



# Supporting a Person Who Is Experiencing Post Traumatic Stress Disorder (PTSD)<sup>1</sup>

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*Hello darkness my old friend.*  
-Simon and Garfunkle

*It's like a snapshot that comes back in my mind in perfect detail, without any words to explain it.*  
-Victim's memory

*...traumatized people are frequently misdiagnosed and mistreated in the mental health system. Because of the number and complexity of their symptoms, their treatment is often fragmented and incomplete. Because of their characteristic difficulties with close relationships, they are vulnerable to become re-victimized by caregivers. They may become engaged in ongoing destructive interactions, in which the medical...system replicates the behavior of the abusive family.*  
-Herman

*Trauma is about separation from the people or beliefs that protect, nurture and guide us...  
Recovery is all about creating attachment in a person's life. It's about the relief of suffering*  
- Elia Vecchione

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<sup>1</sup> **There are a number of people who have helped me to understand the impact of Post Traumatic Stress Disorder on the lives of people with disabilities.** I am especially thankful to Dr. Elia Vecchione, Ph.D., of Upper Valley Services in Vermont, for helping me to understand that despite the terrible things that have happened to some very good people, healing is possible. Al and his colleagues save lives every day. And, in the scheme of things, it doesn't get any better than that. **If you choose to duplicate this material, please be mindful that much of it is adapted or taken directly from these sources:** (1) Legare, G, Ryan, R. & Lewis Herman, J (1998) *Exploring the possible impact of trauma*. Camp Hill, PA: Contract Consultants, Inc. (2) Gabriel, S. (1996). *The psychiatric tower of babble: Understanding people with developmental disabilities who have mental illness*. Eastman, Quebec: Diverse City Press. (3) Ryan, R. (1996). *Handbook of mental health care for persons with developmental disabilities*. Denver, CO: The Community Circle Publications. (4) Vecchione, A. (1996). *The trauma and recovery handbook: A guide to developing programs for individuals with mental retardation*. Moretown, VT: Upper Valley Services (5) Vecchione, A. (1996). *Supporting people who have been traumatized*. Presentation at the April, 1996 Vermont Providers Conference. Rutland, Vermont.. (6) Flannery, R.B. (1998). *Post-Traumatic Stress Disorder: The victim's guide to healing and recovery*. New York, NY: Crossroad Publishing Company. (7) James, B. (1994). *Handbook for treatment of attachment-trauma problems in children*. New York: Simon and Shuster. (Version: 20 January, 2002).



## Understanding Trauma

1. Posttraumatic stress disorder is said to occur in 1% of the general population and in 3.5-23.6% of persons exposed to trauma. People who experience disabilities are more likely than non-disabled people to be abused physically, emotionally, or sexually. Ryan (1994) estimates that 61% of the people with developmental disabilities living in a hospital setting met the criteria for PTSD. To date, there are no systematic studies of PTSD in persons with developmental disabilities<sup>2</sup>.
2. Traumatic events may include one or more of the following<sup>3</sup>:
  - a. Separation from primary relationships at an early age.
  - b. Frequent moves from residential placements
  - c. Institutionalization
  - d. Physical abuse
  - e. Verbal abuse
  - f. Neglect
  - g. Degradation
  - h. Loss of parent, sibling, or significant other
  - i. Significant medical problems/procedures
  - j. Extended hospitalizations
3. In the name of treatment, professionals may expose the individual to trauma. The following procedures are common in the lives of people who experience disabilities:
  - a. Time out
  - b. Overcorrection
  - c. Physical restraint
  - d. Facial screening
  - e. Ammonia or other aversive substances
4. Typical reasons for referral<sup>4</sup>:

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<sup>2</sup> Ryan, R. (1994, February). Posttraumatic stress disorder in persons with developmental disabilities. *Community Mental Health Journal*. Vol 30 (1).

<sup>3</sup> Vecchione, A. (1996). *The trauma and recovery handbook: A guide to developing programs for individuals with mental retardation*. Moretown, VT: Upper Valley Services.

<sup>4</sup> Lègarè, G., Ryan, R., & Lewis Herman, J. (1998) *Exploring the possible impact of trauma*. Camp Hill, PA: Contract Consultants, Inc.

