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Defining Evidence-Based Practice for Practitioners and Parents of Young Children with Autism:

Answers to Ten Frequently Asked Questions

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### Abstract

This paper presents a set of guidelines and addresses unanswered questions to provide parents and practitioners with the tools needed to engage in evidence-based practice. Specifically, the answers to ten frequently asked questions about evidence-based practice for young children with autism are presented. The first three questions address the importance and history of the evidence-based practice movement in early childhood intervention. Derived from a synthesis of the research, a definition for evidence-based practice in early childhood intervention is provided in question number four. In questions five and six, scientifically-based research and levels of evidence are illustrated and explained in the context of early childhood intervention. Parents and practitioners can refer to questions seven through nine for information about current interventions for young children with autism and guidelines for identifying and choosing evidence-based interventions. The final question addresses how parents of children with autism and practitioners in early childhood intervention can keep moving toward an evidence-based practice model.

“Compassion without competence is pure sentimentality. Likewise, competence without compassion is nothing more than manipulation.”

- Dowd, 1994

1. Why are we talking about evidence-based practice?

The 2001 No Child Left Behind reform of the Elementary and Secondary Education Act emphasizes the use of scientifically-based research in public schools (Beghetto, 2003). Particularly, the law requires any federal grantees to use their federal funds on educational methods and strategies that have been “proven to work” through scientifically-based research (Feuer, Towne, & Shavelson, 2002; Odom et al., 2005). Many believe the required use of practices shown effective through scientifically-based research will greatly improve early childhood intervention (Green, 2008; Institute of Education Sciences, IES, 2003). Early childhood intervention is defined here as the services and supports provided to young children with disabilities from birth to age eight in the public sector. Given that there are systems in place in every state, early childhood intervention is the primary service for infants and preschool children with disabilities and their families in the U.S. (Odom & Wolery, 2003). A general concern has emerged that evidence-based practice is not being utilized. The U.S. Department of Education is being pressured by congress to prove that public funds should continue to support early childhood intervention practices (Odom et al., 2005). The latest push maintains that only if practices have evidence of effectiveness are they a good investment of public funds.

The current thrust for the use of evidence-based practice is heightened by the increase in the number of children identified with autism and needing early childhood intervention (Odom et al., 2003). Autism is defined here as a pervasive developmental disorder of unknown etiology that is present from birth and marked in early childhood by deficits in social, communication,

sensory, and cognitive abilities along with restricted, repetitive, and stereotyped patterns of behavior (Dillenberger, Keenan, Gallagher, & McElhinney, 2002; Herbert, Sharp, & Gaudiano, 2002; National Research Council, NRC, 2001; Stahmer, Collings, & Palinkas, 2005). It is not clear whether the prevalence of children born with autism is increasing or if the recognition and diagnosis of the disorder has widened, but nevertheless, the number of children with autism in early childhood intervention has grown (Herbert et al., 2002; Odom et al., 2003). The last decade has demonstrated a more than 500% increase in the number of children diagnosed with autism and served under the Individuals with Disabilities Education Act (IDEA, Stichter et al., 2006). Callahan, Henson, and Cowan (2008) found that evidence-based practice is being minimally attempted in the public sector causing inadequate and ineffective autism programming. Given the escalating diagnosis and desperate need for high quality service provision, the evidence-based practice discussion appears suitable and timely.

## 2. Where did evidence-based practice originate?

Beghetto (2003) argues the debate about evidence-based practice dates as far back as the early 1890s when Josiah Royce wrote “Is There a Science of Education?” More recent is the view that evidence-based practice has its origins in medicine in the early 1970s (Buysse, Wesley, Snyder, & Winton, 2006; Dunst, Trivette, & Cutspec, 2002; Green, 2008). Archie Cochrane, a Scottish epidemiologist, voiced his concern in 1972 about the lack of evidence for health care, thus beginning the evidence-based practice movement. Cochrane believed there was an evident gap between research and practice. Specifically, practitioners were not turning to research to solve practice dilemmas, nor were researchers producing evidence that was useful to practitioners (Buysse et al.). The initial intent to bridge the research to practice gap eventually turned the evidence-based practice movement to an approach to practice (Odom et al., 2005).

Defined in the 1980s by David Sackett, the McMaster Medical School began using the evidence-based approach to practice by integrating “the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients” (Sackett, Richardson, Rosenberg, & Haynes, 1997). Sackett later added a reliance on clinical expertise and patient values to the evidence-based practice definition which is still being used today (Sackett, Straus, Richardson, Rosenberg, & Haynes, 2000; Snyder, 2006).

