

JOE SCHIAPPACASSE ON ^{everyone's} BEHAVIOR

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

Joe Schiappacasse has been recognized as one of the leaders in best practices in behavior issues. He generously shared his time and expertise for this interview in 2001. Sadly, Joe passed away in 2002; his teachings, however, continue to motivate and inspire new ways of thinking about behavior issues.

WHAT'S YOUR BACKGROUND, JOE?

I've been a behavior specialist for over 15 years. Before that I did a fair amount of work in vocational and residential services. At one time or another, I've had the opportunity to experience most aspects of the service business. For the past 15 years, my efforts have been focused on providing training in understanding behavior and supporting healthy behavioral growth. For the past 12 years, I've been involved in a federally-funded project involving several universities across the nation that specialize in understanding behavior supports. This project is a network of over 20 state projects that, along with universities, conduct research, develop training materials, and try to capture and expand examples of best practices in positive behavior support for public dissemination and application. Currently, I'm employed half-time by Colorado Developmental Disabilities Services. The other half of my time is spent as a member of the Community Circle, a Denver-based consortium of mental health professionals. The Circle focuses on serving under-appreciated populations, providing education, consultation, and behavior pharmacology clinics. And this work is important to me personally, as I'm both the parent and the brother of individuals with disabilities.

WHAT DO WE NEED TO KNOW ABOUT BEHAVIOR AND PEOPLE WHO HAVE BEEN LABELED?

The most important thing we all need to keep in mind is that people with disabilities need the same supports you and I take for granted, including the same level of quality and availability. We're still offering people with disabilities supports that are very different, based on a "deficit" focus rather than a whole person focus. In other words, there's still a

very clear "us/them" orientation. Unfortunately, what's available to persons with disabilities too often depends on the disability label.

In practical terms, what we offer to the people who we see as different—different from a "deficit" point of view—is a very limited array of strategies and supports that are often based on external control. These are usually comprised of very mechanical, quick-fix, textbook type strategies, rather than real life strategies.

Because we focus on the *perceived deficits* instead of the *whole person*, the behavior strategies people use on others are frequently based on the results of narrow, limited assessments. In addition, these deficit-focused evaluations frequently result in misunderstanding. I'm not saying we should ignore those parts of a person's life that are problematic. But the real—and long-lasting—solutions to a person's "problems" will come from understanding his strengths, the things he's good at, his personal goals, and what he enjoys in life. So we need to use more assessments that examine a person's strengths, capacities, dreams, and gifts.

Many people still rely on assessments and analyses focused primarily on core "problem behavior." But that's just one small part of a functional analysis. We must also analyze *what works* in people's lives. We need to ask questions about positive behavior: "When does the 'problem behavior' *not* occur? In what settings? With whom? Under what circumstances?" and so forth. Then, not only can we *add* more of those things to people's lives, we can also—and perhaps more importantly—do in-depth analysis of *why* those things work. This information will tell us more and help us better understand a person's successes, and it will give us direction for expansion and growth.

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Here's an example. If the main place you *don't* act up is at church, Kathie, we could say, "OK, Kathie could benefit from spending more time at church." But that's probably not a practical solution, day in and day out. So we'd ask, "What are the *characteristics* of church that make the difference? Where else can we find similar qualities in other environments? What's the intrinsic motivation for positive behavior and participation in the church environment?" This is probably at the core of what we need to better understand behavior issues.

Traditionally, a person with a disability is on the receiving end of punishment, aversive behavior management, and extrinsic/external reinforcers that someone else dishes out, as methods of control. But if I use these strategies to control you, Kathie, not only do I remove the balance of equity in our relationship, but I'm also making you dependent on me, and we know this is not good. Your dependence on me (or anyone else in a similar position) will not lead to long-lasting change or success for you and, in fact, it sets you up for greater victimization. I'm not saying all extrinsic reinforcers are bad, but they should *not* be the main form of teaching and encouragement.

JOE, EARLIER YOU SAID WE NEED TO OFFER PEOPLE WITH DISABILITIES THE SAME SUPPORTS YOU AND I TAKE FOR GRANTED. WHAT DO YOU MEAN BY THAT?

I'm talking about the *unconscious supports* that are so common, most of us don't even think about them—those things that are the "positive natural consequences" of living in a community. Being part of a family, having at least one unpaid person in your life who is a friend, easy access to one's community, healthy sexuality, frequent social opportunities to belong, and a wide array of other typical activities that provide natural behavior supports. The ability to call in sick when you're not really sick is a natural behavior support! But these things are missing from the lives of many people who have been labeled. They don't have the same level of power, choice, and control of their lives that most of us take for granted.

Think about all the self-help things we do on a daily basis to manage our own mental health and

behavior: we exercise, use relaxation techniques, go shopping, take medication, go out to dinner, eat chocolate, and do so many other things for ourselves! We use a wide, wide array of self-help strategies.