- a. Unexplained (inexplicable) “bout” or episodes of anger.
  - b. Inexplicable episodes of screaming, throwing things or destruction of property.
  - c. Out of proportion kinds of reactions to normal changes or stressors. People who have an out of proportion reaction to moderately stressful but not catastrophic situation may have had something worse happen to them in the past that is stirred up by the event.
  - d. Rage attacks.
  - e. Abrupt physical assault (often on the people they like).
  - f. Being extremely afraid (terrified) of people they know and trust at times.
  - g. Calling someone they know by a different name.
  - h. Appearing unfocused, not with it (speculated seizures).
  - i. Sometimes behaving like they are somewhere else.
  - j. Dissociative experiences.
  - k. Unable to respond to people during the experience.
5. Commonalities found in person’s histories<sup>5</sup>:
- a. The person has received all kinds of psychotropic medications.
  - b. The person has a vague and unclear psychiatric diagnosis; more often a collection of different diagnoses over the years.
  - c. Often problem behaviors were unintentionally attributed to his/her developmental disability.
  - d. Long history of placements, referrals, comprehensive behavioral interventions and many consultations have been arranged over time. If positive results were found, they were short term and would not be generalized to the rest of the person’s life.
  - e. The person a severe reputation as being manipulative, aggressive, explosive and assaultive.
  - f. The person has spent a lot of time in restrictive settings (seclusion and restraints).
  - g. Usually have a very expensive support system.
6. It is not uncommon for a person experiencing PTSD to also be experiencing, or to have been mis-diagnosed with one or more of the following: depression, Schizophrenia, autism, alcohol abuse, dissociative disorder, kleptomania, pedophilia, panic disorder, anxiety disorder, Tourette Syndrome, Asperger’s Syndrome.
7. DSM-IV Diagnostic criteria for PTSD<sup>6</sup>:
- a. **Traumatic event.** The person has been exposed to a traumatic event in which one or both of the following were present:
    - i. The person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others.

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<sup>5</sup> Ibid., p. 2

<sup>6</sup> Lègarè, G., Ryan, R., & Lewis Herman, J. (1998)., pp. 3-5.

- ii. The person's response involved intense fear, helplessness, or horror.
- b. **Persistent re-experiencing.** The traumatic event is persistently re-experienced in one (or more) of the following ways:
- i. Recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions (body memories or conversion disorders (not a conscious recollection of what they are re-experiencing but will experience the same physical pain).
  - ii. Recurrent distressing dreams of the event (nightmares).
  - iii. Acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations and dissociative flashback episodes, including those that occur on awakening or when intoxicated).
  - iv. Intense psychological distress at exposure to internal or external cues (triggers) that symbolize or resemble an aspect of the traumatic event.
  - v. Physiological reactivity on exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.
- c. **Avoidance:** Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before trauma), as indicated by three of the following:
- i. Efforts to avoid thoughts, feelings, or conversation associated with trauma.
  - ii. Efforts to avoid activities, places, or people that arouse recollections of the trauma (these may appear as unusual phobias or, for example, avoiding the Doctor's office, a former place where the person lived, certain types of clothes people won't touch, certain rooms, sounds, smells, etc.)
  - iii. Inability to recall an important aspect of the trauma.
  - iv. Markedly diminished interest or participation in significant activities.
  - v. Feeling of detachment or estrangement from others.
  - vi. Restricted range of affect (unable to have loving feelings).
  - vii. Sense of a foreshortened future (the person does not expect to have a career, significant relationships or a normal life span).
- d. **Hyper vigilance/increased arousal:** Persistent symptoms of increased arousal (not present before the trauma), as indicated by two (or more) of the following:
- i. Difficulty falling or staying asleep.
  - ii. Irritability or outburst of anger.
  - iii. Difficulty concentrating.
  - iv. Hyper vigilance.
  - v. Increased or exaggerated startle response.
- e. **Duration:** To meet the criteria, the cluster of symptoms has to be present for at least one month.

- f. **Functional impairment:** The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- g. **Associated Features (DSM-IV):** the following associated constellation of symptoms may occur and are more commonly seen *in association* with interpersonal stressors:
- i. Impaired affect modulation.
  - ii. Ambivalence.
  - iii. Self-destructive and impulsive behaviors.
  - iv. Attention seeking, needing to be around others.
  - v. Re-enactment of past traumas.
  - vi. Dissociative symptoms.
  - vii. Somatic complaints.
  - viii. Feelings of ineffectiveness.
  - ix. Shame.
  - x. Despair or hopelessness.
  - xi. Feeling victimized.
  - xii. Feeling permanently damaged.
  - xiii. Loss of previously sustained beliefs.
  - xiv. Hostility.
  - xv. Social withdrawal.
  - xvi. Feeling constantly threatened or unsafe.
  - xvii. Impaired relationships with others.
8. According to Lègarè, Ryan, and Lewis Herman (1998), “Addictions are often an associated issue with trauma. People may try to self-medicate the symptoms with some substance or other activities. One of the most common forms of self-medication seen in people with developmental disability is self-injurious behavior or self-mutilation. People may try to release their own endorphins as a way to (either) treat, master, repeat, or heal (there is a lot of speculation regarding the exact nature of the mechanisms involved) what has happened to them” (p. 5).
9. How might a person be experiencing trauma? Judith Lewis Herman, in her book *Trauma and Recovery* (1992) writes, “*The human response to danger is a complex, integrated system of reactions, encompassing both body and mind. Threat initially arouses the sympathetic nervous system, causing the person in danger to feel an adrenalin rush and to go into a state of alert. Threat also concentrates a person’s attention on the immediate situation. In addition, threat may alter ordinary perceptions: people in danger are often able disregard hunger, fatigue, or pain. Finally, threat evokes intense feelings of fear and anger. These changes in arousal, attention, perception, and emotion are normal, adaptive responses. They mobilize the threatened person for strenuous action, either in battle or in flight...Traumatic reactions occur when action is of no avail. When neither resistance nor escape is possible, the human system of self-defense becomes overwhelmed and disorganized. Each component of the ordinary response to danger, having lost it’s utility, tends to persist in an altered and exaggerated state after the actual danger is over....Traumatic events produce profound and lasting changes in physiological arousal, emotion, cognition and memory. Moreover, traumatic events may sever these normally integrated functions from one another. The traumatized person may experience intense emotion without clear memory of the event, or may remember everything in detail but without emotion. She may find herself in a constant state of irritability without knowing why. Traumatic symptoms have a tendency to become disconnected from their source and to take on a life of their own.*” (P. 43).