### 3. How has evidence-based practice affected early childhood intervention?

The evidence-based practice movement spread wildly in medicine, psychology, criminology, occupational therapy, nursing, social services, mental health, speech and language pathology, education, and other fields (Dunst et al., 2002; Green, 2008; Whitehurst, 2002). Major initiatives are under way to identify and disseminate practices that have the best available scientific evidence (Green; Strain & Dunlap, n.d.; Odom et al., 2005). Organizations are focusing their work on research syntheses and professional associations are proposing standards for practice (Sandall, Hemmeter, Smith, & McLean, 2005). The Cochrane Collaboration is the largest and longest standing research synthesis organization ([www.cochrane.org](http://www.cochrane.org)) and a number of others have followed. In fact, there are now more than 100 centers dedicated to reviews and synthesis of research (Dunst et al.) The evidence-based practice movement has equally affected research initiatives and priorities in early childhood intervention (Wesley & Buysse, 2006). The synthesis and dissemination efforts of the What Works Clearinghouse, DEC recommended practices, Center for Evidence Based Practice, and the Center for the Social and Emotional Foundations of Early Learning signify the evidence-based practice movement in early childhood intervention (Snyder, 2006).

Evidence-based practice is a term that has become everyday vocabulary in early childhood intervention, but the movement is at an early stage of development and there are still questions that need to be addressed before evidence-based practice can become reality (Buisse et al., 2006). According to Dunst and colleagues (2002) the rapid growth in synthesizing research evidence has yet to bridge or even decrease the research to practice gap. Parents and practitioners need the tools to identify evidence-based interventions (IES, 2003). In particular, systematic guidelines for specifying the types and levels of evidence necessary to identify a practice as evidence-based are needed (Odom et al. 2005).

#### 4. How is evidence-based practice defined in early childhood intervention?

Literature on evidence-based practice can be confusing because in some cases, evidence-based practice is defined as a noun or a thing. That is, an evidence-based practice is described as an intervention strategy or support that has documentation of its effectiveness (Strain & Dunlap, n.d.). Typically defining evidence-based practice as a noun eliminates a very important piece of the definition in which professional wisdom and family values are involved. Evidence-based practice will be defined here as a method or strategy. Expressly, evidence-based practice is a decision making process that integrates scientifically-based research with family and professional preferences, values, and expertise to inform decisions about how to deliver services or instruction for individual children and their families (Buisse et al., 2006; Green, 2008; Sackett et al., 2000; Sandall et al., 2005; Snyder, 2006; Whitehurst, 2002).

#### 5. What is scientifically-based research?

A variety of definitions are available in the literature for the term scientifically-based research (see Table 1). For some, scientifically-based research denotes a specific type of study (i.e. randomized, controlled clinical trials). For others, it refers to the quality of the research.

Scientifically-based research will be defined here as persuasive research that empirically examines important questions using appropriate methods that ensure reproducible and applicable findings (Beghetto, 2003). Looking across the various definitions for scientifically based research, there are common characteristics that can be identified. Common characteristics include (a) a match between the research question and the method, (b) peer review, (c) reliance on measurement and observation, (d) applicable questions, and (e) replicable studies. Beghetto’s definition was chosen as exemplary because it includes each of the common characteristics without overly specific parameters that might exclude valuable research. There is quite a bit of debate in the field about what types of research should be included and excluded from consideration for scientifically-based research status. There is an underlying notion that “not all research is created equal”, resulting in a lack of agreement as to what constitutes scientific rigor (see Table 1).

Table 1

*Definitions of Scientifically-Based Research*

Resource	Definition
Beghetto, 2003	<p>Persuasive research that empirically examines important questions using appropriate methods that ensure reproducible and applicable findings</p> <ul style="list-style-type: none"> <li>• Persuasive: Appropriate research design, methods and techniques, logic and reasoning, &amp; replicable results (typically determined by a team of peer-reviewers)</li> <li>• Empirical: Based on measurement or observation - “experienced through the senses”</li> <li>• Important questions: Questions that build upon, add to, fill a void in, or</li> </ul>

