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# The 21 Lessons for supporting persons with disabilities: Lessons 8-14

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This article reflects the second in a series of articles which are based on a five-part series entitled: "How to maintain a therapeutic relationship when your buttons are being pushed. This and the 21 lessons for supporting persons with disabilities." For more information on this series and the entire "Qualified Brain Injury Support Provider (QBISP)" program, the reader is referred the following website: https://qbisp.training.com

In a brief recap from last month's article, the 21 lessons were originally developed in 2005 as a training to help direct support staff to better serve adults who sustained a traumatic or acquired brain injury. The purpose of the 21 lessons is to debunk common misconceptions that inexperienced staff believe about changing behavior. This article will focus on lessons eight through 14.

Lesson 8: Treatment should not sound parental or be punishing

For most of us, our first example of the care provider role was that provided by the primary adults in our childhood: our parents, grandparents, aunts/uncles, teachers, and coaches. These adults may have used an authoritarian style, sometimes referred to *here* as the "parental tone," to ensure control and safety. For children, adults are often the "boss," the "do as I say" and "because I said so" figures in our early lives.

"Dinner is at 6:00, set the table."
"Go to your room."
"Finish your homework before TV."
"Raise your hand before speaking."

The parental tone exists in all of us. Sometimes, "the tone" lies dormant for many years until we are in a parental role ourselves. And then, it happens. After it comes out, you may hear someone remark, "Did I just say that …. Oh my God, I sound like my mother (or father)." The parental tone can also emerge as our default or "go-to response," when we assume the role of a care provider. The obvious similarities between parenting and care providing can cause us to reflexively use what was effective in one scenario (to raise and assist children) in a different scenario (to support and assist adults with disabilities). Yet most adults do not like to be treated like they are children. The top-down, command and control relationship style is experienced as infantilizing and disrespectful. When I observe a 20-something staff person send a 56-year-old resident to his room for disruptive behavior, I know lesson eight is not being followed. Furthermore, if an adult participant demonstrates behavior that we, as staff, perceive as "child-like," it does not give us permission to act authoritarian. Remember, we are supporting adults, and our tone should reflect this.

While it has been shown that punishment can change behavior, punishment does not teach adaptive or appropriate replacement behavior and leads to many negative side effects. Punishment is not an approach we have permission to use when supporting adults with cognitive and behavior challenges. Corporal or physical punishment can do long-term damage to relationships and is UNLAWFUL in care settings.

By definition, punishment is any stimulus that reduces the future probability of the occurrence of a behavior.

The natural environment rewards behavior that is successful and punishes behavior that is not. For example, tapping trees for maple sap is rewarded when it is below freezing at night and above freezing during the day (February/March), but you'd be wasting your time if you waited until August. By attending to prosocial behaviors in our participants, we encourage more prosocial behavior. But when we "expect" or take for granted pro-social behavior, we miss the opportunity to attend and reinforce it. A collaborative, relationship-focused style that is quick to reward positive behavior is much more useful in fostering adaptive prosocial behavior (see lessons 11 and 13).

Lesson 9: Understand the difference between providing assistance vs fostering dependence

Providing assistance and support is a dynamic process and a moving target. Every decision to provide support should be based on the following:

1. The needs of the participant in that situation,
2. The participant's willingness to accept assistance,
3. The relationship between the participant and the direct support provider (DSP), and
4. The conditions of the environment.

I once observed a staff member and a participant leave for a lunch outing in the community. When they returned quickly, I inquired why the outing was so short. The staff member innocently replied, "We went to get fast food, and the drive thru is easier than helping him into the restaurant and telling him not to flirt with the wait staff. I just pull up to the window, order for him, and we are home. No muss, no fuss."

"Easier for whom?" I asked. If the goals of a participant are to practice mobility and interact with his community, then the therapeutic purpose of the outing was not addressed. By doing "more" for the participant, the staff member may risk fostering dependency and social isolation. Our basic therapeutic task is mostly "to do with" and not "to do for" because it is easier for us. Supporting incremental successes in personally meaningful life activities should be among our top priorities.