10. Betrayal is often at the root of Posttraumatic Stress Disorder (P.T.S.D.)<sup>7</sup>. The trauma is perpetrated by someone the person should have been able to trust; in short, the person has been betrayed.



## How can you help?



### Get to know the person.

One of the most important (and pragmatic) things you can do to support a person who experiences PTSD seems almost too obvious to state: *get to know the person!* It is too often the case that the people who develop interventions for the person don't know the person in any meaningful sense. They know the person as the sum total of his or her labels, but know little about the person as a "whole" human being.

1. Make a point of spending time with the person in places that he or she enjoys, during times of the day that he or she chooses. It should be a comfortable place where both of you feel safe and relaxed (e.g., a quiet room, a walking trail in a nearby park).
2. At a time that feels right (you will have to trust your intuition on this one), tell the person about your concerns and *ask* for his/her permission to help (it's rude not to). If the person has no formal means of communication, *ask anyway*. Sometimes people understand what is being said, but they have a difficult time letting others know what they understand. The important point, always, is to *ask* the person for permission to stick your nose into their business, even at the risk of sounding silly to the people who think the person cannot understand (they're usually wrong).



### Help tell the person's story in a way that you would want your story to be told.

Many people, who experience PTSD, hold a story that few understand. Their story may be buried beneath layers of pain and humiliation. The person's real history may be hidden beneath layers of evaluations and

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<sup>7</sup> Vecchione, A. (1996). *Supporting people who have been traumatized*. Presentation at the April, 1996 Vermont Providers' Conference. Rutland, Vermont.

incomplete social histories. It is important to spend time with the person and his/her supporters to recover their true story.

1. Lègarè, Ryan, and Lewis Herman (1998) suggest an approach for gathering this information: “A useful process for the group would be to gather over a few days and try to piece together the person’s biography and look at what we can learn from their history. Here are some things you might want to keep in mind as you get to know someone:
  - a. Paying attention to the person’s answers to the questions (non-verbal or not) and then verifying the information with other people. Remember that the person cannot always tell the story.
  - b. Doing a careful review of the person’s history and family history. We have to piece the story together (using objective, reliable information) and as much as we can (without creating it), confirm the diagnosis.
  - c. As people gather information on past events, it’s important to look at a few important dimensions:
    - i. Type of trauma or abuse (what -- sexual, physical or psychological, where, who and when -- spontaneous, unpredictable, repetitive, or ritualistic).
    - ii. Role and relationship of the person to offender.
    - iii. Intensity of trauma or abuse (number of times and number of people involved).
    - iv. Reactions and responses of the person to the trauma or abuse (the autonomic response to trauma or abuse can vary: numbing, hyper arousal, hyperactivity, mood lability, depression, anger, hostility, defiance, rebelliousness, fearfulness, passivity, timidity, anxiousness, night terrors or nightmares, stomach aches, startle reflex, avoidance of places and people, crying, enuresis, acting out aggressive or sexualized behaviors, and lack of empathy for others).
    - v. Duration of abuse (length over which the abuse or trauma occurred).
  - d. It may also be helpful to construct a time line of the person’s life. Simply draw a straight line across a large sheet of paper. On the far left end of the line, write down the person’s birth date. On the far right end of the line, write down today’s date. Your job is to fill mark important events in the person’s life along the time line (e.g., the point in time when the person was institutionalized, the person’s major accomplishments, milestones). By constructing a time line, it is often easy to understand why the person is in distress and what has helped in the past.



## **Help the person to develop a support plan based on things real and authentic.**

People who exhibit difficult behaviors are usually subjected to a behavior plan at some point in their life. It is rare that they are asked if they want a plan, let alone invited to the meetings where one is developed. Instead, a plan is developed by strangers (e.g., the agency behaviorist who has spent less than two hours "observing" the person).