Resource	Definition
	<p>otherwise clarify what is known and practiced</p> <ul style="list-style-type: none"> <li data-bbox="402 348 1409 600">• Appropriate methods: Use of designs, methods, and techniques that fit the nature of the question the study is attempting to answer. However, no research design, method, or analytic technique on its own makes a study or program of research scientific.</li> <li data-bbox="402 642 1419 821">• Replicable and applicable findings: Consistent, meaningful findings that are understandable, accessible and applicable to a wide audience. The research presents sufficient detail to allow for replication.</li> </ul>
Buisse,	Associated with the best available research component of evidence-based
Wesley,	practice
Snyder, &	Applies the highest standards of scientific rigor
Winton, 2006	
Education	Applied research, basic research, and field-initiated research in which the
Sciences	rationale, design, and interpretation are soundly developed in accordance with
Reform Act	scientifically-based research standards
of 2002	Scientifically-based research standards:
	<ul style="list-style-type: none"> <li data-bbox="402 1434 1346 1549">• Employing systematic, empirical methods that draw on observation or experiment</li> <li data-bbox="402 1591 1365 1621">• Involving data analysis that are adequate to support the general findings</li> <li data-bbox="402 1663 1377 1778">• Relying on measurements or observational methods that provide reliable data</li> <li data-bbox="402 1820 1289 1850">• Making claims of causal relationships only in random assignment</li> </ul>

Resource	Definition
	<p>experiments or other designs (to the extent such designs substantially eliminate plausible competing explanations for the obtained results)</p> <ul style="list-style-type: none"> <li>• Ensuring that studies and methods are presented in sufficient detail and clarity to allow for replication or, at a minimum, to offer the opportunity to build systematically on the findings of the research</li> <li>• Obtaining acceptance by a peer reviewed journal or approval by a panel of independent experts through a comparably rigorous, objective, and scientific review</li> <li>• Using research designs and methods appropriate to the research questions posed</li> </ul>
Green, 2008	<ul style="list-style-type: none"> <li>• Direct testing of interventions</li> <li>• Controlled analyses comparing intervention to no intervention or another intervention</li> <li>• Careful selection and assessment of participants</li> <li>• Objective, accurate, and reliable measurement of the intervention as well as its effects</li> <li>• Replications by multiple investigators (not just one group, especially if they are the principal developers, promoters of the intervention)</li> <li>• Peer review and publication in scientific journals</li> </ul>
No Child Left Behind Act of 2001	<p>Research that involves the application of rigorous, systematic, and objective procedures to obtain reliable and valid knowledge relevant to education activities and programs</p>

Resource	Definition
	<ul style="list-style-type: none"> <li>• Employs systematic, empirical methods that draw on observation or experiment</li> <li>• Involves rigorous data analyses that are adequate to test the stated hypothesis and justify the general conclusions drawn</li> <li>• Relies on measurements or observational methods that provide valid data across evaluators and observers and across multiple measurements and observations</li> <li>• Has been accepted by a peer reviewed journal or approved by a panel of independent experts through a comparably rigorous, objective, scientific review</li> </ul>
Shavelson & Towne, 2002	<ul style="list-style-type: none"> <li>• pose significant questions that can be investigated empirically</li> <li>• link research to relevant theory</li> <li>• use methods that permit direct investigation of the question</li> <li>• provide a coherent and explicit chain of reasoning</li> <li>• replicate and generalize across studies</li> <li>• disclose research to encourage professional scrutiny and critique</li> </ul>
Snyder, 2006	<ul style="list-style-type: none"> <li>• Beyond the quality of evidence: relevance, significance, transparency, and social validity are important characteristics of scientifically based research.</li> <li>• Descriptive, causal, process or mechanism forms of evidence should “count” as legitimate evidence to help inform evidence-based practice decisions.</li> </ul>
What Works Clearinghouse	<p>In order to meet evidence standards (either with or without reservations) a study has to be a randomized controlled trial or quasi experiment with one of the</p>

Resource	Definition
	following three designs: quasi experiment with equating, regression discontinuity designs, or single-case designs.

## 6. What are levels of evidence?

Levels of evidence are a way of ranking evidence for interventions in order to guide evidence-based practice. Similar to scientifically-based practice, levels of evidence have been interpreted in a variety of ways by professionals in early childhood intervention. There is a consistent lack of agreement on the appropriate number of levels and what constitutes each level. Further, levels of evidence hierarchies have been criticized because they typically emphasize some types of research over others (Dunst et al., 2002). The levels of evidence proposed here acknowledge that scientifically-based research is not synonymous with a particular method (Feuer et al., 2002). Figure 1 displays a hierarchical diagram of proposed levels of evidence for scientifically-based research in early childhood intervention. The figure was derived from a synthesis of the literature, including interpretations from a variety of sources (Gerston et al., 2005; IES, 2003; Oxford Centre for Evidence-Based Medicine; ACCESS Center Research Continuum; Whitehurst, 2002).

