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STRAIGHT TALK About Autism

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The Use and Misuse of Evidence-Based Practice

Implications for Persons with ASD

As service providers and parents, we want to make sure that we are effective in our efforts to support persons with ASD. Hence, the selection and implementation of educational and treatment practices ideally should be based on substantial evidence that they are effective; that is, *evidence-based* (shown to be effective based on accepted sources of evidence). On the surface, evidence-based practice (EBP) would seem to be a fairly straight-forward concept, not to mention an essential consideration in determining which intervention practice(s) to apply, be they educational, biomedical, or nutritional. This, however, is not always the case in ASD for reasons I will explore in this issue's "Straight Talk" column. In addition, I will also scrutinize the meaning of this widely-used concept and consider the complexities and challenges inherent in applying EBP in "real-life" situations. As I hope to demonstrate, there are differing interpretations of what it means to be evidence-based, so application of the standard is not as simple or straight-forward as it may seem.

Evidence-Based Practice Defined

Evidence-Based practice is a concept initially introduced by and borrowed from medical practice. Over the past decade, it has been adopted by the behavioral sciences (e.g., psychology, communication disorders, occupational and physical therapy) and educational fields.

Let's consider how EBP has been defined. According to the American Psychological Association (APA, 2005), the "definition of EBPP [evidence-based practice in psychology] closely parallels the definition of evidence-based practice adopted by the Institute of Medicine (2001, p. 147): 'Evidence-based practice is the integration of best research evidence *with clinical expertise and patient values* [italics added].'" The APA goes on to assert that "Evidence-based practice in psychology (EBPP) is the integration of the best available research with *clinical expertise in the context of patient characteristics, culture, and preferences* [italics added]" (APA, 2005). I have italicized portions of the previous definitions to underscore that decision-making in EBP is not strictly confined to the issue of research evidence, but also takes into account the expertise of the clinician and family / patient preferences and values.

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The American Speech-Language-Hearing Association (ASHA) further emphasizes these points by noting that,

> "In making clinical practice evidence-based, audiologists and speech-language pathologists—recognize the needs, abilities, values, preferences, and interests of individuals and families to whom they provide clinical services, and integrate those factors along with best current research evidence and their clinical expertise

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in making clinical decisions" (ASHA, Evidence-Based Practice in Communication Disorders, 2005).

To summarize, currently accepted definitions of EBP indicate that research should be used, when available, as an important source of evidence to guide clinical and educational decision-making, but other factors must be considered as well. These factors include: clinical expertise based on experience (referred to by some as *wisdom-based practice*); educational and clinical data about effectiveness of practices; family preferences; individual differences in children and families; and when appropriate, feedback from the client as to the effectiveness of the practices. Elevating research findings to a position of predominance or supremacy over these other factors, or to the exclusion of these factors - though commonly the case—constitutes a misuse of EBP. In my experience, the majority of practitioners, and many parents, construe EBP as meaning research-based ONLY, a position that continues to be perpetuated by many professionals and agencies serving persons with ASD.

Given the current tenuous and preliminary state of treatment research in ASD, many of these "other" factors (professional expertise, family preferences, individual differences, etc.) should play a significant role in such decision-making. For example, recent reviews of treatment research in ASD indicate that there is no strong evidence that any one approach or category of approaches is superior to other approaches (Ospina et al., 2008; NIMH, 2009; Warren et al., 2011). Ospina et al. concluded, based on their meta-analysis of treatment research: "As no definitive behavioural or developmental intervention improves all symptoms for all individuals with ASD, it is recommended that clinical management be guided by individual needs and availability of resources." Despite these findings from relatively unbiased sources, claims about the superiority of one approach over others in ASD are pervasive (e.g., see Straight Talk column, Spring 2009 available online at www.ASQuarterly.com). Such claims continue to be used to steer parents and professionals to specific interventions to the exclusion of others based on assertions that certain approaches are evidence-based (using published research as the *only* source of evidence) and others are not. This is most apparent in recent attempts to pass legislation in a number of states to require that insurance companies and/or school districts fund only certain identified interventions to the exclusion of others, even in the face of weak evidence and in some cases, the absence of research supporting such claims of superiority. This is but one example of the misapplication of the concept of EBP; but there are other challenges as well.

Differences in How the Concept of EBP is Used

In the following discussion, I will be referring to two uses of the concept of EBP: 1) *EBP-A,* to refer to the appropriate use of EBP as stipulated by accepted definitions of professional organizations noted above; and 2) the narrow use of EBP, which I will refer to as *EBP-N,* where sources of acceptable evidence are not only restricted to research considerations only (with client / family preferences virtually ignored), but also where the application of EBP goes well beyond clinical and educational decision-making to include or exclude funding of specific practices through political / legislative processes.

