

Evidence-based Medical and Therapeutic Intervention? Who Needs It?

A discussion for parents of children with special developmental needs about evidence, consensus and anecdotal-based interventions

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After more than four decades of working with parents of children with special developmental needs, I've learned that they often find it difficult to know what the best approaches or interventions are to help their children. Conflicting statements, recommendations and opinions from fellow parents and/or from professionals involved in the child's treatment can cause confusion and uncertainty. Understanding *why* there can be such variation within always well-meaning advice may help parents make the difficult decisions that confront them.

Earlier in my career, the idea of "evidence-based" interventions or even "consensus-based" interventions was little understood, particularly for those with an intellectual disability. Things were done because we (the special educators) or someone we respected, had a good idea. It was the caring and helping that were important. And tracking the long-term benefits of an intervention, though talked about, was not integral to the process.

Anecdotal Evidence

Much, if not most, of our disability work in the early days was based on "anecdotal evidence." That is, we were told, heard about, or read that so-and-so had done such-and-such and there had been an improvement in a child's skills or behavior—at least as reported by the person who had provided or supervised the intervention. All well and good, considering that up until that time many people with special developmental needs received little to *no intervention at all!* Indeed, some children did seem to improve. But, as we now understand, the questions that should have been asked at the time were whether or not the improvement was the result of the intervention, or unintended actions by the interventionist (e.g. more attention given to the individual), or maturation (growth

and development—even when delayed), or not real at all except in the eyes of those working with the individual.

No blame is assigned here. People wanted to help and they used what seemed to be common sense and their own life experiences to try and do so. Just the act of helping and caring sometimes *did* produce desirable results—results that should not be discounted. For example, if parents believed and/or had been told that their child with a disability was incapable of learning, and, through the act of caring and help from others the child became a focus of that help and care, learning may have occurred that was the result of nurturing. This is something *we now know to be crucial to the healthy development of all humans*, and not merely the direct result of the techniques being applied by the parents or interventionist.

Anecdotal-based intervention is still practiced today and, while it should never be entirely discounted (What's anecdotal-based today could be the basis for evidence-based intervention tomorrow!), it is not the foundation on which to build a good intervention plan. Families should always inquire about and look for interventions that have a history of being used by mainstream professionals and, at minimum, have a body of literature from numerous practitioners that attempts to describe the mechanisms that make the interventions successful. That is, look for some “consensus” by professionals that the intervention may be helpful.

Consensus-Based Intervention

Consensus-based interventions develop over time, as enough people work with enough children for a consensus to develop about what works and what doesn't. That is, a large number of people who are trained to provide intervention, whether anecdotal-based or not, begin to agree that they have seen improvements in the behavior, self-help skills, communication, and other factors in children they have worked with, and that these improvements are, *or likely* are, the result of the intervention.

In many ways, consensus can be equated to “professional opinion.” It is based on the notion that if a significant number of professionals, particularly from a variety of relevant disciplines, agree about a particular topic, it may indicate that there is some validity to the matter on which they agree. Coming to consensus can be a time-consuming

process, involving much discussion and a critical review of any literature that already exists regarding the intervention.

Is consensus-based intervention based on scientific proof that it was the intervention itself that was producing the results? It is not, but I will note here the extreme difficulty (and expense) of meeting a standard of scientific proof in educational interventions (more on that below), and that in the absence of such proof, often the best we can do is to rely on the training, expertise and insight of the relevant professionals who have concluded it is a given intervention itself, and not some other variable, that is causing improvement in a child's performance. As we often do when it comes to matters that we don't fully understand, we tend to trust the "experts" in their *expertise*. Over time, consensus-based intervention has become the mainstay of much of special education.

Evidence-based Intervention

We've all heard of the scientific process. Over the past few hundred years, scientists/researchers have developed and refined a system of checks and balances to try to accurately separate fact from fiction. Much of what we take for granted in this day and age exists thanks to the scientific method. Common medications used for a variety of medical and mental health reasons are just one example. All of these medications are approved, at least in the U.S., by the Food & Drug Administration, based on the best scientific evidence available at that time.