The three levels of evidence denoted in Figure 1 are labeled as promising evidence, probable evidence, and pure evidence. At the bottom tier, promising evidence is considered evidence found in the professional literature that has not yet been examined carefully but that shows potential for effectiveness. Probable evidence at tier 2 is backed by scientifically-based research conducted with participants similar to the participants for whom the intervention is intended. At the top of the pyramid is pure evidence, consisting of at least four scientifically-

based studies conducted with participants similar to the participants for whom the intervention is intended and in settings similar to the setting in which the intervention is to be implemented.

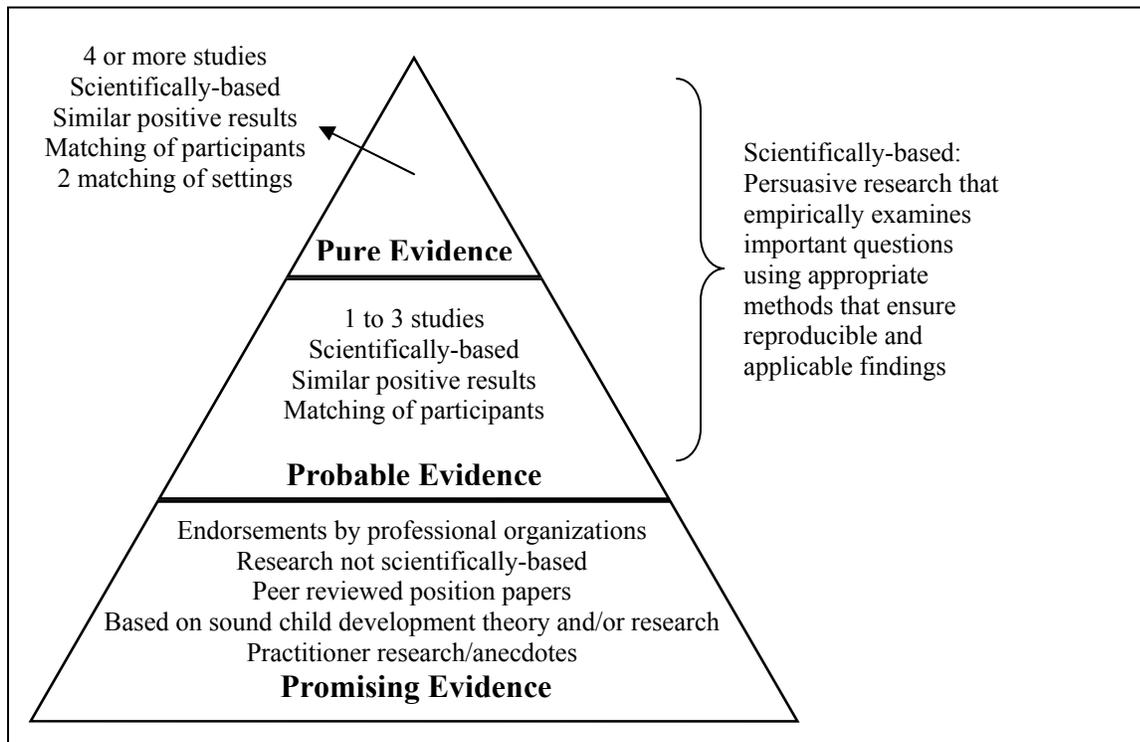


Figure 1. Levels of evidence for scientifically-based research in early childhood intervention

7. What kind of intervention is available for young children with autism?

Because autism is considered a quite distinctive and life-long permanent disability, autism has attracted a number of highly controversial (i.e. un-validated) intervention strategies (Simpson, 2005). Given there are scores of intervention options for young children with autism, outlining the complete array is beyond the scope of this paper (Green, 2008). A search for different kinds of therapy for young children with autism will turn up masses of intervention approaches with exaggerated claims of effectiveness and irresponsible promotion of “cures” (Herbert et al., 2002). Various types of sensory-motor therapies, psychotherapies, biological

treatments, behavioral programs, and pharmacological therapies are among the hundreds of popular treatments being enthusiastically promoted as producing extraordinary and incomparable results. In fact, *all* intervention types are claimed to be effective by someone (Green). Despite scientific evidence suggesting some interventions are ineffective and sometimes even harmful, they remain in wide spread use (Green; Herbert et al.; Simpson). Both evidence-based and non evidence-based interventions exist, but very few have been evaluated in studies that produce credible research-based evidence of success (Green; Stahmer et al., 2005).

