

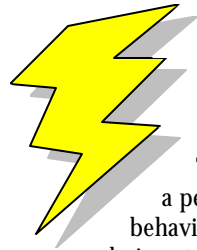
10 Things You Can Do to Support A Person With Difficult Behaviors

David Pitonyak

Supporting a person with difficult behaviors begins when we make a commitment to *know* the person. Sadly, it is often the case that the people who develop an intervention to stop someone from engaging in difficult behaviors do not know the individual in any meaningful sense. Instead, they see the person as a someone (or *something*) that needs to be fixed, or modified. But attacking a person's behavior is usually ineffective and always disrespectful.

Think about someone you know who engages in difficult behaviors. Ask yourself, "What kind of life is this person living?" Consider how you would feel if you lived the person's life. How would you behave?

What follows are 10 things you can do to support a person whose behavior is troubling you. It is not a list of "quick fix" strategies for stopping unwanted behavior. It is a list of ideas for uncovering the real things that a person might need so that you can be more supportive.

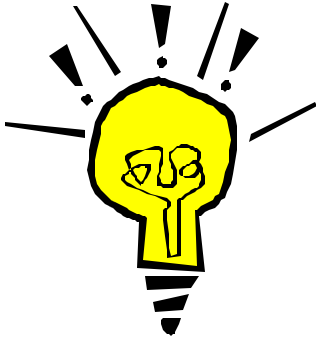


1. Get to know the person.

The first step in supporting a person with difficult behaviors almost seems too obvious to state: *get to know the person!* It is too often the case that people who develop interventions to eliminate unwanted behavior do not know the person in any meaningful sense. They know the person as the sum total of his or her labels, but know little about the person as a "whole" human being.

Make a point of spending time with the person in places that he or she enjoys, during times of the day that he or she chooses. It should be a comfortable place where both of you can feel safe and relaxed (e.g., a quiet room, a nice restaurant, a walking trail in a nearby park).

At a time that feels right (you will have to trust your intuition on this one), tell the person about your concerns and *ask* for permission to help (it's rude not to). If the person has no formal means of communication, *ask anyway*. Sometimes people understand what is being said, but they have a difficult time letting



It's almost too obvious to state: *spend time with the person*

others know that they understand. The important point, always, is to *ask* the person for *permission* to stick your nose into their business, even at the risk of seeming silly in front of people who think the person cannot understand up from down (they're usually wrong).

2. Remember that all behavior is meaningful.

Difficult behaviors are "messages" which can tell us important things about a person and the quality of her life. In the most basic terms: *difficult behaviors result from unmet needs*. The very presence of a difficult behavior can be a signal that something important that the person needs is missing. Here are some examples of the kinds of the kinds of messages a person may be conveying with his or her behavior:

"I'm lonely."

Michael's older brother was invited over to a friend's house for a sleep over. Michael is never invited to the homes of children because he goes to a "special" school 35 miles from his neighborhood. Michael has no friends to play with.

"I'm bored."

Roberta's sister is a doctor at the local hospital. She has her own house and is her parent's pride and joy. Roberta works all day at a sheltered workshop where she packages plastic forks and knives. She lives at home and is tired of packaging. She wants to get a real job. Roberta's case manager says she day dreams too much.

"I have no power."

John likes to sit down on the sidewalk when the bus arrives to take him to school. His mother becomes very angry and tells him that there will be no dessert when he gets home. John laughs when the bus driver threatens him with time out.

"I don't feel safe."

Conrad uses a wheelchair and is not able to defend himself adequately from attacks by another man. Conrad worries that he will be hurt and often cries when left alone. Staff think he has a psychiatric illness.

"You don't value me."

Gloria has a "severe reputation." People from all over the state have heard stories about her terrible tantrums. No one knows that she is a very caring person who worries about environmental issues. The only part of Gloria people pay attention to is her problem behaviors.

"I don't know how to tell you what I need."

June does not know how to use words or sign to let other people know what she was thinking. She lives in an institution where she learned that the best way to get people's attention was to bite your arms. It hurts, but it is the only thing that "works."



"My ears hurt."

Walter hits his ears with his fists. His job coach wants to stop and wrote a behavior plan for "not hitting." Weeks later, at a scheduled doctor's appointment, it was learned that Walter had a low-grade ear infection. Anti-biotics cleared up the infection and Walter has stopped hitting his ears.

