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Service, Support and Success
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No Borderline between Respect and Care:
Supporting People with Intellectual Disabilities Who have Borderline Personality Disorder

vita community services
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When we are no longer able to change a situation . . .
we are challenged to change ourselves. *Viktor E. Frankl*

Developmental Service agencies and their teams work in a variety of settings and support a variety of member needs. The overall goal of service is to understand and support individuals experiencing a dual diagnosis. The mission is to provide support using an integration of models that include validation, safety and allows for bio feedback. At the same time, we strive to promote community involvement, integration, opportunity and education to both members and employees. To achieve this, we have focused heavily on addressing the gaps between the networks involved within the Developmental Sector (the community, health care and emergency care services, etc.) and more recently, recognized a need to direct attention to mental illness considerations that are present in the Developmental Sector. When mental illnesses occur in addition to a developmental disability we refer to this as a 'dual diagnosis'. Common co-existing mental illnesses include: depression, anxiety, obsessive compulsive disorder (OCD), schizophrenia, bipolar disorder and borderline personality disorder. It is necessary to explore this part of the dual diagnosis as mental illness can significantly affect how we manage and support members in a validating, safe and respective manner.

A Word About Words

In this article the word 'member' is used in reference to people in service. This is a word chosen by the Vita Rights Group as they objected to the word 'client.' Further, in order for ease of reading the members referred to in the remainder of the article are those with Borderline Personality Disorder even when this is not specifically indicated.

Begin at the Beginning

We begin with a look at Borderline Personality Disorder (BPD), a human experience that has frequently been misunderstood, diagnosed and treated. Border Line Personality Disorder is both rooted and maintained in two areas: it has been hypothesized to stem biologically from genetic and developmental predisposition to dysregulated emotions and from environmental reactions to frequent dysregulation. Borderline Personality Disorder is characterized by unusual variability in moods. Common behaviours related to the diagnosis of Border Line Personality Disorder include impulsive behavior, intense and unstable interpersonal relationships, unstable self-image, feelings of abandonment and an unstable sense of self. Individuals may feel emotions more easily, more deeply, and for longer than others do. Moreover, emotions might

repeatedly re-fire, or reinitiate, prolonging emotional reactions even further. Consequently, it can take a long time for the individual to return to a stable emotional baseline following an intense emotional experience. Individuals can feel overwhelmed by negative emotions, experiencing intense grief instead of sadness, shame and humiliation instead of mild embarrassment, rage instead of annoyance, and panic instead of nervousness. Members are especially sensitive to feelings of rejection, isolation, and perceived failure. In addition, individuals may often feel a sense of perceived 'unfairness', which often times may be entirely accurate perceptions but their reactions to the perceived unfairness eclipses the inequity about which they are reacting

The summary below is intended to support professionals supporting individuals in this capacity. I review several common tips for working and responding to members in a way that will facilitate growth, validation and perpetuate a sense of self and the ability to make good choices. Many professionals find it difficult to support members with such complex needs as the approaches that tend to be effective with other diagnostic groups are not. This leads to significant burn out, staff changes inconsistencies, and frustration among the teams that are working in such environments. So how do we support such members and promote a mandate to provide a safe, validating and supportive service? Below is a collection of ten tips for professionals and agencies that support members with such complex needs through the journey. The information provided below is not in order of importance or hierarchy but rather work collaboratively with the end goals of:

1. Increasing validating environments
2. Facilitating problem solving solutions
3. Becoming grounded through mindfulness skills
4. Learn distress tolerance skills
5. Learn how to regulate emotions
6. Increase interpersonal effectiveness skills

PROVIDE A VALIDATING ENVIRONMENT

It is essential to validate, recognize, and label emotions and thoughts as Individuals have lived or experienced invalidating environments throughout their lives. This characteristic is probably a significant influential feature in the development of this disorder and therefore providing a validating environment is step one. Validation may be seen as helping the member see how their thoughts, feelings or behaviour makes sense within a particular context, but whether or not it is effective in solving the problem that faces them is another matter. Focus on choices and control in making better choices. At the same time, hold the person accountable to his/her choices and the actions/consequences that follow. Treat the person as an adult, respectfully, honestly, but always objectively. In addition, we can validate and reinforce changes when we challenge the person to improve his/her situation in a positive manner. Challenge his/her choices for the better. It provides hope.

CONSISTENCY WITHIN THE PROGRAM AND RULES

Consistency within the residential or day program environment among teams, the community and family unit with regards to the expectations and rules is essential. Perceived unfairness can arise quickly and the individual may negotiate or push limits and boundaries. For this reason the team requires to know, by heart, the program and individual protocols, rules, and expectations.