The team can ask, "Is our vision for the person similar to the vision we hold for ourselves and each other? When we think about what the person needs, do we focus on remedying deficits or do we think about supporting the person in achieving a *real* life?"

Instead of a behavior plan to "fix" the person, help the person and the person's supporters to develop a support plan that reflects a real and authentic life. John and Connie Lyle O'Brien suggest the following questions for building a support plan. Note how different these questions are from those we typically ask, such as "How can we reduce this person's problem behaviors?" or "How can we manage this behavior?"

1. *How can we help the person to achieve a sense of safety and well-being?*
2. *How can we help the person to expand and deepen his/her friendships and connections with family?*
3. *How can we increase the person's presence in local community life (and/or in the school?)*
4. *How can the person have more control & choice in life?*
5. *How can we enhance the person's reputation and increase the number of valued ways he/she can contribute in community life?*
6. *How can we assist the person to develop competencies?*
7. *How can we support the person's supporters?*



## **Help the person to achieve a sense of safety and well-being.**

It is almost always the case that a person experiencing PTSD is not feeling well. A body under constant stress is quick to deteriorate. Each of the person's health concerns should be taken seriously!

1. Be sure that you obtain help from a qualified professional (e.g., psychiatrist). Some of the symptoms of PTSD are also the symptoms of other disorders (e.g., manic depressive disorder, autism, Tourettes). Also remember that a person may experience PTSD and other disorders at the same time (e.g., mood disorder, Autism).
  - a. Not all psychiatrists have an understanding of the role PTSD may play in the life of a person who experiences disability. It is important to secure the services of a qualified professional who would not automatically rule out a diagnosis of PTSD (simply because the person has a disability).
  - b. You may wish to share information about PTSD (e.g., the work of Ruth Ryan, M.D.) with the person's psychiatrist if they are not familiar with the disorder or how it may affect someone with a disability (see References).
  
2. Ruth Ryan (1993) recommends the collection of the following information before meeting with a psychiatrist<sup>8</sup>:
  - a. Specific information on symptoms: Describe, in as much detail as possible, the symptoms that are causing the most trouble. Hearing voices? Feeling sad all the time? Feeling scared? Discuss whatever is causing the most problems.
  - b. Medication problems: any side effects of any medications, psychiatric or non-psychiatric.
  - c. The basics: Describe sleep pattern (when go to bed, when get up, any awakenings or nightmares), appetite (cravings, rituals, refusals, other patterns), sexuality, or ability to concentrate.
  - d. Baseline: What is the very best level of functioning? Describe what life is like when doing well.
  - e. Stresses: Describe any major stresses, like losses of job, pet, family members, health, or others. Even if it is something like a person at work who is being a bother, it is important to know.
  - f. Any use of alcohol or other drugs: Even things like sniffing paint, over the counter drugs, or caffeine/cigarettes.
  - g. Any other prescribed medications: It is a good idea to check on interactions before taking any new medications.
  - h. Complete medical history: It is very helpful to provide all past medical history, or be

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<sup>8</sup>Ryan, R. (1993). How to use a psychiatrist. Reprinted from NADD Annual Meeting Synopsis. Reprinted in *The Community Circle*. For your copy, write: The Community Circle, 1556 Williams Street, Denver, CO 80218 or call: 303-316-8794 (voice) 303-316-8796 (fax).

prepared to sign releases to get these histories. This prevents repeating old things that did not work. Do not edit this information.

- i. Treatment plan add-ons: Describe what would be most preferred priorities on treatment plan.
  - j. Goals: Make an explicit statement of what is expected from the treatment.
3. Know that medications can be helpful, but understand clearly that medications alone are *not* the answer. According to Ryan (1994): "Medications are used to treat con-current psychiatric conditions, such as depression, anxiety, constant dissociations (which must be carefully distinguished from seizure phenomena), or compulsive self-mutilation, utilizing such agents as flouxetine, nortriptyline, cabamezepine, or naltrexome. Sedation is not considered treatment and is not recommended."<sup>9</sup>
  4. It is important that the person be given a complete medical evaluation and be treated for any additional health concerns.
  5. It is important to reduce complications of other medication or treatments (e.g., side-effects from other medicines, or insisting that the person eat foods forced on them by the abuser because it's "good for them."). Ryan (1994) writes: "In general, persons with developmental disabilities manifest an increased susceptibility to paradoxical reactions to benzodiazepines and barbiturates, cognitive impairment (in persons who do not have schizophrenia spectrum conditions) and/or toxic reactions to neuroleptic, and depression and nightmares with treatment with certain beta blockers. Neuroleptic are of special concern in PTSD in that many individuals suffered abuse in settings while receiving neuroleptic. Thus, the neuroleptic effect may interfere with the client's ability to process trauma (by diminishing cognitive ability), and may also act as a dissociative trigger. Other iatrogenic issues may include programming which inadvertently recreates the traumatic event, such as isolating the individual after fearful screaming, or withdrawing reinforcement from a client for "excessive crying."
  6. Individual and/or group therapy *can* be helpful, but remember that some people have a difficult time in groups. Above all else, you must find a therapist who is sensitive to the person's disability and the traumatic past.
  7. **Exercise is important!** Remember that people are often in a hyper-state of arousal and aerobic exercise will help to dampen physiological arousal. For example, with a doctor's approval, you may wish to develop a routine in which the person takes long walks. If the person is assaultive, it might be helpful to take these walks in safe places, such as a hiking trail or local park. Make sure the person has comfortable, loose fitting clothing and good walking/running shoes. The staff should also be so fitted, but in addition, they may wish to carry a fanny pack with plenty of water, sun screen, and a cellular phone (in case of emergencies).