Then there are the *active* strategies we consciously use to manage our behavior, such as counseling and other mental health assistance. But even these are often denied to people with disabilities. Let's take the example of someone who is thought to have a "low IQ." Many mental health professionals don't believe the person has the insight to benefit from counseling. It's easier and safer to assume this, rather than taking the time and making the effort to figure out *how* to make it work.

We've all heard the recommendation to "count to ten" when we're upset or angry. How many of us really do it? Yet this is one of the most common strategies offered to people with disabilities! Why? Because it's a simple activity we can easily get our arms around and it meets *our*—the support giver's—immediate needs. Many of us simply don't want to take the time or spend the effort trying to figure out what's really right for a person.

What we do with *our* behavior is based on our *capacities*; what's done to people with disabilities is usually based on a person's *perceived deficits*. "Behavior reduction plans" are the logical outgrowth of this type of focus.

Our behavior supports are usually in alignment with what internally motivates us. People who are labeled are frequently limited to *external* motivation strategies. The methods we use on ourselves are based on pleasurable activities, while methods used on people with disabilities are often based on pain and restriction.

There are awesome discrepancies between the quality and characteristics of behavior supports available to people with disabilities as compared to people who haven't been labeled. Ultimately, the way a person is *valued* dictates what opportunities are available to him.

WHAT ARE THE BIGGEST ISSUES FACING PEOPLE WHO HAVE BEEN "BEHAVIORALLY" LABELED?

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Misunderstanding and misdiagnosis. Many serious, ongoing behavior issues are actually the result of undiagnosed and untreated pain. By not looking at the whole person, we fail to identify all the contributing biological, neurological, medical, and contextual conditions. For example, many people have undiagnosed or misunderstood seizure disorders. Some seizures can look like a sudden outburst or aggression that we see as “problem behavior.” But because the person doesn’t foam at the mouth or fall to the floor when a seizure occurs, the condition is misdiagnosed.

Our behavior pharmacology clinic is geared to understanding folks with complex behavior issues. Over 85 percent of the people we see in our traveling clinics actually have an undiagnosed or untreated medical or neurological condition that is causing or contributing to the “problem behavior.” Our society has been programmed to see a person’s “problem behavior” as a willful act of choice, instead of as a *symptom* of a person’s whole being—current biology included.

We’ve come across many people who have been misdiagnosed with autism, because assessments were focused on perceived deficits rather than actual capacities. For example, a family member of a person labeled with autism will describe the person as the most loving and intuitive person in the family, as someone who enjoys physical closeness, who enjoys change, and so forth—all of which are in opposition to some of the classic characteristics of autism. But because the person has a certain type of communication pattern or behaviors we see as “self-stimulation,” he has been labeled with autism. In some cases, an individual may have been the recipient of certain types of behavior strategies for years, or been in a particular environment, and these strategies or environments have imposed limitations on what he can do. Thus, the *symptoms* of autism have become entrenched and the *autism label is erroneously validated*.

We’ve seen many people in our clinics who have been labeled with autism when they actually have Tourette syndrome or a type of movement difference. Here’s what happens: as a child, the person exhibited

certain characteristics that led to his being labeled with autism. Then he’s put in environments with others who share the same or similar label. Many people with Tourette syndrome have echopraxia—which means they have a tendency to imitate the behaviors of others. If this person has received treatment for autism, and has been put in “autism environments,” he’ll *learn* to mimic symptoms of autism. No one questions the diagnosis, since his “autism symptoms” not only continue, but expand the more he is isolated with persons with autism! Based on national averages, we should be seeing four times the number of people with Tourette syndrome compared to the number of people with autism, but the reverse is occurring.

The solution to people being undiagnosed and misdiagnosed rests in providing a “whole person” evaluation, that includes current medical, neurological, and biological—as well behavioral, contextual, cultural, and spiritual—assessments. A person’s full life history is a critical component in the “whole person” evaluation.

WHAT IS APPLIED BEHAVIOR ANALYSIS AND IS IT VALUABLE?

Applied Behavior Analysis (ABA) is the attempt to understand a person’s behavior and use that information to support a better life. However, it has been misinterpreted by many as a way of *managing* a person’s behavior. ABA can be a good source of information when it’s viewed as just *one of many ways* to learn more about a person. It can be a valuable tool to help us understand the conditions under which certain behaviors do and don’t occur. But serious miscalculations occur when people expect it to provide all the answers—the whole solution.

Unfortunately, we often use ABA to *reinforce* the perceptions we already have about a person! ABA should never be seen as the whole solution, but it should also never be totally disregarded. ABA is a tool that can help us better understand by providing useful information. But it must be combined with medical, neurological, biological, contextual, spiritual, and cultural assessments. And through these processes, our goals must always include a plan to discover, *from the individual being assessed*, “Who do you want to

The real solutions will come from understanding a person’s strengths.