This would also include staff responding to the members with the same information, and if one cannot provide an answer then one should be honest and tell them that. Some members become extremely anxious when they do not have all the information needed. Like you, information is power and if we have the answer it should be provided unless, of course the individuals' protocol says differently.

EFFECTIVE INTERVENTION TEAM

- It is essential that an effective intervention team has confidence in one another, and confidence in each other's skills. Do not be shaken when the member "tests the limits." It is nothing more than an interactional ritual of trust for the person.
- Monitor your own speech pattern and tone of voice. Monitor how you are now interacting with him/her...Your structural interaction. How has the distance between you and him/her changed? Did you change into a character easily placed? If you did, you have allowed yourself to be manipulated. Pull back, let another team member handle or end the 1:1, regroup and refocus, and be more mindful the next time during the next interaction.
- Shy away from the victim mentality. Most folks ***were*** victims at one time. That is not the problem, however. The problem is that the person derives some benefits in remaining a victim and don't have any idea how to hold onto these benefits any other way. Lots of rewards, lots of power, and lots of attention are won by victim status. The past is the roadblock to genuine progress. If the person pulls you back to the past or back to victimhood, redirect and redirect again. It is better to focus on being a survivor, moving forward. The past holds no hope. The future does. That is the goal, not reliving or replaying the past. Setting boundaries on this is important. It's important for them to work on reducing the power of the past. If the person chooses not to despite persistent redirection, it is time to shut down the interaction. I would be safe in saying to him/her "our purpose together is to see you succeed, and that can only happen by moving forward. We can continue to talk about your progress now or get together later."...Give the person the choice.
- Do not reward or give undue attention for misbehavior. During these times, you are to keep the most objective, matter of fact. Address the situation calmly, and directly. Do not provide the emotional response that the person hopes to gain from you. For little misbehaviors/comments, use benign neglect and/or have it be a topic for your 1:1. The focus would be to make much more satisfying emotional support and reinforcing attention easily and readily available for engaging in coping behaviors (and responding to redirection toward coping behaviors).
- For larger misbehaviors, remove the person from other members...Do not provide an audience (secondary gain) or ask the other members to leave, thereby removing the audience. This can be via room times or having the individual perform some structured exercise or task within skill level. Restraint is a last resort. Typically when it comes to this, it means the team missed the boat somewhere or did not intervene early enough...For whatever reason.
- During 1:1s, share your honest, objective observations about the individual's behaviour, choices that were present, and progress made. Focus on the positive, but do not lie. The individual has superb radar in picking up dishonesty. If you cannot be congruent in honesty with the person during 1:1s, it will come back to haunt you. You may also become a focus of staff splitting later on, and as a result, he/she has lost his/her respect and trust for you. Trust and integrity often go hand in hand. We have to model that integrity in order to genuinely gain that trust.

- Now, the subject of 1:1s. It is best to plan your 1:1 with your member at the very beginning of your shift...Make them first. If pushed off to the end, they often interpret this as the other peers having special treatment. Do not play that game. Knock out the 1:1s first if possible...It removes the person argument and game. Structure the 1:1 and make it count for something. Very important...Objectively indicate when the 1:1 time will be over (right off the bat) and when it ends, it ends. Life does not wait for the person, neither do 1:1s. There are time frames. It also helps the person to remain focused. Structure what is to be discussed initially...The 1:1 needs to have an agenda...Purposeless 1:1s to shoot the breeze are not therapeutic... You can do that on the unit. Make the 1:1 time valuable, focused. Use much of what I have just discussed above. Assign/agree upon homework/practice exercises till the next 1:1...In actuality, it continues the 1:1 past the 1:1 time for the person. Allow for collaboration between the professional and member when choosing the next 1:1 topic. Have the person feel valued in his/her 1:1 time, especially in the progress made. Always reward positive outcomes and progress in the 1:1. If after the 1:1 the person approaches you again for further 1:1s, inform the person that 1:1 time is over for you and that journaling, homework, or making notes to bring for the next 1:1 would be the best option at this time. Make the 1:1 time as a valuable commodity... Something not to waste or to take lightly. Encourage the person to bring his/her notes back to the 1:1...It helps the person to objectify...Very good.
- Be objective...Always...During your interactions. Lose your objectivity; you pay the consequence of being manipulated now or later by the individual.
- Focus on hope and the ability/courage to change for the better. Most folks actually become empowered knowing that they can eventually beat the odds despite the setbacks...Even if the person feigns/believes in the hopelessness.
- Focus on the self, not on anyone else...Externalizing keeps the problem unresolved.
- Consider involving the member in weekly meetings to collaborate about his/her supports and review progress in a validating and cheerleading environment.