"My body does not move like I want it to."

Aron wanted to order a hamburger at a the restaurant, but his mouth kept saying, "I want pizza." When the waiter brought him pizza, he became so upset he knocked it on the floor. Later, at home, he typed to his mom, "I wanted a hamburger but I couldn't stop saying, 'I want pizza.'" Aron experiences differences from other people in the way his body moves (see Anne Donnellan and Martha Leary's book, *Movement Differences and Diversity in Autism/Mental Retardation: Appreciating and Accommodating Persons with Communication and Behavior Challenges* for additional information (ordering information on the last page).

Obviously there are many needs that a person may be conveying with her behaviors. A single behavior can "mean" many things. The important point is that difficult behaviors do not occur without reason. All

behavior, even if it is self-destructive, is "meaning-full."

Ask the person (and/or the person's supporters) what he or she needs to be happy. Find out who he or she counts on in a pinch. How often does he or she see loved ones and friends? What are his or her favorite activities? Where does he or she like to go? Ask the person what leads to unhappiness. Who are the people who the person does not like? How often does he or she see them? What are the person's least favorite activities? Since many people are experiencing physical and/or psychiatric distress, it's also important to know something about the person's physical and emotional health. Does the person have a way to let others know what he or she needs and feels? Is the person experiencing physiological or psychological distress? What kinds of medications is he or she taking? Do they help?

Finally, if you're stumped, ask, "Are there times when the person exhibits this behavior frequently?" and "Are there times when person exhibits this behavior infrequently or not at all?" Answering these two questions can tell you a great deal about the meaning of the person's behavior. With time, you should be able to see a discernable pattern.

For example, you might find that the person engages in the difficult behavior in the morning hours, but rarely in the afternoon. Ask, "What happens in the morning that might cause the person to behave this way?" or, conversely, "What is happening in the afternoon that causes the person *not* to behave this way?" (Hint: it often has

something to do with the things a person is being asked to do, and/or *who* is asking the person to do it).

3. Help the person to develop a support plan.

People who exhibit difficult behaviors are usually subjected to a behavior plan at some point in their lives. It is rare that they are asked if they want a plan, let alone invited to the meetings where one is developed. Instead, a plan is developed by strangers (e.g., the agency behaviorist who has spent less than two hours "observing" the person).

Think about how difficult it would be to stop a behavior that a stranger thinks you should stop. It can be difficult enough to stop behaviors we choose to stop (e.g. smoking, excessive eating)!

Instead of a behavior plan to "fix" the person, help the person and the person's supporters to develop a support plan that reflects a real and authentic life. John and Connie Lyle O'Brien suggest the following questions for building a support plan. Note how different these questions are from those we typically ask, such as "How can we reduce this person's problem behaviors?" or "How can we manage this behavior?"

1. *How can we help the person to achieve health and wellbeing?*
2. *How can we help the person to maintain his or her relationships and make new ones?*
3. *How can we help the person to increase his or her presence and participation in everyday community life?*
4. *How can we help the person to have more choices in life?*

5. How can we help the person to learn skills that enhance his or her participation in community life?
6. How can we help the person to make a contribution to others?

The team can ask, "Is our vision for the person similar to the vision we hold for ourselves and each other? When we think about what the person needs, do we focus on "fixing" deficits or do we think about supporting the person in achieving a *real* life?"

4. Develop a support plan for the person's supporters

Just as it is simplistic to treat a person's behavior without understanding something about the life the person lives, it is simplistic to develop a support plan without considering the needs of the person's supporters.

Many of our school and human service delivery systems are based on the idea that a few people with greater knowledge and power should bestow care and skills to a larger number of people with lesser knowledge and power. "Success" is based on compliance or obedience. A person who engages in difficult behaviors presents a real threat to a care-giver or teacher whose competence is being judged by this "compliance/ obedience" yardstick. The caregiver often expends great energy trying to suppress the person's behavior in order to maintain "competence" (in many of our workplaces it is acceptable to share knowledge but not to share power).

Punishment or the fear of punishment (coercion) may be the primary means of

"motivating" staff. Many approach each day with a mixture of fear and dread. If they make a mistake, they could be "written up," demoted or fired. If they try something new, it may violate a policy or procedure. The unspoken message is "do as you are told" or suffer the consequences. Many of our human services environments are "toxic" with fear.