The shaded areas below outline the distinctions between these two different uses of EBP as they apply to practices used with persons with ASD.

EBP- A Appropriate	EBP- N Narrow
1. ASD is construed as a behaviorally-defined spectrum (with multiple causes) existing on a continuum of neurodevelopmental disorders. Individual differences are recognized as the rule rather than the exception, and as such, have a profound impact on clinical and educational decision-making. Evidence of the effectiveness of practices used both in conjunction with other neurodevelopmental disorders and in typical development may also be considered.	**1.** ASD is viewed according to a "disease" model that assumes that all individuals are affected in a similar manner, and in which individual differences are either deemphasized or not addressed. Generalizations are made about the use of clinical and educational approaches and are presumed to apply to large groups of individuals with ASD. While in direct conflict with widely accepted definitions of EBP, *only* evidence from research on ASD may be considered (or serve as the overriding consideration) when specific treatments are recommended and implemented.

EBP- A	EBP- N
2. Peer-reviewed, empirical research, when available, is considered to be but one source of evidence guiding clinical and educational practice. Furthermore, a lack of published research does not necessarily mean that practices are not effective. Therefore, promising, emerging practices may also be implemented as long as data-based decision-making is part of practice, and as long as the potential benefits outweigh the potential costs or risks.	**2.** Peer reviewed, empirical research is the overriding source of evidence for selecting and implementing clinical and educational approaches and practices. A lack of published research is considered to be grounds for prohibiting the use of specific practices. Parents may be dissuaded from considering practices that do not yet have research support, even when risks are minimal and experience supports the effectiveness of such practices.

EBP- A	EBP- N
3. Measurement of progress is data-based, but there is an overriding concern that progress be based upon *meaningful* change. This standard takes into account social validity measures such as family perceptions of the positive impact of progress, as well as client wellbeing.	**3.** Measurement of progress is data-based, but concerns regarding social validity and meaningfulness of change are not necessarily of overriding concern, and hence may be limited or absent.

EBP- A	EBP- N
4. The primary use of EBP is for the purpose of guiding teams and family members in educational and clinical decision-making. Multiple sources of evidence are used to determine funding to support practices.	**4.** Results of published research alone are used for: 1) political purposes such as mandating, legislating, or denying funding for use of specific treatments, and/or for, 2) marketing purposes, such as convincing parents and practitioners to adopt specific practices, often to the exclusion of others .

As noted above, given current "official" definitions of EBP, information that may be used as evidence to inform decisions about education and treatment should come from multiple sources, including research; family factors (priorities and cultural values); educational and clinical data; clinical and educational expertise; and client feedback, when appropriate. It should be specifically noted, however, that in ASD, there has been a strong bias in favor of using the concept of EBP in the narrow sense described above. Importantly, this narrow application of EBP is problematic for a number of reasons which will be discussed in the next section.

Problems in the Narrow Application of EBP

ASD is not a disease—As noted, the concept of EBP was adopted from medical science in its application to the treatment of medical illness and disease. Within such a framework, *what* is being treated and what can be considered as *evidence* of the effectiveness of treatment can be more clearly defined and measured, since the biomedical basis of a condition is often more clearly understood within a medical model. Furthermore, measurement of effectiveness typically is more objective, and there tends to be greater consensus about indicators of meaningful progress, such as lessening of, or abatement of physical/biological symptoms. This is not the case for the core symptoms of autism (although it may be relevant for associated medical conditions such as gastrointestinal distress or seizure disorders). Specifically, while it is well accepted that there are genetic contributions and a neurological basis to most forms of ASD, the spectrum of conditions is nonetheless currently defined as a behavioral syndrome. Furthermore, the overwhelming majority of treatments, whether educational or biomedical, are not designed to directly address the neurological basis of ASD, which remains elusive. Rather, most treatments are designed to mitigate the core behavioral deficits / differences or to build adaptive abilities or skills to enable an individual to be more successful and to enhance quality of life. (As noted, some treatments may be targeted to address co-morbid medical conditions as well.) Further complicating this situation is the fact that significant differences of opinion continue to exist regarding:

1. The core deficits / differences in ASD, and therefore, what needs to be measured when considering progress (e.g., social,

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sensory, communicative, cognitive, or combinations of these domains of functioning)

2. The boundaries in diagnosis of ASD (e.g., As of this writing, DSM V will have a very different framework for diagnosis that will likely impact decisions regarding who would be included or excluded from an ASD diagnosis.)

