

What Works to Support People Who Have Severe Challenging Behaviors

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Often in our work that focuses on supporting disability service agencies to shift from offering congregate services in group homes, center-based day programs and the like, to instead, offering personalized supports that assist each person to live a good, full, self-directed life, training participants ask whether this individualized support model works for people with disabilities who have dangerous or self-destructive behaviors. When we offer rich, satisfying lives, when people with disabilities are in charge of their own lives, when people's wants and needs are heard and we respond to them, when we are not restricting, isolating and controlling people, much of the challenging behavior we see in structured, segregated settings just fades away. Behaviors that challenge us and the people who experience them are often motivated by restrictive settings and abate – or at least recede when those behaviors are no longer needed.

Staff members of agencies that support people with disabilities, often ask questions along the lines of “What should we do with people who have behavior problems?” Questions like this imply that people's behaviors are an indication of intrinsic deficits – problems *within* people that need to be fixed. When asked how to best support people whose behaviors present challenges I often ask for an example. “Well,” explained one woman recently, “there's this guy -- he can get violent. He'll hit or kick for no reason. Of course, we have a hard time finding staff who will work with him. We don't pay people enough to want to work with a person like him.” I asked her to tell me about this person and *when* he might hit or kick. “Any time – completely unprovoked – he'll just go off”. When I asked her to describe the most recent time he hit or kicked someone she said, “Just this week -- staff went into his room to wake him up – he's hard to get up. He never gets going on time. Staff don't yell at him or anything – they just say, just like to everyone else, ‘Gary, time to get up’. And then all morning he's dragging around and resistant – we have to prod him – ‘time to brush your teeth’, ‘you need to get into the shower’...we tell him he's going to hold up the whole group, the van is going to be here any minute, we're going to be late for day program. He's *always* the last person to eat breakfast – and then at any point, he might lash out and hit or kick ...”.

You don't have to have any particular behavioral expertise to analyze this story. Somehow however, this apparently well-meaning person had convinced herself that it was Gary who was the problem rather than the frustration of living a life in which he was constantly told what to do and in which he was expected to do what works for the staff, the agency and the schedule rather than what works for him. The person who spoke with me felt that she was asking a perfectly reasonable question about how to handle people who are problematic. She didn't see that she was telling a story about a person's perfectly understandable response to a dismal ‘we're-in-charge-and-you're-not’ situation that our service system had imposed on this man.

People often tell me that some of the people with disabilities they support are ‘noncompliant’. When did compliance become a personality characteristic to which we aspire? None of my women friends have ever said, “I went out on a date the other night. I really like this guy – he’s nice, good-looking and he seemed so compliant!” I’ve never told my friends about my daughter’s accomplishments by bragging about how compliant she is. Compliance is only celebrated in people who we, at some gut level, feel are not our equals or who we feel should act in ways that justify the way we treat them. We’re helping them after all, shouldn’t they be showing some gratitude? If they make our lives difficult through their behaviors, shouldn’t we be able to retaliate just a bit by making their lives a little difficult in return?

I am not a person who thinks that because all people are to be valued and respected, that all behavior is OK. Anyone who has worked in the real world knows that there are people whose behaviors are self-destructive, dangerous or disruptive to the point of interfering in their opportunities for happy, connected, self-directed lives. We owe it to people to help them regain control so they can lead good lives. We don’t owe it to people to control, restrict or isolate them – even if we’ve convinced ourselves it’s for their own good.

I’ve been asked for help to address all kinds of behaviors that people who work in this field find problematic. One staff team requested help to change the behavior of a woman who came home from her life-dulling day program and cut up magazines for an hour or so, keeping her snipped paper in shoe boxes under her bed. “It sounds like she enjoys it, it’s probably comforting”, I offered. The staff were determined to set me straight; to convince me that her behavior was a problem. I asked if she might be bored. What else did she like doing? What other kinds of past-times had they supported her to explore? What were her other options for things to do? I recommended that they try to figure out what other things she might enjoy, but if she liked snipping paper, I suggested they not worry about it. “But it’s not normal”, a staff member insisted. The real answer is to assure that every person who receives support has a rich, interesting life then, if snipping magazines and storing confetti still feels soothing or fun, we should assure a supply of magazines and shoe boxes.

