Best Practices!

The New *(and Improved)* THERAPEUTIC Landscape

Revolutionary Common Sense by Kathie Snow, www.disabilityisnatural.com

Emerging practices are changing the landscape of traditional physical, occupational, speech, and similar "developmental" therapies. In pockets here and there, no longer are children and adults with developmental disabilities seen as "broken" or in need of a "cure." And it's about time!

These new practices are bubbling up from a variety of different sources. But before examining this new therapeutic landscape, let's look at some circumstances that may be driving the change.

Many parents are rejecting the usual routine of toting their children to clinics for direct, hands-on therapies. They've learned that hours spent in therapy (including the travel time to and fro) can have a negative impact on the lives of their children and families: very young children spend their childhoods as "clients" and the family's life is ruled by the therapy schedule! In addition, many moms and dads are refusing to subject their children to the soul-crushing, "You're not-okay," message which children receive over and over and over again with each therapy session.

> ***For your own good.***
> ***What a ghastly phrase that was.***
> ***It covered the most barbarous and inhuman cruelties ever inflicted.***
> Margaret Millar

On the other side, many therapists have recognized there are better ways to help than by providing direct services. Their attitude is not unlike the proverb, "Give a man a fish and feed him for a day; teach a man to fish and feed him for a lifetime." They do "with" more than "for." These therapists have learned that greater outcomes are possible when they focus on what's really important to the child/adult with a disability, instead of focusing on traditional "developmental" milestones. Within this framework, therapists, the person with a disability, and family members, when appropriate, brainstorm what activities can help the person achieve his desires, and this assistance occurs in natural, inclusive environments. In addition, and equally important, instead of providing hands-on direct therapy, therapists teach the child or adult, parents, and/or others in the person's life how to incorporate these activities into the person's daily routine. Again, this method can achieve greater outcomes than "traditional (hands-on) therapy."

In the inclusive educational arena, therapists, parents, educators, and students are working together to ensure the student receives beneficial assistance in the classroom which is *relevant to the child's overall education.* Thus, pull-out therapies which focus on isolated functional skills are replaced with skill-building activities in the general ed classroom: keyboarding skills instead of stacking blocks, strengthening body parts during inclusive PE classes instead of stretching a child's hamstrings in the "special" room, helping a child with communication needs during reading time instead of pull-out articulation exercises, and so forth.

Finally, revisions to the Individuals with Disabilities Education Act (IDEA 1997) mandated that children birth-three are to be served in natural environments. Thus, according to the law, therapies and other early intervention services must be provided in the child's home, at day care, or whatever

setting is the child's natural environment, instead of at a therapy clinic, medical setting, or other *unnatural* environment.

So in this new therapeutic landscape, many therapists are moving away from being direct service providers and are becoming *consultants.* In turn, this leads to unlimited methods to provide assistance to children and adults with disabilities. We are, in fact, limited only by our imaginations.

As mentioned previously, therapists are spending time in the home—as well as in other locations—performing a variety of valuable tasks. These may include, but are not limited to: (1) providing expertise on which assistive technology devices may be helpful; (2) brainstorming with others on ways to make a home, a classroom, or a workplace more accessible; and/or (3) providing technical assistance to a person with a disability, as well as to parents, educators, child care providers, coworkers, and/or others, on how to integrate beneficial activities within the person's usual routine. Let's look closer at each of these.

Therapy is something we give to people who are not like us to help them be more like us.
Lessons are something we give to people that are like us to help them be more like themselves.
Nicholas Biales, 10-year-old with autism
(from a list serve)

Assistive Technology

For many years, therapists have been consulted on the use of wheelchairs and other mobility aids. Some therapists had valuable expertise to share, others did not. Now, the therapist's role in this area is expanded (for those with experience or the willingness to learn), as a therapist helps people explore the benefits of both high- and low-tech devices such as communication and/or mobility devices, computers, adapted clothing, eating utensils, and other daily living tools, as well as anything else that makes life easier and better.

Equally important, however, is a new attitude that can make an enormous difference: that assistive technology be viewed as a *first choice,* instead of a *last resort.* For years, for example, purchasing a wheelchair for a young child was perceived as a heart-wrenching decision that was made only after everyone had "given up" on the child ever being able to walk. In essence, therapists (and parents, as well) saw the child as a collection of body parts, the focus was on the body part that "didn't work," and no effort was spared to "make the legs work" (walk). In the meantime, of course, the child's overall development was often ignored. The "non-working legs" seemed to define who the child was as a whole.

Today, many are recognizing that a child's *overall development* is more important than any one particular body part. Thus, independent mobility is more important than walking. For example, when a two-year-old with a physical disability is provided with a power wheelchair, she can explore her world, benefit from the infinite learning experiences that come with freedom of movement, and play with her brothers, sisters, and other children. Once she's mobile, she's no longer treated like a baby: she's a busy two-year-old at work! Similarly, effective communication (via a communication device, cards, or other means) is more important than talking.

Many of today's occupational therapists are moving beyond spending innumerable hours trying to get a child's hands to write. (Who spends much time handwriting today, anyway?) So a therapist might help identify the type of keyboard which could enable a child/adult to use a computer for communication, for writing/learning at school, or on the job. This strategy can be more beneficial than manipulating fingers, wrists, and arms in therapy.

Today, access to information about high-tech devices, adapted toys, and other helpful products is no longer only in the domain of professionals. In many cases, parents take the lead and contact manufacturers/distributors in search of demos. While the child is using the demo, parents may call on a therapist for her opinion. In other cases,

therapists put parents, educators, or others on the path to AT, by sharing catalogs, web site information, and so forth. No longer do we expect—or want—a therapist or physician to be solely "in charge" of finding the right assistive technology devices for children or adults with disabilities.