3. What constitutes the most meaningful measures of progress (e.g., abatement of "autistic symptoms," IQ score, social behavior, language development, functional adaptive skills)

Promising, emerging practices may not be considered acceptable—There are numerous examples of clinical or educational practices that have been introduced and successfully implemented long before research provided evidence that they were effective. Examples include Social Stories®, inclusive programming in schools, visual supports, and the use of speech generating devices (SGDs). Some of these practices were criticized in the past for not being "evidence-based." Clearly, the potential for advancing clinical and educational practice for persons with ASD would be highly restricted if the tenets of EBP-N were strictly followed. Although some researchers and policy-makers have recently begun to acknowledge and give greater credibility to emerging and "promising" practices, it is still common for such practices to be considered "not supported" by research in attempts to prohibit their use. To be clear, I am not advocating for practices that have risks (medical or health-related, financial, or emotional) that outweigh potential benefits, as the "benefit-risk ratio" must always be an important consideration is choosing any practices, especially in the absence of definitive research supporting their effectiveness.

Individual differences within the spectrum are not taken into account—As noted previously, individual differences in persons with ASD are the rule rather than the exception. One of the acknowledged shortcomings of research in ASD is the lack of clear and detailed descriptions of subjects in both large- and small-sample research documenting such differences. In research that involves larger groups—even when significant and meaningful change can be documented due to treatment—it may remain uncertain as to whether the same treatment would have the same results for a specific child in an educational setting. In recognizing this challenge, current treatment research is shifting to address questions such as *which individualized treatments may be effective for which children*, in contrast to global questions such as, *does treatment A work better than treatment B for persons with ASD.* Unfortunately, current use of EBP relies on a body of past research that has not yet addressed individual differences to any significant extent.

Data is not necessarily evidence of meaningful progress—Too often, data—especially frequency counts of behavior—are presented as the sole source of evidence of the effectiveness of intervention in educational and clinical practice. Recently, this issue was highlighted for me during a school consultation. I was asked to observe an eight-year-old boy who I had been told had made significant progress in school. I was shown graphs of progress indicating that he could now point to and match up to four different hues of each of the primary colors, which he had mastered in the first two months. He was also able to expressively label up to 40 photos of objects, many of which he had never seen before, but this had not "yet" generalized to functional use of language. During the observation, however, it was apparent that he had major challenges in remaining emotionally well-regulated at predictable times during his school day. These times included, for example, when he was asked to stay seated and work for more than 15 minutes; during transitions; or when he became frustrated in the absence of knowing how to request *help*. At these times, he would drop to the floor, and if physically redirected, would physically pull way and push or slap at others. When he engaged in such behavior, he was not able to earn stars that he could trade in for opportunities to engage in favorite activities. Although the staff had collected considerable data that was used as "evidence" of his progress and the effectiveness of their practices, this situation obviously demonstrates that data, per se, is not always evidence of the most meaningful progress.

Final Thoughts

In summary, with EBP now accepted as a mandate to guide our practices, it is imperative that we go beyond the label and consider both how it is being applied as well as its role in everyday real-life decisions for supporting persons with ASD. Moreover, it is unrealistic to assume that we can rely on "evidence" solely from published empirical research on ASD to select and to guide practices. Indeed, doing so would constitute a misuse or misapplication of EBP, since it ignores both key aspects of EBP that relate to clinical expertise and

family / client factors, and often is applied in a manner that does not take into account the individual differences in persons with ASD.

EBP, when applied appropriately, entails consideration of many important factors. The following questions are offered to establish a framework for decision making by service providers and family members:

1. What are the highest priority and most meaningful goals and objectives for the person with ASD? Do parents value these goals and objectives?
2. What are the range of procedures, activities, and supports that may be used to reach these goals and objectives? Can they be implemented across home, school, and community settings?
3. What is the research evidence that supports the use of these procedures, activities, and supports?
4. If evidence from research in ASD is limited or not available, is there relevant evidence from a) research on individuals with related developmental and learning disabilities on which to base decisions; or b) research on child and human life-span development that can inform clinical or educational decision making. Also, what are the potential benefits and risks in implementing these practices?
5. What do the real-life educational and clinical data tell us about the efficacy of our efforts in achieving the specific goals and objectives for the individual with ASD? Additionally, what do parents and other significant people in the child's life tell us about their perceptions of the individual's progress?

Answers to these questions can go a long way toward applying EBP responsibly and in the manner in which it is intended.

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Bio

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