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<sup>9</sup> Ryan, R. (1994). Posttraumatic stress disorder in persons with developmental disabilities. *Community Mental Health Journal*. Vol 30, No. 1 (February)

8. A strong sense of safety is critical. What a person most needs are people who remain committed to the importance of safe, predictable relationships. Things that make can make people feel *unsafe*: crowds, confusion, new places, lack of control, being given orders, and threats.
9. The team must abandon any practices which might be construed as violent or hurtful.
10. Finding the right people to support the person is the right thing to do! Everyone may not fit the bill. Even the best intentioned people may remind the person of his or her perpetrator).
11. Remember that the person may not always have control over his or her behavior. A person's dissociative experiences may be as involuntary as a seizure.



### **Help the person to expand and deepen his/her relationships.**

A person who experiences PTSD may suffer most from loneliness. It is critical that the team seek to broaden and expand his/her relationships.

1. Become the person's champion (if you can't, help the person to find a champion). We all need someone who thinks we are special. People with difficult behaviors often have no one who thinks about them with unconditional regard. Make a commitment to help the person to find joy each day. Help others to see the person's strengths and gifts rather than limitations and shortcomings. Instead of being one more person who "works on" the person, be someone who "works with" the person. Speak about the person's struggles in a way that is respectful of those struggles. Let the person overhear you saying good things about him/her.
  - a. If you can't be the person's champion (for whatever reason), take responsibility for helping the person to find a champion. It's powerful medicine.
2. Support the person in developing enduring, freely chosen relationships. Although paid staff frequently develop meaningful relationships with an individual, they frequently leave. For this reason, it is critical to help the person develop relationships with people who are not paid to be in his/her life -- enduring, freely chosen relationships. Consider these ideas/strategies when helping a person to connect to others in the broader community:
  - a. Never underestimate the corrosive influence of congregate models of care on your ability to help the person establish enduring, freely chosen, relationships.
  - b. Move towards intimate housing arrangements and day supports.
  - c. Make a list of the people who "hold" the person's story. Help the person to make

connections with these people (see above).

- d. Be cautious. Remember, some of the people who “hold” the person’s story may have been abusive. It is not appropriate, in most cases, to help the person to reconnect with perpetrators.
  - e. Be sure the person’s story is told in a way you would want your own story told.
  - f. Practice deliberate acts of kindness (in short, help the person to reconnect with these people with something to give).
  - g. Make a list of the things a person loves to do.
  - h. Find people in the broader community who love to do the same thing.
  - i. Show up again and again....and again.
  - j. Pay special attention to *who* goes with the person. The person providing support should ideally love the same activity.
  - k. Get off the “disability dime.”
  - l. Help the person to make a contribution to the broader community.
  - m. Never lose track of the importance of the mutual nature of relationships.
  - n. Never lose track of joy (make fun a goal).
  - o. Show up and be “present.” Show up again and again...and again.
3. If the person continues to struggle with relationships, ask these questions from Linda J. Stengle’s book, *Laying Community Foundations for Your Child With A Disability*.<sup>10</sup>
- a. Is the relationship between the person and the other person unbalanced?
  - b. Are there too few mutual interests?
  - c. Is this an activity that the person really wants to do, or is it something you want him/her to do?
  - d. Is the activity long enough to encourage the development of a relationship?

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<sup>10</sup>Adapted from Linda J. Stengle’s fine book “*Laying Community Foundations for Your Child With A Disability: How to Establish Relationships That Will Support Your Child After You’re Gone.*” You can purchase a copy by calling Woodbine House, Inc. at 1-800-843-7323.

- e. Is the other person afraid to get close to the person?
- f. Is the other person too busy to take time to get to know the person?
- g. Are needed accommodations being made to allow the person to participate fully in the activity?
- h. Could your presence be interfering with the development of friendships?
- i. Do the same people tend to participate, or are there different people every time?
- j. Are there breaks, joint projects, or committees which allow people to talk with each other freely?
- k. Is the other person in the relationship mainly out of a sense of charity?
- l. Is there enough structure to the activity?
- m. Is the person projecting an attitude that is keeping others away?
- n. Do you think that something is preventing the other person from seeing and appreciating the person's good qualities?

