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The 21 Lessons for supporting persons with disabilities: Lessons 1-7

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Introduction:

This article reflects the first of 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

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. While the 21 lessons were not developed from the literature on Positive Behavioral Intervention Supports, we recognize that many of the lessons reflect behavioral principles taught with user-friendly, everyday language.

In addition, the 21 lessons seek to debunk common misconceptions that inexperienced staff believe about changing behavior. For instance, the inexperienced staff often believes that "all attention-seeking behavior" should be ignored. In reality, attention-seeking behavior is often a sign that a participant is not receiving adequate support.

Finally, although the "21 lessons" were developed for staff supporting individuals with traumatic or acquired brain injuries, we have found them to provide useful skills for developing and maintaining a therapeutic relationship with anyone.

This article will be focusing on the first seven lessons:

Lesson 1: Understand the whole person

In healthcare, we tend to spend too much time focused on a person's diagnosis or on their problematic behavior which, in reality, accounts for a small part of someone's true identity. This is a remnant of the medical model which is problem rather than person-focused. Think, for a moment, if your community identified you by your least favorable quality. Using myself as an example, I would prefer to be known by

my role as a parent, a friend, or a neuropsychologist rather than as the "short, bald guy." While the latter is unfortunately true, I would prefer to be defined by the former. The people we support are no different. No one wants to be referred to as a collection of symptoms but, instead, as a unique individual possessing their own strengths and challenges. One strategy for applying this lesson is to begin descriptive dialogue about the person with "people first" phrases like, "this is a person who wants to be successful" or "this is a person who feels challenged by …" rather than phrases like, "this is a non-compliant patient with an intellectual problem…"

Lesson 2: Understand the behavior; don't label it. What is the person trying to tell you?

All voluntary behavior is purposeful and goal-directed. Behavior is a form of communication, and it has meaning. What is the person trying to tell us? While the specific behavior may be frowned upon by society, the underlying communication is often natural and worthy of our attention. As support providers, part of our job is to understand the behavior and, if it is maladaptive, then our role is to help the person find ways to express themselves in a constructive manner. When we fail to understand the meaning or purpose of behavior and become overly focused on the expression of the behavior itself, we compromise our ability to be effective support providers.

I recently had the privilege to support an individual, Frank, who desperately wanted to get his GED (Graduate Equivalent Exam) rather than participate in a support program designed to enhance his independence. Unfortunately, previous attempts to help him prepare for the GED test had failed due to his intellectual challenges. His treatment team was ready to discharge him from the support program, given that his stated goal was determined to be unachievable. His treatment team, including myself, naively thought we understood the reason for his stated desire (i.e., his behavior) to get his GED. We thought, "He probably wants a GED so he can feel normal" or "He thinks he will get a job if he gets his GED." Then, someone had the brilliant idea to ASK him why he wanted the GED. Without hesitation, Frank responded, "Because my dad said (years ago) that he would buy me a class ring if I passed the test." With this one piece of new information, we finally understood his behavior and could better meet his needs. In short, we designed a rehabilitation program that resulted in his earning a certificate from the clinic, resulting in his father awarding him with a ring. If we had remained focused exclusively on his behavior (i.e., refusal to participate), we would have missed a wonderful opportunity to help Frank be successful. Labels are like check marks on a to-do-list. They indicate an ending rather than a beginning and conclusions rather than possibilities.

Lesson 3: Understand non-compliance before trying to overcome it

The knee jerk reaction to a participant's non-compliance in a rehabilitation program is to assume the person does not want to improve. In my 30+ years of experience, I have yet to meet the person who would not like to improve or lessen the effect of their disability. As in Lesson 2, a person's non-compliance to treatment should be a communication to us that the treatment is experienced as aversive or our negative reaction to the person's refusal is reinforcing for the person.

I once supported an individual who refused to bathe regularly despite the social rejection he experienced from his peers. Staff's belief about his behavior included the following, "He does not care" or "He likes offending others", etc. When asked, he informed me that he was afraid of

getting electrocuted when he was in the shower. Again, with this one piece of information, I learned that, before I could help him overcome his noncompliance with treatment, I needed to address his fear of electrocution. Rule of thumb: seek to understand behavior before trying to change it.

Lesson 4: Understand how an emotion, thought and behavior differ

When I teach this lesson, I am often asked if it applies to ourselves or the people we serve? The answer is both, but we need to begin with ourselves. In our society, we often use the words "I feel" to convey the idea of a thought. For example, "I feel that you're not being fair." Or "I feel that Joe is not working to his potential." Most experts agree that there are about eight basic emotions (e.g., happiness, trust, anger, sadness, fear, disgust, anticipation, and surprise). By using the words "I feel" before expressing a thought, we can derail productive dialogue.