The process of controlled studies for new drugs, in which some of the participants in the study receive only a sugar pill (placebo), and even the professionals running the study don't know who is receiving the real drug and who the placebo (meaning all parties are "blinded"), can also be used to study non-drug interventions used in the disability field. These types of studies are designed to eliminate bias in the researcher, whether conscious or unconscious, as well as the aforementioned seeing of improvement where none actually exists.

At minimum, when looking for evidence to substantiate interventions, researchers look for signs of improvement that are measurable, replicable and that are sustained over time in a significant percentage of those being studied. If an intervention produces only short-term results that don't appear to "stick" (when reassessed at some point in the

future), that particular intervention may not be fully developed nor ready for use in an evidence-based intervention plan. Evidence of long-term results is an important variable to consider when determining the best intervention for a child with special needs.

When Professionals Disagree

Sometimes—make that *often*—intelligent, committed and well-meaning professionals are unable to agree on what constitutes evidence. Some propose a halfway point between consensus and evidence called “evidence-informed.” Unfortunately, this can make life difficult for parents, who may get caught between opposing camps and, as a result, end up not making any decisions or, even worse, jumping from intervention to intervention depending on who makes the latest or most strident claim.

There are many examples of disagreements about the evidence for certain interventions, including those having to do with medical treatments. Such disagreements are common in the use of medications, and in educational, therapeutic or counseling interventions.

So what is a parent to do? Common sense suggests that one should do what anyone does when presented with conflicting advice: get a variety of opinions. Ask questions. Listen carefully. Read up on the topic. Weigh what you learn against your own experience. Work with your child’s intervention team. Make informed choices.

Self-Appointed Experts

One important caution is to always question the comments of self-appointed experts, i.e. those whose training or experience doesn’t qualify them to be making definitive statements about an intervention, and whose statements are significantly different than the majority of others in the field. While it is true that a lone individual can have a critical insight that the majority has missed, an abundance of caution is still encouraged when evaluating the “evidence” that a given “expert” is citing.

“Do No Harm”

Most everyone knows of the Socratic Oath, first documented in ancient times, modified over the years, and taken by most doctors at the conclusion of their training. It says in essence that one should first and foremost “do no harm” when providing a medical intervention. That is, sometimes it may be better to do nothing than to risk causing harm. This point is particularly relevant when it comes to the use of drug treatments, but it can also have relevance for other types of interventions. For example, interventions that might cause a child to experience undue fear, anxiety or stress may do more harm than good.

The concept of doing no harm includes the harm that might be caused by doing *nothing*. In human development there appear to be windows of opportunity in which interventions have the greatest chance of success. Ignoring those windows may result in harm sometime in the future. One of the best examples of this within the disability field has to do with the original legislation that mandated the states to provide special education services. Originally, these services were required to be provided for children above the age of 5. But with a growing body of evidence showing that the greatest window of opportunity existed earlier in life, the requirements were subsequently modified to mandate services be offered for those birth to 5. (What we now call “early intervention.”) So, one could argue, doing nothing from birth to five could be harmful. (At least that was the *consensus* of the experts.)

Why is any of this important and what is the right answer?

Whether you are parent, teacher, doctor, therapist or counselor, everyone who chooses to work with children who have special needs does so to help make a difference in the quality of life for those children. Understanding that there are different standards when considering interventions, and varying opinions about what constitutes evidence, will help with the decision-making process. I strongly recommend that you always favor evidence-based interventions, and if there is no evidence or the evidence is unclear, then look for consensus-based approaches. Then, assuming that an intervention passes the “do no harm” standard, proceed with what feels right for you, your child, and your family, but *always* in full consultation with the professionals who, like you, truly have your child’s best interests at heart.

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