It is in this context that human services workers are "told" to be supportive. Workers are trained in positive approaches when the underlying organizational message is "maintain obedience." Under the deadening weight of these systems, even the kindest and most respectful of caregivers may begin to exhibit their own difficult behaviors. They become excessively controlling and resistant to change. They begin to believe that individuals are worthy of their labels and "beyond hope." They may even resort to forms of punishment procedures that the average citizen would find repulsive and unacceptable.

Take time with your colleagues to develop support plans for each other. For example, what can you do to increase each other's level of safety and comfort when someone is behaving dangerously? What can you do to have more fun at work? How can you have more control over your schedule and input into decisions? How can managers better support you?

A fundamental question is, "If you stopped responding to the person's difficult behavior the way you do now, who would *you* be?"

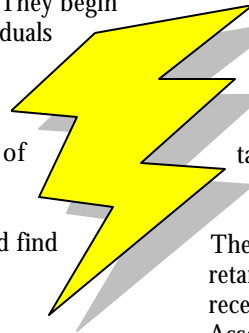
5. Don't assume anything.

It is easy to make the mistake of underestimating a person's potential because of her labels or because she has failed to acquire certain skills. This is a tragic mistake.

I have worked in the field for 15 years and am less confident in my ability to predict how much a person understands with every passing day. Recent developments make clear the folly of making predictions about a person's potential on the basis of diagnostic labels or past performance. Hundreds of thousands of people deemed "unfit" for society have left our institutions and now live in community. One hundred and twenty thousand people who were assessed "unemployable" because of the severity of their disability now work and pay taxes thanks to supported employment services.

The very definition of mental retardation itself has changed in recent years. The American Association for Mental Retardation (AAMR) has recently overhauled the definition. Gone are pessimistic predictions that saw little hope for the "severely retarded" and "profoundly retarded." The new definition eliminates such terms altogether and emphasizes the importance of our supports. In short, an individual's potential depends largely upon the adequacy of his/her supports rather than some inherent flaw or "defect."

Always remember that people are people first. Labels tell us nothing (in any real sense) about how we can be supportive. We



need not forget the person's problem behaviors, but we must understand that people have gifts and capacities that eclipse our labels (or, as Herb Lovett has said, our "clinical accusations.") Always remember to speak directly to the person and explain things as clearly as you can, even if the person's labels suggest that he cannot understand (at the very least the person will understand the tone of your voice). Never speak about the person as if he were not in the room.

6. Relationships make all the difference.

Loneliness is the most significant disability of our time.

Many people with disabilities, young and old, live lives of extraordinary isolation. Some depend entirely upon their families for support. A brother or sister or mom or dad are the only source of company. Friends are often absent altogether.

All too often, the only relationships people have are with paid staff. Although staff can offer a great deal, they change jobs frequently or take on new responsibilities. The resulting instability can be devastating to someone who is fundamentally alone.

Remember that there are many people in the community who will benefit from knowing the person. Chances are the person has already made someone's life fuller. Be confident that she or he will make someone's life richer again and again.

Learn more about personal futures planning and other person-centered approaches to

planning.

7. Help the person to develop a positive identity.

John Bradshaw writes, " Our identity is the difference about us that makes a difference."

Many people with disabilities develop identities as "problem people." They are segregated into "special" programs where they are treated as people who have little to offer. Soon their "treatment" becomes a kind of cage to protect them from themselves and others. The real danger is that if enough people begin to think of the person as a "problem," she will begin to believe it too.

We all need to be needed.

Help the person to find a way to make a contribution. Start when the person is young if you can. Giving is a lifelong endeavor. Things as simple as helping with household chores or helping out at church can teach the person that she *can* make a contribution.

Pour over the newspaper and find the "Volunteers Needed" section. Talk to the person about joining an organization with you or with a friend (e.g., Habitat for Humanity, a local food shelter, an environmental group).

Help the person to learn how to support friends (e.g., an invitation to a sleep over, birthday cards, learning to ask "How are you doing?" or "What's new?").