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be?” and to learn what intrinsic (internal) motivators and reinforcers he prefers.

Unfortunately, there is a center on the East Coast that still uses electric shock, noxious stimuli, and other forms of diabolical punishment to manage or control a person's behavior. What other population is subjected to these strategies? It's *against the law* to use these methods on the most heinous criminals in our prison system. Yet they're used on people with developmental disabilities, without the choice or consent of the individual! We must get better at offering the right supports—in our communities—to individuals and their families.

Some people with autism (especially young children) are frequently subjected to highly-mechanized, intensive 40 hour a week therapies. But we have to ask ourselves: how does the person receiving this treatment feel about it? Shouldn't we care? And, second, is the person really benefiting from the treatment? Often, no benefit is seen, but we keep doing it, thinking if we do it long enough or with enough intensity, we'll eventually see results. In the meantime, we could have been using other strategies that work—strategies that are important and relevant to the individual.

WHEN THINKING ABOUT CHILDREN WHO ARE LABELED WITH “BEHAVIORAL CONDITIONS,” WHERE IS THE BEST PLACE FOR THEM TO SPEND THEIR TIME?

In inclusive, natural environments—in schools and communities. We should *never* offer strategies based primarily on a person's label; this practice leads to the exclusion and isolation of children and adults with disabilities. The methods we use should be based on who the individual really is—who the *whole person* really is.

Too often, some of the highly respected, nationally recognized systems of support and intervention are based on a person's label, rather than on how the individual really learns. My experience is that each person with autism, for example, has a unique way of learning, just as you and I have our own unique ways of learning. But there's a widespread assumption that people with autism are all alike, so treatments, interventions, and supports are based on the label instead of the person's individual needs and learning style.

WHAT CAN PARENTS DO REGARDING THE “BEHAVIOR ISSUES” OF THEIR CHILDREN?

The most important thing parents can do is to remember to be Mom and Dad. Behavior supports should not interfere with your ongoing love and unconditional acceptance. That's the strongest support you can offer. It's important to realize that our own children's behavior can be the most difficult to understand! Parents and children develop invisible patterns of behavior and systems of interactions over the years, and it can be very difficult for parents to step back and analyze what's really happening.

Typical “Us/Them” Differences in Behavior Supports

“Us”	“Them”
Capacity Focus	Deficit Focus
Internal Motivation	External Motivation
Pleasure	Pain
Strength-Driven	Weakness-Driven
Wide Thinking	Narrow Thinking
Value Giving	Dehumanizing
Free Access	Contingent
Enriching and Expanding	Limiting

As an example, someone who hasn't seen your child in awhile will say, “Look how she's grown!” But parents don't see the physical growth, because they're around the child all the time. The same is true with behavioral and emotional growth—it's hard for parents to see the changes because we're so close to the situation. Plus, we often get stuck in those old patterns of behavior and systems of interactions I mentioned before.

Parents can get a clearer picture when they ask family and friends for help. Ask, “What do you see going on here?” Others will often have valuable perspectives because they're not so close to the situation.

In the realm of professional help, moms and dads should make sure their children receive a “whole person” evaluation, that includes medical, biological,

neurological, contextual, cultural, and spiritual assessments. And when looking for professional expertise, parents need to get references! Ask for the names of people the professional has worked with before—real families and individuals—and talk to them before deciding if this is the right professional for you.

WHAT RECOMMENDATIONS DO YOU HAVE FOR EDUCATORS REGARDING CHILDREN WHO NEED BEHAVIOR SUPPORTS?

Educators and parents both need to be really clear about what the goals are for the child. And the goals should be growth-oriented, leading to the child's greater self-control and self-management.

In many cases, one of the first behavioral actions of a teacher at the beginning of the school year is listing the classroom rules on the blackboard, basically saying: "You must do/not do this or you can't be in my classroom." But this creates a situation where children are responding to a teacher's rules—which are temporary, during the time the child is in the class—instead of a child's own rules that will last a lifetime. We end up focusing on obedience and compliance instead of creativity and internal motivation.

When we allow children to generate their own rules, they create rules that are usually more stringent than the rules adults set for them! And kids will help

each other honor their *own* rules more than they'll honor the rules of others. When children are *internally* motivated, they are much more likely to experience long-term success in inclusive, natural environments—in other words, in the real world of community. In addition, at school, home, and in other settings, we must give people real reasons for why they're expected to behave and participate, rather than just obedience for the sake of obedience. And then we must ask ourselves hard questions. *Why* should he do such-and-such? Is it *important* to him? Is it *relevant*? Is it *right* for the person? What supports does he need to be successful in this activity or environment?

WHAT ABOUT THE IDEA THAT "BEHAVIOR IS COMMUNICATION"?