**4. Keep your promises.** Many people who engage in difficult behaviors have too much experience with *broken* promises. Life has been full of tricksters -- people who say one thing and mean another. For example, Carl was told that he would be able to live in his own apartment if he improved his behavior. But the truth is much more complex. The funding streams which pay for the group home will not pay for an apartment. In the *real* world, Carl lives in the group setting because people are unwilling to deal with the "politics" the organization, funding streams and State regulations. In short, people don't want to deal with the *real* problems, so they make Carl *the* problem<sup>11</sup>.

Teach the person that your word is good by following through on your promises. Give the person a chance to learn that you are trustworthy, but don't be surprised if the person is reluctant to trust you at first. It can take time for a heart that has been betrayed to open up one more time.

And remember, in the real world there will be times when you can't keep your promise (for reasons beyond your control); life happens. But it will almost certainly be easier for the

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<sup>11</sup>Consider how long you could live with people you would not choose to live with. Imagine how you would feel if someone made you live with other people who share certain characteristics. For example, imagine being told that you must live with people who have brown, or people who wear glasses, or people who are your height and weight. Assuming that people will 'get along' because they share a particular diagnosis is equally ludicrous. We choose our mates for far more complex reasons. When people with disabilities protest this kind of arbitrary selection of house mates, we put them on behavior programs or dispense psychotropic medications. When people without disabilities live with people they don't care for, they generally move!

person to accept the change in plans if, on balance, you keep your promises.

5. Lègarè, Ryan, and Lewis Herman (1998) write, "In the beginning, rebuilding some minimal sense of trust and safety is the primary task for everyone, both therapist and support staff (each in their own way). Assurances of safety and protection are of the greatest importance. Everything we can do for the person should convey and emphasize that:
  - a. We care...
  - b. We are trying to help...
  - c. We are trying to reassure...
  - d. We understand...
  - e. We will hang in there with you...
6. **Infuse all of your help with *hope*.**
7. Establish traditions and rituals (things to look forward to).<sup>12</sup>
8. Speak of the future. Make plans for fun in the future. Try not to make these events contingent on good behavior.<sup>13</sup>
9. Teach the person that part of the work of healing is to accept the past, not hide from it. <sup>14</sup>
10. Be an advocate for the person. Do not discuss the person's circumstances or background with anyone in the community who does not know the person well.<sup>15</sup>
11. Do not expect the person to thank-you for your help. *They might, but don't expect it.*<sup>16</sup>
12. Be prepared for the person's concept of love to be fundamentally different than yours.<sup>17</sup>

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<sup>12</sup> James, B. (1994).

<sup>13</sup> Ibid.

<sup>14</sup> Ibid.

<sup>15</sup> Ibid.

<sup>16</sup> Ibid.

<sup>17</sup> Ibid.



## **Help the person to have more fun.**

People with substantial disabilities often live in ghettos of reward. Indeed, it is often this poverty of reward, not a lack of skills, that keeps people separate from other community members. Many must endure reward schedules for good behavior. The very few things that they enjoy are used contingently to reinforce compliance (talk about spoiling a good thing).

Fun is a powerful antidote to problem behaviors.

1. Count the number of things the person enjoys, the number of places she likes to go. Compare this to the number of things other people enjoy, the number of places other people go. Ask yourself, "Is the person having fun? Is she experiencing enough joy? Is this an interesting life with things to look forward to?"
2. When people have things to look forward to, they generally have fewer problem behaviors.
3. Make fun a goal.
4. Make a list of the things the person enjoys. Ask, "Who in the broader community enjoys doing the same things?" Help the person to show up in those places again and again in a way that promotes his/her success.



## **Help the person to have more control and choice in life.**

Many people with disabilities have little or no control over their own lives. Many of the decisions that we take for granted -- such as what to wear and whether or not to have a cup of coffee -- are made by other people. How would *you* feel if you lived such a life?

Choice is a powerful alternative to punishment. If the person's behavior challenges you, help him to find more desirable ways to express the needs underlying the behaviors. Instead of ultimatums, give choices (e.g., "Bill, I know you're upset. What would help? Would you like to go for a walk? or take a ride? You need a chance to calm down.")

1. Allow the person to make decisions throughout the day. If he/she has trouble making choices, find a way to help. Make sure there are at least three desirable outcomes to choose from. As Norman Kunc has said 1 option = tyranny; 2 options = a dilemma; 3 or more options = a real choice.