Lesson 10: Keep in mind the big picture

While lesson nine cautions against providing too much assistance to the participant, lesson 10 cautions against not providing enough.

Too often, I have observed assistance being withheld for fear that it will create dependence or "reinforce that behavior." Admittedly, there is a delicate and dynamic balance that needs to be struck. When in doubt, check with a colleague, or better still, ask the participant if the relationship can support such discussions.

On a different visit to a group home, I asked a direct support person why a resident was not at his job. A staff member replied, "I told him he needed to tie his shoes before I would bring him to work, and he refused." I asked, "What is the big picture, shoe tying or getting to work and earning a paycheck?"

The direct support person believed that by helping the participant tie his shoes, she would be fostering dependence, since he was capable of tying his own shoes. She may be correct, but if helping him tie his shoes gets him to work so he can earn a paycheck, then do it for him. We can fix "shoe tying dependency" later.

Lesson 11: Teach new skills to replace problem behavior

All voluntary behavior is purposeful and goal-directed. Behavior is often a communication that the person is trying to meet his or her needs in a particular context. For instance, food-seeking is a behavior that the person engages in when he/she is hungry. A person's needs are like their emotions, they are neither good nor bad, *they just are*.

Sometimes, the behavior used to meet the need is ineffective. For instance, persistent flirtation with an un-interested party is rarely helpful in meeting the need for companionship.

I frequently observe inexperienced DSPs telling a participant that their ineffective behavior is "inappropriate" in hopes that the participant will appreciate this advice and exchange their behavior for something prosocial. (More about the word "inappropriate" in Lesson 17.) While the behavior is being recognized as ineffective and an attempt is made to extinguish it, the underlying need, the "meaning" of the behavior, is not being addressed. Our job is to teach new skills (behaviors) to replace ineffective ones. If throwing a mug across the room is an ineffective means of getting attention, what is an effective behavior to secure valued social attention, and can we teach this skill without reverting to the parental tone?

Desiring attention is a normal need. By ignoring attention-seeking behavior, we miss an opportunity, not only to provide attention but to teach our participants an effective skill for acquiring it. Once we teach the skill, it is imperative that we consistently reward it by providing attention. Do not fall into the habit of only responding to challenging behaviors and ignoring pro-social behaviors. If the goal is to achieve behavior change by replacing an ineffective behavior with a new positive behavior, we should be rewarding positive more often than correcting problem behaviors. What would happen if we went to the emergency department with an injury and the triage nurse said we were "attention seeking?" She would be right! We are seeking medical attention.

Lesson 12: Providing control and predictability will reduce stress

A number of years ago, a very discerning series of experiments were conducted at the University of North Carolina. The experiments showed that an event was experienced as stressful if rats were unable to control their environment or predict the outcome of the environment. For instance, if caged rats were consistently shown a light prior to being shocked over multiple trials, they experienced less stress (as measured by stomach ulcers on autopsy) than rats who received the same schedule of shock without a "warning light." The warning light created predictability.

The same holds true for controllability. If a rat can control the amount of shock it receives by using an exercise wheel, it will demonstrate lower levels of stress than rats who receive the same amount of shock but are not in control of the schedule. Use of the wheel provides a sense of control.

The same principles apply to people. In general, stress can be reduced by increasing people's sense of control and predictability.

In a different study by Dr. Edward Tronick called, "The Still Face" (see YouTube video), mothers and infants were observed playing together. The infant and mother had a strong verbal and non-verbal communication link. When the mothers were asked to turn away, then turn back and keep their face still (not react), the infants instantly knew something had changed, and they became upset and restless. After a few minutes, the mother turned away again, then back and responded to the infant as usual and the child calmed. Behaving in predictable and cooperative ways are key to feelings of safety and security.

Persons with cognitive and behavioral challenges, such as memory impairments, can experience a lot of unpredictability in their lives because they are challenged to keep track of upcoming events. If a person cannot recall what the "plan for the day" is, it is difficult to have a sense of what will happen next. We can help enhance a person's sense of prediction by providing them with supportive and personalized reminders and memory aids.