With input from some people who have been victim to our, at-best clumsy and controlling, and sometimes downright cruel and manipulative attempts at behavior control, I have put together some suggestions for people who work with people with disabilities. This article discusses better ways to think about behaviors that challenge us and to support people who have these behaviors.

- 1. Make sure the person is able to communicate their preferences *and* that we are listening and responding.** ‘What about people who don’t communicate?’ I am often asked. Everyone communicates – but not always with words and not always in ways that are easy to interpret. People who know and work closely with people with disabilities know what pleases them and what annoys them. It’s our job to try to build a full understanding of what works (and doesn’t work) for each person we support. At an early morning visit to a group home, one woman was stomping about – clearly peeved. “Don’t mind her”, the staff person explained. She hates eggs

and she gets mad whenever we have them for breakfast. “Couldn’t she have something else?”, I asked. The staff person said she guessed so but in a tone that conveyed that this would present an inconvenience. This staff person had correctly interpreted the reason for the woman’s behavior – she’d just decided that following the menu and going along with what was planned was more important than responding to personal preferences. I was left wondering if the response of the woman with disability was wholly about eggs being on the menu or also about her communication of her preferences being ignored.

If people can’t (or don’t) communicate with words, it is incumbent upon us to try all possible ways to identify a communication method that works for them so they are able to get their feelings and desires across. People who can communicate using any effective method have less of a need to communicate through their behavior. Once we know what people are conveying through their behavior, it’s our job to make the changes in the environment, schedule, or available options to respond to their communication. This kind of personalized responsiveness is much more likely to happen when each person’s supports are tailored to them, rather than when they are expected to fit into the more structured service models we’ve constructed.

2. Make sure the person’s behavior isn’t a response to a medical or psychiatric problem.

When people’s behaviors challenge us they are likely either protesting against the limiting and restrictive lives we offer or telling us that they are in physical or psychological pain. There have been hundreds of instances in which people have been punished, had treasured belongings taken away, were made to earn things that they like or want, or had rights restricted because people were responding to pain, discomfort or confusion and were trying to convey this in the only way available to them. Prior to addressing any behavioral issue, we need to address any possible physical or emotional pain and assure that medical treatment or supports that may be helpful such as counseling, a change of environment or demands, or psychoactive medications for depression, bipolar disorder, major depressive disorder, schizophrenia and the like, are offered.

3. Assure that people have choice and control. Our field has a long tradition of staff and agencies thinking that they know what is best for people with disabilities. We often have offered people services that work for the agencies and staff that serve them or that achieve goals others think are right for them, but that are not what people want. There is a need to re-think the whole other-centric approach to serving people and instead offer lives, environments and supports that honor each person’s needs and preferences. We have slots, openings or beds that may not be what a person would choose but that we need to fill to make the financial side of services work. We design systems that we think will work for all but may not work for each. Some people need solitude, some want social, engaged lives. Everyone needs to feel safe and everyone wants people in their lives who love and support them.

Being the lifelong target of care-taking can be oppressive. We are sometimes benevolent to the point of malevolence. Our ‘being there’ for the people we support has created a barrier to their being a part of their communities and to their building real and sustaining friendships. Paid relationships are almost always time-limited and this kind of relationship can’t hold a candle to

friendships that form naturally out of shared interests or compatible personalities. All people should live the life they choose, design and control with the supports they need for success.

