifungal medications, neurosurgery, fatty acids, etc. (Green, 2008)

Current Treatment Evidence Base in ASD (Cont.)

- Limited scientific testing: TEACCH, developmental approaches, “social stories,” PECS, several comprehensive ABA models (e.g., CABAS, Pyramid, Applied Verbal Behavior, Competent Learner Model, incidental teaching and other “naturalistic” models, LEAP), fluency training, some psychoactive drugs (but must have negative side effects)
- Substantial scientific evidence of effectiveness: Many (but not all) applied behavior analysis techniques and “packages,” early intensive applied behavior analysis (Green, 2008)

Current Treatment Evidence Base in ASD (Cont.)

- Found ineffective in scientific studies: Vitamin B, DMG, patterning (Doman-Delacato), sensory integration and other sensorimotor therapies, secretin, “eclectic” treatment, typical early intervention/special education
- Found harmful in scientific studies: Facilitated Communication, auditory integration training, intravenous immune globulin, withholding vaccinations (Green, 2008)

Sources When Seeking for Treatment Evidence

- Evidence-based practice journals
- Organizations and associations devoted to promoting EBP
- www.winginstitute.org
Evidence-based Communication Assessment and Intervention
- Selects and appraises the latest and highest quality studies and reviews related to
  - Assessment, intervention, diagnosis, and prognosis published across 60+ professional journals in speech-language pathology and related fields
  - Full peer review
  - Published by Informa Healthcare

Evidence-based Practice Briefs
- Seeks to answer some of the biggest questions of clinical daily activities, supported with evidence and written practically and efficiently by leaders in speech-language pathology and related disciplines.
  - Full peer review
  - Electronic and paper format in addition to audio file (“Podcast”)
  - Published by Pearson

ASHA Compendium of EBP Guidelines and Systematic Reviews
- ASHA’s National Center for Evidence-Based Practice in Communication Disorders (N-CEP):
  - Project to identify and obtain clinical practice guidelines from all over the world related to audiology and/or speech-language pathology
  - Whenever possible, clinical practice guidelines were tied directly to a systematic review of scientific evidence
  - Check out: http://www.asha.org/members/ebp/compendium/

The National Professional Development Center on ASD
- Goals: Promote optimal development and learning of infants, children, and youth with ASD and provide support to their families through the use of evidence-based practices
  - Resources for families and professionals on evidence-based practices for individuals with ASD and on early identification
  - Professional development activities for 12 states that focus on evidence-based practices for ASD
  - Technical assistance to 12 state partners that focuses on evidence-based practices for ASD and on early identification and diagnosis of ASD
  - Check out: http://autismpd.fpg.unc.edu/

National Autism Center
- Goal: to establish a set of standards for effective, research-validated educational and behavioral interventions for children with ASD.
  - These standards identify treatments that effectively target the core ASD symptoms of ASD.
  - Resulting National Standards Report is the most comprehensive analysis available to date about treatments for children and adolescents with ASD.
  - Check out: http://www.nationalautismcenter.org/index.php

The Wing Institute
- Created to promote evidence-based education policies and practices, offers services including:
  - The Evidence-based Education Knowledge Network
  - Information Clearinghouse
  - Professional Forums
  - Publications
  - Research
  - Public Policy
- Grant support for graduate students
- New feature on its web site: “What do the data tell us?”
- Check out: http://www.winginstitute.org/
Pseudoscience in Autism Treatment

University of Florida - Jacksonville
June 16, 2015

Questions???

Contact Information

- Oliver Wendt, PhD
  Dept. of Speech, Language, and Hearing Sciences
  Purdue University, West Lafayette, IN 47907
  Phone: 765-494-2462
  E-mail: olli@purdue.edu

References

- Lang, R., Harrison Tostanoski, A., Travers, J., & Todd, J. (2014). The only study investigating the rapid prompting method has serious methodological flaws but data suggest the most likely outcome is prompt dependency. Evidence-Based Communication Assessment and Intervention, 8(1), 40-48.

References (Cont.)