#### 8. Why is finding an evidence-based intervention so hard?

Parents of children with autism have reported feeling powerless during the lengthy and unnerving process of diagnosis and decision making during early childhood (Callahan et al., 2008). Given the unique circumstances associated with an autism diagnosis, it seems reasonable that parents and professionals are highly motivated to attempt any promising treatment (Herbert et al., 2002). Understandably, parents and professionals connected to children with autism have become extraordinarily well-known for their uncritical use and advocacy of controversial interventions and miracle cures, leading to many unhealthy and unrealistic expectations (Simpson, 2005). Not surprisingly, many of the more controversial interventions are associated with individuals or organizations with a direct and substantial financial stake in the intervention (Herbert et al.). Today the term “evidence-based” is being used as a marketing ploy for virtually every intervention for young children with autism, most of which have never been scientifically validated. Often times, personal accounts or testimonials and interpretations or opinions are used to label interventions as “evidence-based”. Studies are rarely utilized to show effectiveness, but when they are, they often use subjective methods, have no replication, and don’t even include children with autism (Green, 2008). Stahmer and colleagues (2005) conducted a study in which

they determined program marketing, provider preferences, and parent requests influence practitioner use of interventions more than whether the intervention has any evidence of efficacy. Additionally, they found that very few practitioners have a clear understanding of how to engage in evidence-based practice (Stahmer et al.).

9. How can parents and practitioners engage in evidence-based practice?

Evidence-based practice:

A decision making process that integrates scientifically-based research with family and professional preferences, values, and expertise to inform decisions about how to deliver services or instruction for individual children and their families (Buisse et al., 2006; Green, 2008; Sackett et al., 2000; Sandall et al., 2005; Snyder, 2006; Whitehurst, 2002).

The first step to engaging in evidence-based practice is to identify the needs and priorities of the individual child and family (Buisse et al. 2006; Simpson). The needs of the child will determine the choice of intervention procedures. Next, conduct a literature search to determine the best available evidence for the chosen intervention. Table 2 contains a list of research synthesis organizations on the Internet that can serve as good starting places. University libraries typically have hundreds of peer-reviewed journals and online research data bases that can also prove to be extremely useful in tracking down research.

Table 2

*Research Synthesis Organizations on the Internet*

Organization	Web Address
<i>The Campbell Collaboration</i>	<a href="http://campbellcollaboration.org/">http://campbellcollaboration.org/</a>
<i>Center for Evidence-Based Practice: Young Children with Challenging Behavior</i>	<a href="http://challengingbehavior.fmhi.usf.edu/index.html">http://challengingbehavior.fmhi.usf.edu/index.html</a>

*Center on the Social and Emotional Foundations for Early Learning* <http://www.vanderbilt.edu/csefel/>

*The Promising Practices Network* <http://www.promisingpractices.net/>

*Research and Training Center on Early Childhood Development, Center for Evidence-Based Practices* <http://www.researchtopractice.info/>

*The What Works Clearinghouse* <http://w-w-c.org/>

In order to assess the quality of the individual research articles, a comparison to the definition of scientifically-based research will be necessary. Part of the definition of scientifically-based research is the use of appropriate methods. For those unfamiliar with research methods, appropriate methods can be identified by comparing the research to quality indicators for special education research (see Table 3). The quality indicators for special education research can be found in their entirety in a series of articles published in *Exceptional Children, Volume 71*.