Accessibility

In the home, in school, at work, on a park and rec team, at church, or in any other setting, therapists can provide valuable expertise on creating environments that are more accessible for, and supportive of, individuals with disabilities. A home visit, for example, can enlighten parents on what modifications will ensure a child has freedom of movement in his own home while using a mobility device. Similarly, a therapist or other professional may suggest environmental modifications to reduce the amount of stimulation for a child who has autism or is easily overstimulated.

Going to therapy doesn't make me feel like a regular person.
Benjamin Snow, at age six

Therapists are also working with educators, employers, church leaders, park and rec coaches, and others on creating supportive, accessible environments to ensure the inclusion of people with disabilities. In a perfect world, the requests of people with disabilities and/or family members would be respected. But in the real world, a "professional opinion" may carry more weight, and a therapist's recommendations may fill the bill!

Technical Assistance

In the area of teaching and providing technical assistance, therapists in the new therapeutic landscape can have an extraordinarily large sphere of influence. In the home, therapists can help parents learn how to incorporate beneficial activities throughout a child's day. Unlike traditional "home programs," however, in which a parent *assumes the role of therapist,* these activities are done in the normal course of a family's day, and in the most natural way.

In our home, when my then six-year-old son formally resigned from his lifelong therapy career, we realized there were many natural ways to accomplish the same things therapists had worked on. Over the years, occupational therapists had sat behind Benj and stretched his shoulders, rotated his trunk, and did similar activities during the two therapy sessions each week. At home, we could do these same activities twice a day, 365 days a year, while helping Benj get dressed and undressed each day. The dressing/undressing routine presented the most logical and natural time give Benj a "shoulder massage"—it was easy, natural, and we made it fun! Most importantly, it worked for Benj: he didn't see it as "therapy." Prior to this, when I tried to do a prescribed "home program," Benj resisted and said, "Mom, you're not the therapist. Just be *mom."*

A variety of natural activities can produce benefits. Having fun on a rocking horse (for balance), setting the table (for fine motor), playing in a hot tub or pool (helps with many skills), and any number of other *ordinary* activities are helpful, and do not send the "not-okay" message of traditional therapies.

Another positive outcome of the changing therapeutic landscape is the "demedicalization" of pleasurable activities. Parents and therapists alike are realizing that benefits can still occur when a child simply rides a horse for fun instead of receiving horseback riding therapy. Ditto for swimming and water play instead of hydrotherapy, gardening for fun instead of horticulture therapy, and so forth. We're learning not to risk turning an activity that a child loves into a medicalized treatment which she will then hate!

While I've focused on how a therapist as a consultant can enhance the lives of individuals with disabilities, this doesn't mean a therapist is always necessary. The true experts are children and adults with disabilities, along with their family members. As a parent myself, I trust in the wisdom, experience, and intuition of other parents to know how

to meet their children's needs. Similarly, I trust in children and adults with disabilities to know what they need. So if parents or individuals with disabilities do not feel the *need* for a therapist, this decision should be respected and supported. In our family, my son knew what was best for him when he tearfully stated at the tender age of six, "Going to therapy doesn't make me feel like a regular person."

There is no magic in traditional therapies, even though many of us have *believed* therapy is "the magic bullet." In fact, there is little *proof* that traditional therapy works! Prior to my son having spinal cord surgery at the age of three, I spent lots of time in medical libraries researching the procedure. In the process, I came across other articles of interest, specifically one that studied the benefits of physical and occupational therapy on very young children with cerebral palsy. According to the report, at the end of two or three years, there was little or no difference between the children who received intensive PT and OT and the children who did not!

We often believe therapy works because of the "cause and effect" theory: we observe a child doing something he didn't previously do, and believe this new skill is a direct result of therapy. But we have no proof he wouldn't have done the new skill without therapy! In my son's case, therapists sometimes worked for months on a particular skill or movement that Benj could not (would not?) master. Then, months later (sometimes years), he *did* do it, on his own schedule and in his own way.

A variety of universities are using my book *(Disability is Natural: Revolutionary Common Sense for Raising Successful Children with Disabilities)* to train emerging professionals in a variety of fields. My book includes the ideas presented in this article, and much more. In some places, students are learning how to help children *without* making them "go to therapy."

Lorrie Sylvester, a therapist/professor at Oklahoma University Health Science Center (OUHSC) vehemently states, "Doing therapy to change a child doesn't work!" She speaks from years of experience as a practicing therapist—and as a child, she received years of therapy herself. Beth DeGrace, another OUHSC therapist/professor has this advice for parents: *"Before a therapist touches a child,* parents should ask, 'Can you show me the evidence that what you want to do is effective?' And once a therapist has started working on a particular thing, if there isn't change within a reasonable amount of time, the therapist needs to stop wasting time and money!"

No, the magic is not in therapy, the magic is in the child and his desires, hopes, and dreams. Our job (parents and therapists) is not to make a child acquire particular skills, but to help with activities, AT devices, and supports/accommodations that will enable a child to achieve his hopes and dreams.

When we turn children into clients, send them "not-OK" messages, rob them of their childhoods, and try to force them to do things they may never be able to do, we can easily kill the magic within. When we focus on a child's *overall* childhood and development, we'll use our common sense and find ways to easily incorporate pleasurable and helpful activities into a child's daily routine in the natural environment. Not only will this demonstrate respect for the child, but it will also enhance the child's desires, hopes, and dreams.

The new therapeutic landscape is helping forge a positive new perception about the "wholeness" of individuals with disabilities, and it is also paving the way for successful, natural lives in the community. Again, it's about time! My hat is off to therapists, parents, people with disabilities, and others who are making the world a better place via this new therapeutic landscape.

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