Yes, behavior *is* communication. In some instances,

it's not necessarily a direct attempt at communication, but an attempt to address what's important to a person at the time. And we can move even further and recognize that many forms of behavior—especially what's called "problem behavior"—is a *symptom* of something not working right in a person's life. All behavior meets a need or serves a purpose. One behavior may meet multiple needs, while the very same behavior can mean two or more *different* things.

Not only is behavior communication, but it is frequently more valid than typical communication. It takes much more effort to lie with your behavior than to lie with your words. My older brother, who has been labeled with a variety of disabilities, taught me, "The truth is in what you do, not what you say." He's taught me a great deal.

CAN NON-PROFESSIONALS PROVIDE THE APPROPRIATE HELP AND INTERVENTIONS?

Of course. It's up to each of us to figure out better ways to get our needs met. We need to move away from the generic goal of "a reduction in problem behavior." This isn't really the issue or the solution.

We often implement behavior reduction programs when we think a person's behavior is dangerous or unhealthy. The solution is never just a behavior reduction program. The *quality* of someone's life is the real acid test. When we're providing supports, one of the best measures of whether what we're doing is right is to simply ask a person, "Are these supports making your life better?"

Have we ever considered that many of us who have *not* been labeled have "problem behaviors?" We each have certain ways of self-stimming, body movements, perceived personality flaws, and other traits that will be with us forever. Look at your own life—maybe you have a nervous habit or an in-law that brings out the worst in you and vice-versa. How do you deal with that? You improve the quality of your life in other ways. Maybe you take a few more days vacation, spend more time reading a great book, listen to more music, or do something else. Soon enough it will be time to deal with the in-law again, and the gnawing behavior is still there, so you once

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again kick in behaviors or actions to compensate. It's all about balance.

But for people with disabilities, there is often no balance and no compensatory opportunities. Look at the number of people who have had their communication systems taken away as a punishment within the context of "behavior management." I remember a teenager I'll call "Mike." He had his wheelchair taken away as a "consequence" for running into some students who had been secretly tormenting him. Professionals saw his behavior as inappropriate and aggressive! Why? First, because they failed to see and understand the behavior in its full context, as a healthy expression of self-protection. And second, because they probably saw the behavior through their "perceived deficits" filter.

Look at facilitated communication. "Mary" is accused of lying while using FC, so her only tool for effective communication is taken away as a punishment/consequence. Hey! Who among us doesn't lie? Why can *we*—people without labels—lie with few, if any consequences, but people with disabilities can't?

Would we take away the legs from someone who walks or the tongue of someone who talks, as a punishment or consequence? No! So why is it okay to rob people with disabilities of movement or communication?

IN YOUR WORK, YOU TALK ABOUT "ENVIABLE BEHAVIOR SUPPORTS." WHAT DOES THAT MEAN?

It's a concept I use in an attempt to get at the core of what positive behavior supports really are. The concept of positive behavior supports has been twisted into so many different things. Some people define positive behavior supports as "not using aversives." Well, that's a nice start, but it's only a fraction of what positive support requires. While I appreciate the concept of not using aversive treatments, people with disabilities *can still be hurt* under the auspices of what some people call positive behavior supports.

Not taking a long-term, whole-person perspective; building in artificial supports without a plan to fade them to natural and community supports; indiscriminately reinforcing certain system/staff behavior; or predominately using extrinsic forms of reinforcement are just some of the ways that well-intended support can create greater problems for the individual.

For example, food is often used as an extrinsic reinforcer. Some people provide food as a reward when a person sits quietly doing nothing. What does that teach someone—that being a couch potato is a good thing? Positive behavior support is a good process, but it's often misconstrued. Part of this comes from its name: we assume we're doing a good job if we provide positive reinforcers, instead of negative ones. But, again, these can do more harm than good.

It's time to up the ante and focus on *enviable* behavior supports. We'll know supports are "enviable" when a person looks at the supports and approaches being used in another person's life and says, "Hey, that looks good to me! Can you do the same thing with me? Those are the things I need in my life."

Consider the flip side: how many of *us* have ever read the behavior plan written for a person with a disability and said, "Gee, I'd like this to happen in *my* life..."

Providing enviable behavior supports is really a commonsense approach that's right for all human beings. We've got to move beyond offering supports from an "us vs. them" orientation.

It's time to recognize first and foremost that people with disability labels have abilities! The solution to behavioral complexities will come not from focusing solely on a person's perceived deficits, but from identifying and understanding a person's abilities, gifts, and desires. Looking at the whole person is the key. And the ultimate test of whether we're providing healthy behavioral supports is really quite simple: do the supports sustain and increase an individual's belonging, autonomy, and competence?

We have to ask ourselves: how does the person receiving this treatment feel about it? Shouldn't we care?