Table 3  
*Sample Quality Indicators for Special Education Research*

Resource	Method	Quality Indicators
Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005	Qualitative Studies	<i>Interview Studies (or Interview Components of Comprehensive Studies)</i> <ul style="list-style-type: none"> <li>• Appropriate participants are selected (purposefully identified, effectively recruited, adequate number, representative of population)</li> </ul>

Resource	Method	Quality Indicators
Gersten et al., 2005	Group Experimental and Quasi-Experimental Research	<p>of interest)</p> <ul style="list-style-type: none"> <li>• Interview questions are reasonable (clearly worded, not leading, appropriate and sufficient for exploring domains of interest)</li> </ul> <p><i>Quality Indicators for Implementation of the Intervention and Description of Comparison Conditions</i></p> <ol style="list-style-type: none"> <li>1. Was the intervention clearly described and specified?</li> <li>2. Was the fidelity of implementations described and assessed?</li> <li>3. Was the nature of service provided in comparison conditions described?</li> </ol>
Horner et al., 2005	Single-Subject Research	<p><i>Independent Variable</i></p> <ul style="list-style-type: none"> <li>• Independent variable is described with replicable precision</li> <li>• Independent variable is systematically manipulated and under the control of the experimenter</li> <li>• Overt measurement of the fidelity of implementation for the independent variable is highly desirable</li> </ul>

Resource	Method	Quality Indicators
Thompson, Diamond, McWilliam, Snyder, & Snyder, 2005	Correlational Research	<p><i>Measurement</i></p> <ul style="list-style-type: none"> <li>• Score reliability coefficients are reported for all measured variables, based on induction from a prior study or test manual, with explicit and reasonable justifications as regards comparabilities of (a) sample compositions and (b) score dispersions</li> <li>• Score reliability coefficients are reported for all measured variables, based on analysis of the data in hand in the particular study</li> </ul>

Based on results of the literature search, the intervention should fall into one of four levels of evidence, (a) no evidence, (b) promising evidence, (c) probable evidence, and (d) pure evidence. If the intervention has no evidence of effectiveness, stop and consider a new intervention strategy. When an intervention falls under any of the other three levels, family and professional preferences, values, and expertise should be considered before moving forward. For example, even if the intervention is found to have pure evidence of effectiveness, if the parents or practitioner feel strongly against it, or know from experience that it won't work for the child, stop and consider a new intervention strategy. An important consideration when making the final decision is that intervention options that a professional feels are typically less effective should never be excluded from discussion as an option. It is the right of the child and family to have all

options in order to make an informed decision. The evidence-based practice decision making model for parents and practitioners is illustrated in Figure 2.