2. Make sure the person is invited to his/her meetings. It is important that he have input whenever possible. This is especially true when a problem behavior is being discussed (imagine how you would feel if people were trying to change your behavior and never stopped to ask you what you think). It is also important that the person be allowed to say "no" to a meeting. If he does, ask for permission to talk about the problem; if he says "no" to this, have a meeting in which you focus on *your* needs (try to think about what would help you if the person refuses to budge).
3. If the person does not speak, ask anyway. Remember that even if a person cannot understand your words, he probably can understand that the tone of your voice is respectful and caring.
4. Don't assume that helping the person to have more choices means letting him do whatever he wishes. Limit-setting is an important and fair part of any relationship. The real question is who is setting the limits and why. If limits are imposed upon the person without their input, and if the limits are part and parcel of a life in which the person is powerless, even your best advice may even be interpreted as one more statement of "do it my way or else." You can expect a general disregard for your advice if the person on the receiving end of the advice is "out of power."
5. Make a sustained commitment to the person to "fairness" in the relationship. If the person has been on the outside of power for too long, you may need to bend more often than not for awhile. The goal is to teach the person that giving is a two-way street. Support staff must work to create a warm and safe environment, but at the same time they must **set limits in ways that are supportive and not threatening**.
6. **Structure and predictability are critical.** A regular, but not rigid, schedule must be followed. For example, a picture schedule can be very helpful for many people who cannot read. The schedule might include photographs of the staff who will be providing support, the days events, etc.
7. Don't be overly impressed or frightened by emotional displays.<sup>18</sup> For many people who experience PTSD, it is important to know that the people providing support cannot be overwhelmed. It is important to remain calm during emotional displays to communicate to the person that they are "safe."



## **Help the person to develop competencies (mastery over symptoms).**

It is critically important that the person develop mastery over his/her symptoms. In other words, the person must learn to recognize that he/she is decompensating and engage in behaviors that help achieve a sense of safety and well-being.

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<sup>18</sup> Ibid.

1. **Rehearsal** may be a powerful way of helping the person to “work through” a problem. Make a list of things “that help.” Make the list with the person and/or people who know the person well. When the person is calm, rehearse “dealing with the problem” (e.g., going for a walk, getting distance from people). You may wish to video tape these rehearsals to help the person “see” what to do when dissociative triggers take place.
2. Reduce dissociative triggers. It may be impossible to identify all of a person’s triggers, but you should seek to identify as many as possible and help to eliminate them, as much as possible, from the person’s life.
3. Possible triggers:
  - a. Visual
  - b. Auditory
  - c. Olfactory
  - d. Taste
  - e. Tactile
  - f. Contact with abuser
  - g. Anniversaries
  - h. Movements
  - i. Activities
  - j. Medication effects
4. The person could be dissociating during typical daily activities and it is important to try and understand what they are experiencing.
  - a. If you believe that the person is experiencing a “flashback,” consider these questions and suggestions offered by Lègarè, Ryan, and Lewis Herman (1998, pp. 2-4) :
    - i. *Where are you?*
    - ii. *Do you know where you are?*
    - iii. *Do you know where you live?*
    - iv. *What’s happening?*
    - v. *Who is around you?*
    - vi. *What are they doing?*
    - vii. *What’s your name?*
    - viii. *Do you know who you are?*
    - ix. *Are you in pain?*
    - x. *Are you hurt?*
    - xi. Look for the other symptoms associated with PTSD.
    - xii. Take the staff experience and knowledge into account (above).
    - xiii. Use video tapes to capture the episodes.” (Pp. 2-3).
  - b. Make a record of what you observe. A careful analysis of the information may reveal what the person’s specific triggers.

5. According to Lègarè, Ryan, and Lewis Herman (1998, pp. 6-7), “A useful strategy for the team is to remember that the anger we witness is the survivor’s reaction to the continuous re-experiencing or remembering of very painful and overwhelming experiences. Keeping the following “respectful guesses”<sup>19</sup> in mind regarding the person’s experience will help the team remain grounded and respond more effectively. People who have been hurt a lot and traumatized describe the following experiences:
- a. Feeling terrorized...
  - b. Paralyzed...
  - c. Isolated...
  - d. Alone...
  - e. Unsafe...
  - f. Out of control...
  - g. Disconnected from others...
  - h. Ashamed...
  - i. Guilty...
  - j. Humiliated...
  - k. Helpless...
  - l. Hopeless...
  - m. Violated...
  - n. Overwhelmed...
  - o. Feeling scared...
  - p. Uncertain...
  - q. Ambivalent...
  - r. Vulnerable...
  - s. Powerless...
  - t. Hurt...
  - u. Inferior...
  - v. Suicidal...
  - w. Angry...
  - x. Fearful...
  - y. In pain....
  - z. Unloved or unlovable...
  - aa. Betrayed...
  - bb. Distrustful...
6. Change situations in the environment to avoid triggering events. Some persons are still forced to visit abusing family members. A person who is sent to their room as punishment may trigger memories of being locked up in isolation.
7. Know that the person’s repetitious speech may be a symptom of the trauma. Be willing to hang in there with the person while he or she is talking.

