



Complex Child E-Magazine

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How to Evaluate and Choose Therapies by Susan Agrawal

Most children with complex medical issues participate in one or more therapies. These may include standard therapies like physical, occupational, and speech therapies, or other therapies such as hippotherapy, massage, or conductive education.

With so many different types of therapies out there, it can be difficult to know what might be effective for your child. Many therapies are not covered by insurance, and they tend to be extremely expensive. In addition, many therapies—alternative or not—have not been evaluated by medical science at this time, leaving little reliable evidence of their effectiveness or lack thereof.

Unfortunately, there are practitioners out there who are complete quacks, and prey on your vulnerability to make money. While these are relatively uncommon, they do exist, and it is important to be able to identify them.

The remainder of this article will focus on strategies to help you carefully evaluate a therapy.

1. Avoid any therapy that promises a cure. Any legitimate program or therapy will avoid making these sorts of claims, since success will vary by child. Therapies are designed to improve a child's ability, and not provide a cure, though some children may improve dramatically. Similarly, avoid any therapy that makes you stop all of your current therapies. While some therapies may not be compatible, almost all are.
2. Make sure the therapy is safe. There are certain therapies, including nutrition and herbal therapies in particular, that may not be safe for a given child. Some herbs and nutritional supplements may lower the seizure threshold, provoking seizures in some children. Other imported items may contain hidden allergens dangerous to certain children. Make sure you get a full list of ingredients contained in every item and carefully research each one to make sure it will not interact with your child's medication or cause other side effects. Similarly, other therapies may not be physically safe for some children. Aquatic therapy may not be a good choice for children with trachs and respiratory problems, while intensive physical therapies may be inappropriate for a child with very thin bones. Always ask your child's doctor and research on your own.
3. Try as much as possible to use therapies covered by your insurance or Medicaid program. This is, of course, simply cost effective, but insurers tend to be stingy about

coverage and the therapies they do cover are more likely to be proven effective. Besides the standard therapies, insurance will sometimes cover therapies such as hippotherapy or aquatic therapy (if staffed by a physical or occupational therapist), chiropractory, cranio-sacral therapy, massage, acupuncture, and occasionally even hyperbaric oxygen therapy. If a therapy is NOT covered by insurance, this does not necessarily mean it is worthless. We all know insurance companies love to deny even the most necessary and beneficial items.

4. Pick therapists or therapy centers that bill insurance or Medicaid. Once again, this shows that these therapies are more likely to be proven effective and that the practitioners are making an effort to provide services and not simply make money. There are, unfortunately, many legitimate practices who do not bill insurance who may or may not be good practices. For example, my daughter receives communication therapy using a communicator which we pay for out of pocket because the center does not bill insurance. While on the one hand I have a moral problem with this, on the other hand it is extremely valuable therapy, and this is the only place nearby that offers it.

5. Evaluate the evidence. Whenever thinking about a new therapy, look up the scientific evidence for it using Medline. Go to <http://www.ncbi.nlm.nih.gov/pubmed/>, a free service offered by the federal government, and search for the therapy. If it is relatively common, search for the name of the therapy along with your child's condition. Look in particular for "review" articles that gather the evidence from multiple studies. This database only provides abstracts, but they will usually provide you with a decent amount of information. Large studies that are double blind and randomized provide the best evidence, while case reports are the least reliable. Unfortunately, many therapies have not been fully researched at this time, so there may or may not be conclusive evidence for the specific therapy you are looking at.

6. Talk to friends, family, teachers, other therapists, and doctors. These people may have the best information about different therapies that they or other people they know have tried. Other parents tend to be a wealth of information and can give you lots of information on their experiences. If no one you know has tried a specific therapy, ask the therapy center for the names and numbers of some previous clients, but be aware that testimonials may not be true or honestly and freely given.

7. Check the Better Business Bureau (BBB) or Google the therapy center. Therapy centers that tend to be profit-only enterprises are likely to have negative comments made about them on the BBB or the web. Visit the BBB at <http://welcome.bbb.org/> Other good sources include checking to make sure the therapy center has been cited by the FDA or a state medical association.

8. Weigh the cost and benefits. If a therapy costs \$20,000, many families will most likely only be able to do that one therapy, sacrificing other therapeutic and equipment needs, as well as possibly endangering your family's financial status. Several types of therapies are set up so that you must attend many sessions before a benefit is expected, making it very easy to spend an exorbitant sum before you realize the therapy is simply

not effective for your child. Unless you can really justify the cost of an expensive therapy, you may be better off saving your money and spending it on equipment and therapies that are of a greater benefit to your child.

9. Evaluate YOUR motivations. This is, of course, a very difficult issue to think about and comprehend. Many parents have difficulty accepting their child's medical condition or disability. Some parents are so intent on finding a cure that they will try almost anything, even if the cost is great. These same parents are also the ones most vulnerable to the schemes of for-profit quacks. Take a moment to really evaluate your motivations and determine if the therapy is truly in your child's best interests or if YOU are attempting to use the therapy as a way to make your child into the child you picture in your dreams.