

Guidelines for working with people with disabilities

General Guidelines

- ***People with disabilities are people first.*** That is to say that references to “the disabled” or “Autistic person” or “a Schizophrenic” tend to emphasize the person’s disability rather than their value as a person (“with disabilities,” with Autism,” or “with Schizophrenia.”). While there are clearly some differences to consider with our population compared to other populations (hence the existence of a specialized clinic), one must never forget that we are working with people who deserve our respect. Additionally, we must remember that people with disabilities are represented in all other aspects of diversity (race, national origin, sexual preference, age, etc.) and that these aspects of the person must also be considered when interacting.
- ***Don’t be misled by IQ scores.*** These are used to classify service eligibility for governmental agencies and for diagnostic clarity (e.g. Mild Mental Retardation is defined purely by an IQ range of 52-70). Converting these scores into mental ages can lead to a poor conception of the person. References to “the equivalent of a 4 year old” are extremely unhelpful as these do not account for the sexual, physical, or social development of the person. These scores can help us in a ballpark fashion understand the degree to which a person is able to abstract information or use communication. This can then tell you how concrete or simplistic you may need to be in your communication. For example, References to “later,” or “in two days” may be confusing or anxiety provoking to a person for whom a time concept has not been well developed. Remember that nothing beats interacting with the person to find out their level of functioning; an IQ score can only give you a very basic starting point.
- ***Talking to the person versus talking about the person.*** This is always a balancing act but is an important consideration. You will at some point make the mistake of attending too much to the person and not enough to the caregivers who can give you more accurate information. On the flip side, you will also be criticized at some point for attending too much to the caregiver and ignoring the person. Through practice, you will figure out just how much, in each circumstance (as every patient is different) you will need to take from which party. However, it is never okay to ignore the person no matter how impaired they appear to be.
- ***Don’t assume that “non-verbal” means unable to comprehend.*** Too often, patients who do not speak are labeled as “non verbal” and no one tends to talk to them because they tend not to respond (at least verbally). Usually, even in normal development, a person’s ability to comprehend what is being spoken to them develops prior to their ability to speak. Therefore, many of our clients, while unable to speak, do understand to some degree what you are saying. If you attend closely, they will respond non verbally. In any case, even if you believe there is

no comprehension, speaking to the person reminds you that you are dealing with a person who deserves your respect.

- ***Many of our clients have been institutionalized or isolated.*** This fact can help explain insecurities about property ownership. It can also explain a higher need for attention. There is a tendency to ignore our patients if they are not creating a problem, but it is often wise to be proactive with validation through attention and conversation.
- ***Don't set the person up.*** A product of not considering the limitations of our clients is to ask open ended questions. While this is often done out of respect, it can often create problems. For example, asking what the person would like for dinner when you may not be able to offer what the person answers with is setting the person up. If an open answer is not going to be possible, an open question may not be appropriate. Or, if there is really no choice, don't offer a choice. For example, "Would you like to take a shower?" allows a "No" answer when this is not really an option. A way to avoid these problems is to offer "limited functional alternatives." So with the first example, one would ask whether the person would like a sandwich, a salad, or a bowl of soup. This restricts the choice to things you can provide, things that are healthy (if that is important), and in a way that is easily processed by the person. In the second example, asking "would you like to take a shower now or in 10 minutes?" does not allow for the "No" answer as well as empowers the person with a choice.
- ***Touch can be an important issue for our clients.*** Due to institutionalization, abuse, or other reasons, touch has often been deprived or inappropriate for our patients. Touch may be desirable or undesirable but is often an issue for consideration. Don't be afraid to use validation touch where you know that it is okay to do so. Be aware that some of our clients engage in inappropriate touch or misinterpret touch (sexual, wanting hugs often, etc), and you should take the lead from their caregivers in these instances. Handshakes are nearly always okay.
- ***Structure and predictability are major ways to help the person feel safe.*** This can also be a symptom of institutionalization as well as control being in the hands of other people. Letting patients know what is going to happen next can give a sense of control. It is also helpful to know what the person's normal routine is so as to do things to stay within it rather than deviate. We are all creatures of habit and this is often magnified in our patients.

Behavior Management

- ***There are some common functions of behavior.*** That is to say certain outcomes a person gets from exhibiting behaviors. These include attention, to be alone, to escape (from a demand, from something of frustration), to get something, and to play. Remember that communication is always a function of behavior. Therefore, it is useful to ask "what is the person trying to say with this behavior?" or "What is the function of this behavior?"