Remember that it is important to overcome the belief that the person has nothing to share. It takes time and determination to help the person and others to see strength and the capacity to give

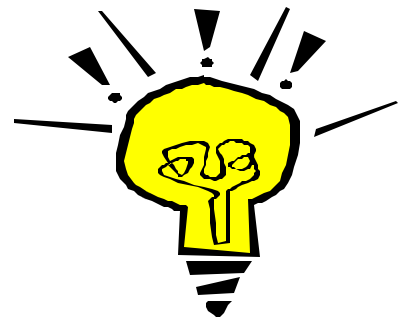
when deficits were all that anyone ever saw before.

8. Instead of ultimatums, give choices.

Choice is a powerful alternative to punishment. If the person's behavior challenges you, help him to find more desirable ways to express the needs underlying the behaviors. Instead of ultimatums, give choices (e.g., "Bill, I know you're upset. What would help? Would you like to go for a walk? or take a ride? You need a chance to calm down.")

Allow the person to make decisions throughout the day. If he has trouble making choices, find a way to help. Make sure there are at least three desirable outcomes to choose from. As Norman Kunc has said 1 option = tyranny; 2 options = a dilemma; 3 or more options = a real choice.

Don't assume that helping the person to have more choices means letting him do whatever he



wishes. Limit-setting is an important and fair part of any relationship. The real question is who is setting the limits and why. If limits are imposed upon the person without their input, and if the limits are part and parcel of a life in which the person is powerless, even your best advice may even be interpreted as one

more statement of "do it my way or else." You can expect a general disregard for your advice if the person on the receiving end of the advice is "out of power."

Make a sustained commitment to the person and to "fairness" in the relationship. If the person has been on the outside of power for too long, you may need to bend more often than not for awhile. The goal is to teach the person that giving is a two-way street.

9. Help the person to have more fun.

Fun is a powerful antidote to problem behaviors.

People with significant disabilities often live in ghettos of reward. Indeed, it is often this poverty of reward, not a lack of skills, that keeps people separate from other community members. Many must endure reward schedules for good behavior. The very few things that they enjoy are used contingently to reinforce compliance (talk about spoiling a good thing!).

Count the number of things the person enjoys, the number of places she likes to go. Compare this to the number of things other people enjoy, the number of places other people go. Ask yourself, "Is the person having fun? Is she experiencing enough joy? Is this an interesting life with things to look forward to?"

Help the person to add to her list of interesting (and really fun) things to do. Spend time in regular community places where people hang out. If you feel compelled to take data on something, take data on the

amount of fun you find. Make fun a goal.

10. Establish a good working relationship with the person's primary health care physician.

Mark Durand has said, "People tend to get immature when they don't feel well." How often have you experienced a general decline in your mood or your ability to empathize with the needs of others when you don't feel well? When we are sick, we are not ourselves.

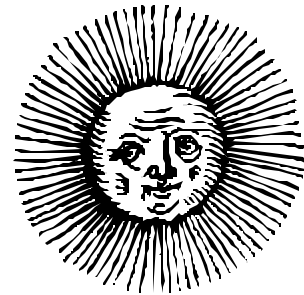
Many people who exhibit difficult behaviors do so because they don't feel well. The sudden appearance of behavior problems may be a signal that the person does not feel well. Illnesses as common as a cold or ear ache can result in behaviors as inconsequential as grumpiness or as serious as head banging.

It is important to establish a working relationship with a good primary health care physician. Although this is easier said than done, the person will, especially if he has difficulty communicating, need a doctor who can help him to stay healthy and well.

Remember that physicians, like many other people who grew up in our "separate" society do not always understand (and may even fear) a person with substantial disabilities.

Don't be afraid of telling the person's doctor that you don't understand a recommendation or finding. It is important to get a

clear and straightforward answer to *all* of your questions.



Remember too that it is important to go beyond a concept of health as the absence of a disease or illness. "Feeling well" and "being healthy" involves everything from a balanced diet to a good night's sleep. Help the person to achieve a state of "wellness."

Ordering Anne Donnellan and Martha Leary's book about movement differences.

Anne and Martha's book *Movement Differences and Diversity in Autism/Mental Retardation: Appreciating and Accommodating Persons with Communication and Behavior Differences* can be ordered through the Autism National Committee Bookstore (AUTCOM). Telephone orders: 1-800-378-0386. Online: www.autcom.org

I can be reached at Imagine, 3694 Mt. Tabor Road, Blacksburg, VA. 24060 (w: 540-552-5629) or Dimagine@aol.com. You can also visit my web site: www.dimage.com