REFRAME FROM PROVIDING SOLUTIONS TO THE PROBLEM, INSTEAD AID IN PROBLEM SOLVING STRATEGIES.

Focus on cause and effect, his/her actions and the resultant consequences. Hold the person responsible for his/her actions (and choices) and how it contributes to his/her current state of unhappiness. Focus should be on how to make better choices next time in a similar situation; what they did right rather than what they did wrong

KEEP IT SIMPLE AND STRAIGHT TO THE POINT

Structure your interactions with a purpose, a plan to be discussed/resolved. Ambiguity or having a vague interaction will get you nothing but ambiguous results. Ambiguous interactions lead to little or no change and are a general waste of precious time. 1:1s and groups are to have a definite focus. Place value on time and on interactions.

SET CLEAR BOUNDARIES AND LIMITATIONS

- Boundaries always. Codependent staff has the most difficulty with this. Folks often hone their radar out for codependent folks, be it other patients or staff. When the person begins focusing on you, shift it back. Individuals have been described as being “actively passive” in that they have so little trust in their inner capacity to make good choices, that they defer to others to

make decisions for them. People who do this should be encouraged to actively participate in problem solving about issues that relate to them, rather than being given whatever the support worker thinks is the “right” answer.

- When your limits/structures set by you are challenged, it is nothing but the person asking “Can I trust you to keep me safe?” Despite the anger or threats made, the person comes to respect and trust you more when you do not collapse in...”I can trust you, can you can keep me safe, even from myself and when I try to steer you.” For the individual, the proof is in the pudding.

TEACHABLE MOMENTS

Teach the person critical skills, focusing on understanding emotional dysregulation and its role in their life.

ROLE PLAY AND MODELING

Making appropriate choices are so crucial for you to model. A genuine choice allows you to always choose differently. Drawing choice charts are useful. Choice A leads to additional choices X, Y, and Z. I can also choose not to make Choice A, which leads me to Choice B, which gives me choices D, E, and F. You get the idea. Again, pull the person into the head or into the world of cognition. The emotional tangle and dirt keep the person stuck in his/her dilemma...Like quicksand. Choices allow hope...Emotional angst does not.

FOCUS ON THE HERE AND NOW

Focus on the here and now, not yesterday or the past. The present is all that matters and where it leads to in the immediate future. The past is what placed the person on the unit in the first place. The future allows a way out.

MAKE EVERYTHING IMPLICIT EXPLICIT AND CONCRETE

We forget that most of what we have learned with regards to rules of society (including boundaries, social skills and relationship management, etc.) has been implicitly taught to us through modeling. We learn through observation and apply those skills without much thought. In saying this, we must remember that these rules must be made explicit and tangible for the members to process. This can be done by explaining who, what, where, when, why something will be done and why. The use of teaching aides to support the learning process is essential and do not assume individuals have the knowledge. I hear so very often “they know what they are doing…. They just want to get me upset”. For the most part this is not the case. What may seem simple and common knowledge only seems that way as we have been able to observe, process information and then apply this information in a variety of settings. Many individuals cannot.

To help individuals understand the intensity of the emotional pain with which someone lives Judith Hermann, describes a person with borderline personality disorder as the equivalent to a third degree burn victim where the injury is of the emotions rather than skin. We need to learn to see behavior through a different scope. In order to successfully support people with disabilities who show the behavior patterns, we start with the use of Positive Behavior Supports. In 1993, Marsha Linehan published her book Cognitive-Behavioral Treatment of Borderline Personality Disorder. This was the first branch of psychotherapy documented in controlled clinical trials to be effective. The therapy is a combination of individual psychotherapy and skills training and she called it Dialectical Behavior Therapy. Combining positive behavioural supports targeting the skills deficits posited by the biosocial theory of Border Line Personality, on which DBT skills

training is based, in addition to using the tips provided, can lead to a great collaboration which helps to create safe, validating and supportive residential services.

Borderline personality disorder is a complex mental illness. Despite its far-reaching effects, it is largely unknown and frequently ignored. Because of its complex, multifaceted nature, it is likely the most misunderstood and stigmatized mental illness. Over the last decade, much progress has been made with the help of sophisticated brain scans that reveal that the brains of people with borderline personality disorder function markedly different from those without the disorder. This research has been key in creating awareness and bringing about a wealth of new resources, although more is needed. It can be a challenge to support members who engage in complex behaviours; however, with adequate specialized training, residential placements and treatment models geared specifically to meet the needs of these individuals, community service agencies can successfully support such individuals with respect, safety, and validation.

Be true to yourself despite being misunderstood.
It is painful but not fatal. *I Ching*