- ***Behavior has some common causes.*** Behavior can be caused by a number of things including internal causes (medical problems, allergies, medication side effects), lack of functional alternatives (knowing they can say “No”, poor communication skills, poor problem solving skills, poor social skills), the behavior is rewarded, or it works (meets the function it is trying to serve), good behavior is perceived as punished (e.g. waiting), and environmental setting events (disrupted routine, irrelevant activity).
- ***One should think less about eliminating maladaptive behaviors but rather replacing them.*** If you think about a maladaptive behavior in time and then remove it, you essentially create a void. This void is more easily filled with familiar behavior (such as the maladaptive behavior). Therefore, behavior management, in a nutshell, involves the elimination of rewards for maladaptive behavior, replacing the behavior with something functional, and rewarding the use of the replacement behavior. For example, if a person is using profanity to get attention, they can be ignored while using profanity and rewarded when they use positive words, which can be taught if necessary.
- ***Generally, positive interventions are more effective than those based upon punishment*** (i.e. rewarding the replacement rather than punishing the maladaptive). One of the biggest mistakes people make in managing behavior is the failure to pay attention to and reward positive behavior. Whenever the person is exhibiting positive behavior, recognize it (this could even be what seems to be non behavior such as waiting patiently); otherwise, the client may force you to pay attention to the negative. Natural consequences to maladaptive behavior are usually better than punishment as they make more real world sense.
- ***Try not to feed the behavior.*** It should be remembered that the person can always up the stakes to make you respond. To take the above example, a person using profanity to get your attention can be ignored but they may begin throwing things at you to get your attention at which point you have to respond. The important thing is to think in behavioral terms and do as little as possible to “feed” the behavior.
- ***There are apparent negative symptoms to effective interventions.*** It is important to realize that initial interventions will often find an increase in maladaptive behavior. This is because the behavior has typically worked for the person. What would you do if a certain behavior that you had always found useful in getting what you want, all of a sudden, no longer worked for you? You would probably do the behavior a little more intensely and frequently because you are sure it should work. Initial increases should be expected as should re-emergences of the behavior over time (extinction bursts). This often occurs under stress which is when familiar behaviors and old habits come back to the surface. The interventions should be continued.

- ***Choose an appropriate schedule to reward upon.*** One should ask how often a reward should be distributed. Is it for a certain amount of time that positive behavior was present or for a certain number of positive behaviors? It should be remembered that with our clients, time can be quite a challenging concept; therefore, rewards spaced too far in time can be misunderstood.
- ***Choose a desirable reward.*** Rewards, of course, should be things desirable to the person. Unfortunately, food is all too frequently a major reward for our clients. Whenever possible, and especially with clients for whom weight or food is an issue, edible rewards should be avoided. There is also a tendency to select the things that are of the most worth to the person and make these available only as a reward. Caution should be used here. Some things should always be available to the person no matter what the behavior. Imagine if everything of meaning to you in your life was contingent upon your behavioral performance? “Screw That!” I hear you say.
- ***Intervention programs should be visible for the person.*** Because of the concreteness of our clients, intervention programs should be visible. Asking the person to count the number of times a certain behavior is exhibited is unrealistic. Putting these up and making them visual helps the person to understand as well as see the program as real.

The Crisis Cycle

- The crisis cycle refers to the process in which a person escalates in their agitation and behavior. This usually follows a cycle in which the person begins to ramp up, goes into full blown crisis, then calms down. See also Code White in the security plan at the end of this document.
- In the initial stages, look for signals that the person is becoming agitated and respond appropriately (with attention, giving space, redirection). Note that redirection is a particularly good technique for this population of people. Mild escalation can be problem solved, timed out, redirected, etc.
- At the high point of escalation, it is unwise to try problem solve as this is agitating to the person. Thinking has become primitive and problem solving is complex thinking (comparatively). Crisis interventions should be used to insure the person and those around him/her are safe.
- It is unwise to look for an apology after an escalation – this is perceived as punishment for deescalating and will re-escalate the person. We are modifying behavior, not installing morality. If anything, the person should be praised for deescalating. Later on, when the person is calm and rested from the event, it may be viable to debrief about the problem, the behavior, and how it may be avoided in the future.