4. **Figure out what behaviors achieve for the person.** People act as they do in an effort to communicate and because their actions fulfill a need or function for them. Sometimes the functions that a behavior achieves for a person are not obvious or straightforward. Figuring out the purposes that a behavior achieves takes conversations with the person when possible, discussions with people who know and love the person, and often, considerable observation and conjecture. Sometimes the behavior *achieved* something for the person in the past and, while it no longer achieves that purpose, the behavior has been learned or has become habit. Believing that a behavior can be learned is good news; one must reasonably then assume that behaviors can be unlearned once they cease to achieve a function for the person. Sometimes behaviors are simply comforting in a world that has stripped people of comfort, control and safety. People may need to learn other ways to attain anything that self-destructive or dangerous behaviors had been achieving for them. Once the purposes or functions of the behavior are revealed, the challenge is to assure that whatever was being sought through those behaviors is made plentiful in the person's life. We tend to do the opposite – we think, ‘how manipulative. He is doing that just to get attention. We won't let him think that he's in charge!’ Our thinking needs to change. We must assure to people that they do have power; that they are in charge. Whatever the behavior sought to achieve needs to be freely available or easily attained so people have their needs met without having to act in dangerous or dramatic ways to achieve comfort, control and a good life.
5. **Support people who are in the midst of a dangerous or severely disruptive behavior to be safe, while helping them find their way back to regain internal control.** The way to help people regain control is different for every person. The goal is to help people find tools that they can learn and use, call upon, keep, and make part of themselves. These might include listening to favorite music, holding a comforting object, going for a run or playing basketball, talking with a friend, spending quiet time in a calm space or with a pet – the tools for each person will need to be discovered through conversation, observation and trying out a variety of things. It is sometimes necessary to prevent someone from hurting themselves or someone else but the *worst* way to help someone feel safe or to regain control is to yell, instruct, physically intervene, argue, berate or punish them. It is just common sense that these approaches will only exacerbate a person's feelings of being out-of-control and less worthy. It is not only cruel and unethical but downright illogical to respond to people's attempts to assert a degree of control over their lives by imposing greater and greater amounts of power over them -- but this is exactly what is often done with little consideration of logic or fairness.
6. **Understand that offering “choices” can be a way to further assert control.** Michael Kennedy, a leader with the Self Advocacy Association of New York State once said that whenever he hears an agency staff person say that they ‘offer choices’ or ‘give people choices’, he knows something is wrong. Choice isn't something to be doled out as one would a treat. The right to choose should be assumed – not something that is granted or withheld. Staff often offer choices that are so narrowly constrained (do you want peas or broccoli?) or so limited (do you want to go to a movie or to the mall?) that they are not real choices at all. Real choice involves

familiarizing people with the whole range of possibilities, letting them experiment, and supporting them to discover their preferences, interests and passions.

7. Recognize that behavior often grows out of a history of trauma. It is the rare person who has severe difficult behaviors and has not had a traumatic life. The statistics on people with disabilities who have been physically and/or sexually abused are horrifying – and even those people who have not experienced particular traumatic events have likely lived lives characterized by way too much external control. They have likely experienced being demeaned, rejected or excluded. It is theorized that living a life that is never your own, being expected to act as you are instructed, and having few opportunities for self-agency is as likely to result in post traumatic stress disorder as does experiencing specific traumatic events. Herb Lovett in his seminal book, *Learning to Listen*, noted, “People who have been hurt in the name of therapy may not understand their plight any differently than survivors of cult abuse or sexual abuse.... every time they recall their previous maltreatment, unless their panic and rage are recognized as a function of stress, they are likely to be further stigmatized as ‘impossible to serve’ ”.¹ All interactions with people who have led lives of trauma and control need to be rooted in understanding that history and acting in ways that serve to acknowledge and heal past hurts.

The critical component of supporting people who have been victims of every day or periodic trauma is providing life environments in which people feel fully safe, have trust and are trusted, and have a range of relationships with people they love and care for and who love and care for them. Such environments are characterized by acceptance, consistency, reliability, predictability, availability, honesty and transparency.²

Some behaviors are difficult for both people who care for/care about people with disabilities and the people themselves who have those behaviors. Some of these difficult behaviors are learned in response to a service system that strips people with disabilities of their power. There is literally no greater human impulse than for each of us to be in charge of our own life. We put people in situations that strip them of control, safety and choice and then wonder why they ‘act out’ in protest.

The most important changes we need to make to do a good job of supporting people who have behaviors that are challenging, usually have little to do with changing the person. Changes need to focus on situations and supports so that they offer opportunities for life-affirming, engaged, fulfilling lives; lives that don’t call for protest. Once choice and control sit firmly where they rightly should, the need to behave in ways that serve to push back against people trying to assert control or that attempt to resist the limiting lives that are offered, naturally resolves.

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¹ Lovett, H. (1996). *Learning to listen: Positive approaches and people with difficult behavior*. Brookes Publishing: Baltimore. p. 208

² Bath, H. (2008). *The three pillars of trauma-informed care*, *Reclaiming Children and Youth*. Vol. 17, no. 3, p. 17-21