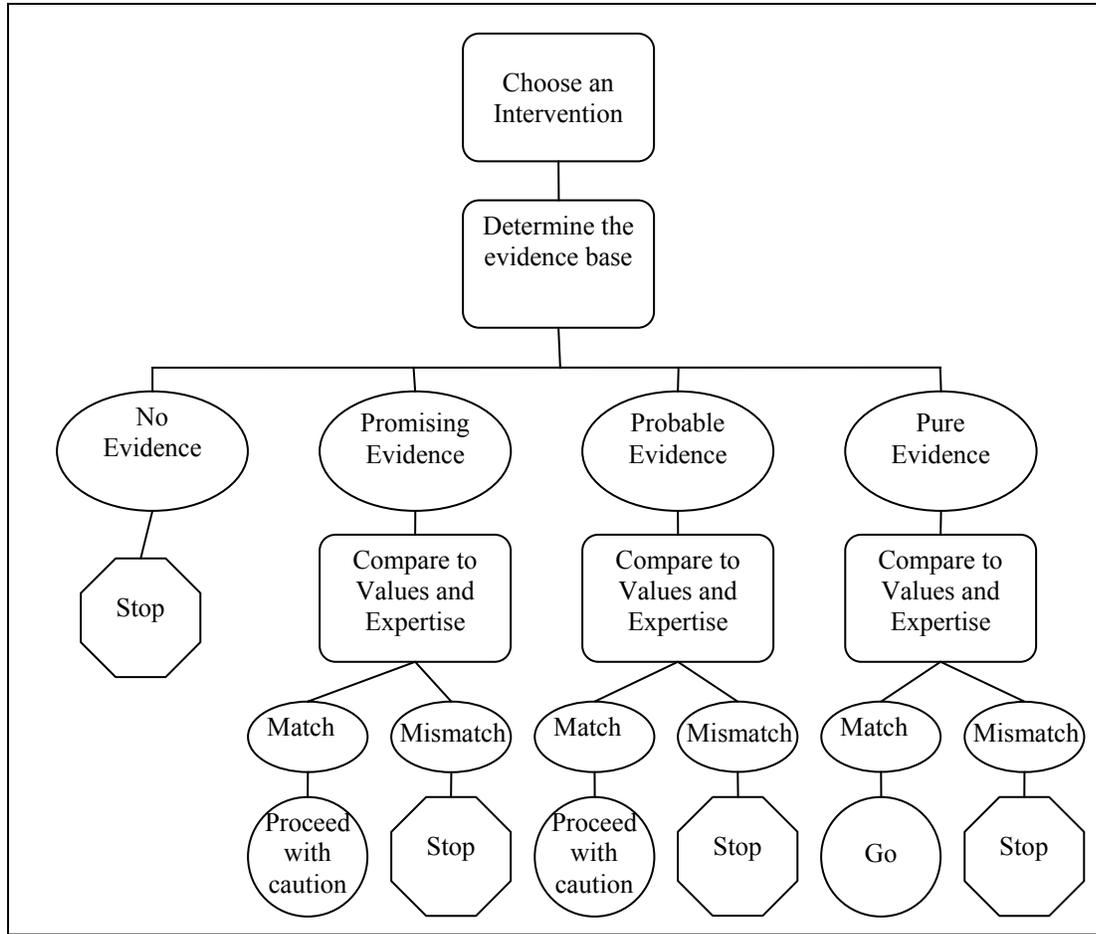


Figure 2. Evidence-based practice decision making model for parents and practitioners.

Example #1 Jack

Jack is a child with deficits in registering and modulating sensory inputs. Jack’s parents have made it clear that functional responses to sensory stimuli are a priority concern. Jack’s teacher and parents are considering sensory integration therapy to support his needs (Ayres, 1979). After searching the literature, Jack’s teacher found “promising evidence” that sensory integration therapy produces benefits for young children with autism (Dawson & Watling, 2000;

Green, 2008; Herbert et al. 2002; Simpson, 2005). After consideration of past experiences, Jack's interests and preferences, and possibly harmful effects, Jack's teacher and parents decide that sensory integration therapy is a match with their expertise and values and is something they are willing to try. They decide to implement the intervention, but agree that if no progress is made in a reasonable amount of time, they will try something new.

#### Example #2 Tara

Tara is a child with social and communicative deficits resulting in a disability to form relationships. Her parents have clearly stated their priority is for Tara to develop an attachment with her mother. They are considering the use of holding therapy to establish a bond between Tara and her mother. Working together, Tara's parents and teacher search the literature for evidence of the effectiveness of holding therapy. They found what they thought was "promising evidence" of effectiveness. Some research had been completed, although it was not scientifically-based research, and there were anecdotal reports of effectiveness (Green, 2008; Herbert et al., 2002; Pignotti & Mercer, 2007; Simpson, 2005). Further consideration and reading revealed that child deaths and injuries had resulted from the use of holding therapy and there was no sound theoretical basis (Pignotti & Mercer). Tara's parents decided the intervention was a mismatch with their values and began a new discussion with her teacher about possible intervention strategies that could help them reach their goals.

#### Example #3 Hunter

Hunter is a child with severe behavior problems. Both his parents and his teacher have agreed that helping Hunter decrease some of his inappropriate behaviors should be a priority for his educational programming. Hunter's teacher suggests they look at the evidence for discrete trial training, a component of applied behavior analysis (ABA). The evidence available for ABA

is outstanding and the parents and teacher decide the intervention falls into the category of having “pure evidence” (Dillenburger et al., 2002; Green, 2008; Harris & Delmolino, 2002; Herbert et al. 2002; Simpson, 2005). Hunter’s parents then compare the intervention with their values and preferences and decide that even though the evidence is great, they aren’t comfortable with Hunter being exposed to discrete trials and declare it a mismatch. They decide to examine other options.

#### 10. How do we keep moving toward a model of evidence-based practice?

It is critical that enthusiasm and popularity are no longer mistaken for proof of evidence (Green, 2008). Parents and practitioners need to be aware that just because a brochure indicates that a particular method is research based does not make it so (Simpson, 2005). It simply doesn’t stand to reason that all interventions are equally effective (Green). In order to promote a reliance on scientific methods to separate speculation from fact, parents and practitioners must become critical consumers of research (Buysse et al. 2006; Herbert et al., 2002; Simpson, 2005). Consideration of consequences and local circumstances along with a healthy dose of skepticism will be central components to promoting evidence-based practice (Whitehurst, 2002). According to Dillenburger and colleagues, empowering parents is central to the treatment process (2002). Knowledge is power, but emotional comfort levels will play an influential role in what parents ultimately accept for their child. Utilizing the model provided here will support the integration of research evidence with the field’s collective wisdom and values and improve programming for young children with autism.

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