Couples therapists are aware of this confusion and often teach their patients to use phrases such as:

> "I feel sad when you forget to take out the trash" rather than statements like,
> "I feel you don't care about me when you don't take out the trash."

The former invites the listener to offer support and understanding. The latter invites defensiveness and resistance to change.

A common phrase in "pop" psychology is "follow your gut." I think we would be better served by amending this to "understand your gut before acting." Our "gut" is a barometer to our past experiences. Our gut (sometimes referred to as our buttons) is an internal instinct or intuition (a feeling) that notifies us that the current situation resembles a past experience or something we genuinely feel and yet has no obvious inherent logical rationale. The emotion that we felt the last time the situation occurred, we now feel again. Our gut signals us to avoid historically harmful situations and to pursue historically pleasurable situations. Sometimes our gut can set off a "false alarm" in us.

Here is an example:

> As a six-year-old child, Maggie got bitten by the neighbor's dog. Now, as an adult, Maggie feels scared every time she sees a dog. Her gut (emotions) tells her to avoid all dogs.
>
> Adaptive outcome: As a result, Maggie never gets bitten by a dog again.
>
> Maladaptive outcome: Unfortunately, Maggie is afraid to go visit her friends who have gentle dogs in their home. She misses out on opportunities to enjoy social engagements at her friends' homes. Also, she has taught her six-year-old son to stay away from all dogs.
>
> When Maggie sees a dog, her buttons get pushed and her "gut" feels fear. This feeling causes her to avoid contact with any dog. However, the button does not discriminate between safe dogs and unsafe dogs. Maggie avoids all dogs.

The concept of understanding our gut before acting will be revisited in some detail in a later article.

Lesson 5: The starting point for resolving direct support staff-participant conflict is the staff

Without sounding sappy, the commitment needed to provide stellar direct support to individuals with disabilities supersedes any job description and is more in line with "a calling" rather than an hourly position. The job requires a level of devotion and tenacity that will never be reflected in one's paycheck. If you do your job well, you will have a set of skills that few people will have ever achieved and, most importantly, your contributions to the lives of others will be immensely rewarding. One of the strengths of a good direct support provider is the ability to suspend one's own needs (when your gut may be telling you just the opposite) and serve the needs of others. One example of this is during times of disagreement when a participant's offensive behavior may push our "buttons" and distract us from our job as support providers. It is our responsibility to refrain from reacting (i.e., following our gut) to the behavior and, instead, remain focused on the participant and their needs. Our behavior should be guided by first answering these two simple questions:

What are the needs of this participant?
How can I best meet these needs?

When we, as providers, react to offensive behaviors, or words, we place our personal needs above that of the participant and lose sight of an opportunity to create a therapeutic connection.

Lesson 6: Be careful of how we measure success for our participants and for ourselves

If you're an outcome-driven person who needs the immediate daily gratification of quick and sustainable results, then the field of direct support may not be for you. On the other hand, if you like to approach each day as a new challenge, which may or may not build on the prior day but is never dull, then the field of direct care may be something to consider.

What may have been easy for a participant to accomplish on Monday may be impossible on Tuesday. Our job is to engage with the participant and gauge what is possible today. Some days the measure of success might be getting to work, other days it might be getting out of bed. It is our job to figure this out with the participant every day and then do our best to support and assist the person.

Lesson 7: Provide reasonable safety while respecting reasonable choices

Dr. Wolf Wolfensberger, in his works on social role valorization and normalization in human service settings, highlighted the principle that, "If you can't fail, you can't succeed." It is our job as direct support staff to shepherd our participants through life, not shelter them from life. While safety will always be job number one, our next priority should be assisting participants to experience a full life, including failure, disappointment, and sadness. By creating an artificial environment that is free from these "life realities," we deprive participants of an important part of adulthood and, in essence, "infantilize" them. Our tendency to shelter participants from disappointment is often brought on by our own desire to avoid dealing with their negative

feelings. Instead, a participant-focused approach requires us to support them through the FULL range of life experiences and challenges. In sum, both success and disappointment can be used as valuable learning tools.

As always, we welcome comments on the first seven lessons. Many of the refinements to date have come from people working in the field. Stay tuned for the next seven lessons in the upcoming June edition of the Journal.

About the authors

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