People with disabilities who become dependent on others for assistance are also at risk for experiencing increased stress due to loss of control. Part of our therapeutic task is about enhancing the person's sense of control and prediction by designing supportive environments and schedules that increase a sense of prediction and control over the course of the day. This is most often accomplished by providing meaningful choices and responsibilities daily, as well as creating living and work environments, and schedules that work for the person (e.g., predictable access to food, hygiene, grooming, work and leisure preferences, memory and mobility aides, schedules for outings/appointments, sleep, self-care, and household activities of daily living).

Lesson 13: Celebrate success

In our training as healthcare professionals, which follows the medical model, we are taught to focus on the problem, the ailment, the symptom. This can be a highly effective and efficient means for addressing *acute* medical needs. However, when this model is applied to long-term behavioral support, we miss an opportunity to help someone reach their full potential.

One of the most powerful reinforcements for behavior is social praise. Why not dispense it generously and graciously? Praise is inexpensive, renewable and easy to practice. As we noted in Lessons 9 and 11, we should be quick to praise, and slow to criticize. Instead, we tend to focus on the problem and ignore the success, becoming quick to criticize, and slow to praise.

By doing so, we risk getting caught in a relationship pattern of micro-management, error correction, and critical "I gotcha" communications.

I served a participant once who would often be disruptive in the waiting room before his clinic appointment. When disruption occurred, the staff would provide him with more than ample direction to calm himself. However, when he would wait quietly, everyone would privately sigh a sense of relief and ignore him. We had unintentionally set up a negative pattern that reinforced his disruptive behavior with increased attention and ignored him when he respectfully waited patiently. The message became clear: he wants to be acknowledged when he arrives, so let's acknowledge him, and let's do so as quickly and positively as possible.

Rewarding others with praise and social engagement for doing something well is perhaps our most powerful means for achieving lasting behavior change. Not only do reliable habits of positive reinforcement contribute to positive behavior momentum among participants, positive reinforcement improves positive feelings and beliefs (like self-esteem and self-efficacy) among both participants and support providers. Positive reinforcement also helps people tolerate stress, such as the stress of waiting. When positive behavior is ignored, because it is an "expectation," we miss the opportunity to reinforce it. Celebrating even small successes with positive reinforcement is a win-win.

Lesson 14: Respect the healing power of listening

This is one of our favorite lessons because of its universal effectiveness and applicability. Everyone has a need to be listened to. Before we can tell you what good listening should look like, allow us to describe what it is not.

Good listening is not active listening. Frequent parroting back at someone what they have already said can be disruptive and meaningless and feel like a power play or being managed. Good listening is more than "being heard." An occasional sign that you understand the person's point is fine and can be effective, but keep it to a minimum.

Good listening is not multi-tasking while saying you are listening. Good listening requires time, openness, and focusing on the *person*. If you do not have time or the "bandwidth" to listen, tell the person and set up a time when you can be more fully available to listen attentively, letting them know that you want to be *present* in the way that they deserve.

Good listening does not require you to solve a problem (see, "It is not About the Nail" YouTube video). In fact, most challenges that require good listening are long-standing problems that do not have an easy solution or cannot be resolved by some inspirational message that you read on your last fortune cookie or self-help book. Good listening is often the acknowledgment that a problem is painful or that the person feels caught in mixed feelings.

Good listening attempts to understand the person's feelings about a particular experience or situation. Good listening validates a person's feelings and confirms that their experience makes sense. Good listening recognizes when we fail to understand (which we all do at times) and responds with an apology and greater openness. Good listening is grounded in empathy (see, "Empathy vs. Sympathy," YouTube video). This can be communicated by good eye contact and facial expressions of interest, tone of voice, encouragement, and understanding. We all have a good listener in us, and good listening builds strong working relationships.

In our next article, we will discuss lessons 15-21. Thank you for taking an interest in this series.

Still Face https://www.youtube.com/watch?v=apzXGEbZht0
It's Not About the Nail https://www.youtube.com/watch?v=-4EDhdAHrOg
Empathy vs. Sympathy https://www.youtube.com/watch?v=1Evwgu369Jw

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