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<sup>19</sup>Lovett, H. (1997) *Learning to listen*. Baltimore: Paul H. Brookes.

8. Help the person to learn ways to handle his or emotion (e.g., identify feelings, coping strategies, problem solving, positive self-statements, helping others).
9. Talk *more* when the person is on track. Talk *less* when the person is engaging in difficult behaviors. It's not always clear that a person can process language when they are upset. It's likely they cannot process your words when they are dissociating. Tell the person that you want to help and then stop talking. Wait until the person begins to calm, or relax, and then provide the person with support (e.g., "That's great. I'm glad you're calming down. How can I help you?"). And then, by all means, follow through on your promise to be supportive!



## **Help the person to make a contribution to others.**

John Bradshaw writes, " Our identity is the difference about us that makes a difference."

Many people with disabilities develop identities as "problem people." They are segregated into "special" programs where they are treated as people who have little to offer. Soon their "treatment" becomes a kind of cage to protect them from themselves and others. The real danger is that if enough people begin to think of the person as a "problem," she will begin to believe it too.

We all need to be needed.

1. Help the person to find a way to make a contribution. Start when the person is young if you can. Giving is a lifelong endeavor. Things as simple as helping with household chores or helping out at church can teach the person that she *can* make a contribution.
2. Draw a circle 1 mile in radius around the person's home. My bet is there are dozens, if not hundreds, of people who are making a contribution to the broader community. Help the person to get involved with these groups not as someone "in need," but as someone who has something to give.
3. Pour over the pages of the newspaper and find the "Volunteers Needed" section. Talk to the person about joining an organization with you or with a friend (e.g., Habitat for Humanity, a local food shelter, an environmental group).
4. Help the person to learn how to support friends and family (e.g., an invitation to a sleep over, birthday cards, learning to ask "How are you doing?" or "What's new?").
5. Remember that it is important to overcome the belief that the person has nothing to share. It takes time and determination to help the person and others to see strength and the capacity to give when deficits were all that anyone ever saw before.



## **Provide on-going support to the person's supporters.**

Understand clearly that the work of supporting someone who is experiencing PTSD can be difficult and challenging. **It is important to provide on-going support to the members of a person's team.**

1. Assure staff and family receive training and support regarding PTSD. Front line staff are unfortunately some of the last ones to learn about PTSD and the first ones to be assaulted when they inadvertently trigger a memory.
2. **Meet regularly.** It is very important that people have time to discuss their experiences with the team.
3. Remind each other often that the person is a survivor and that he or she can heal.
4. It is important that relationships between the team members be solid. The person may attempt to relieve the violence and disruption of his/her abusers in an effort to separate the team members.
5. It is not uncommon for care givers who receive little support to form tight knit relationships that may interfere with the person's long-term interests. This "nesting" behavior is understandable, particularly when it is the only source of encouragement and support care givers receive. Managers must respond to the needs of these care givers and gently encourage them to let go of their resistance to outside input and support.
6. Make sure the person's supporters have a good reputation because their reputations may be questioned frequently.<sup>20</sup>
7. Be prepared to experience feelings that you might never want to admit.<sup>21</sup>
8. Be able to forget. This is not a place to hold grudges.<sup>22</sup>
9. Appreciate that the person has a warrior personality. He/she has survival techniques that allowed him to persevere through severe abuse. Accept and respect his techniques while helping to give him healthier defense mechanisms.<sup>23</sup>

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<sup>20</sup> James, B. (1994). *Handbook for treatment of attachment-trauma problems in children*. New York: Simon and Shuster.

<sup>21</sup> Ibid.

<sup>22</sup> Ibid.

<sup>23</sup> Ibid.

10. Build a support plan for the person's supporters. Just as it is simplistic to treat a person's behavior without understanding something about the life the person lives, it is simplistic to develop a support plan without considering the needs of the person's supporters. Meet regularly with the person's supporters and ask them what they need to continue doing their best work.
11. Build a crisis support plan that really works. It is critical that contingencies be developed to handle difficult times. Ask caregivers questions such as, "What would you need if the person had a terrible day and nothing you could do would make him calm down?" "What would you need to feel safe?" "What would you need so that you can go home at the end of a day without a knot in your stomach?" Once caregivers are assured that they will be safe in the "worst case scenario," they are usually ready for the work ahead. Also include information about emergency back-up and assure this back-up is reliable. You may also need to develop protocol for the use of physical restraint if the person requires it during a crisis.
12. Remember that frequent crises are a symptom that the support plan is not working. An occasional crisis should be expected, but frequent crises mean that the team has overlooked an important element of support. Invite the person's most immediate supporters, and objective outsiders, to join in a problem-solving session to assess what's missing and develop additional support strategies.
13. **Laugh often. Celebrate often. Joy is powerful medicine.**



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