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Modified Treatment of Post-Traumatic Stress Disorder with Individuals Who Have a Developmental Disability

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Abstract

On a daily basis somebody encounters a traumatic event. People who have a developmental disability encounter such events three to four times more often. As a consequence of some of these traumatizing events, post-traumatic stress disorder (PTSD) results. Psychotherapy has been proven to be necessary and effective in aiding with some of the symptomatology. This article outlines some modifications that have been developed in order to provide psychotherapy to individuals who have a developmental disability.

Years ago, it was believed that the only way to provide treatment to individuals who have intellectual or developmental disability (IDD) was through pharmacology. Then with the advent of behaviour therapy, this treatment approach was added. Later on came the advent and use of psychotherapy. Pharmacology can sometimes mask the problem. Behaviour therapy addresses the symptoms of the person's difficulty. Psychotherapy is said to try and address the underlying cause or root of the problem. Most of the research related to persons who have a developmental disability is in the areas of medical or behavioural research. With the arrival of psychotherapy as a mode of treatment, more and more research has begun to look at the efficacy of this approach (i.e., evidence based treatment) with regards to its utilization in persons with IDD. The current article will look at modifications that have been used in the treatment of post-traumatic stress disorder (PTSD) in IDD during 25 years of clinical practice. Further research will determine if these modifications have been successful. Anecdotal information will be presented to demonstrate the merit of these changes to some classic templates. To protect confidentiality, names used in this paper are pseudonyms.

Statistics on the rates of PTSD has alone justified the need for the development of treatment of this disorder. "Between 10 to 80% of people exposed to traumatic events develop PTSD at some point and time" (Williams & Poijula, 2002, p. 5). The news reports daily of various traumas people have encountered (e.g., another gun shooting victim dies; people killed or injured in a car accident; mass genocide; hurricane hits; oil spill; child falling from a 3rd story window; coach accused of abusing his players; mother of three killed by former husband). The people that are traumatized are not always those directly involved. Sometimes it is the family, friends, others involved, soldiers in war zones, first responders, witnesses, people who have heard of the trauma and many more.

The statistics for persons with IDD being abused and most likely traumatized are staggering. Estimates of abuse rates, varies according to definition, location of study, subject pool, etc. Sobsey (2008) reported that children and adults with disabilities are at least three to four times more likely to experience abuse then those without a disability. If one form of abuse occurs, it is likely that the person also has experienced other forms of abuse. Often when abuse has occurred, it is likely that there has been more than one occurrence.

> When Ray told the police about a restaurant employee groping her, either Ray was not willing to tell them, or the police did not hear, that this had been occurring for months. The man that had been sexually assaulting her had also been psychologically abusing her – probably so that she would submit to him.

Since the rates of abuse, one form of trauma, are so high, treatment for PTSD was a logical step. Modifications were necessary to make available PTSD treatment to IDD. As Meichenbaum (1994) has pointed out, the guidelines for therapy should not be seen as a steadfast prescription, but rather a flexible framework with which to work. The manner, in which changes or modifications are made should depend on the client's needs and treatment goals**.** Consequently, some adaptations were made in the implementation of some of the standard methods of treatment for PTSD (e.g., Pharmacology, Behaviour Therapy, Cognitive Behavioural Therapy, Art Therapy, Solution Focused Brief Therapy, Psychoeducational, Systematic Desensitization, Narrative Therapy, Psychodynamic, Symbolic Interactive Therapy, Group Therapy, Relapse Prevention Model, Mindfulness, Critical Incident Stress Debriefing, Self-Help). Components of some of these approaches subsequently were applied, and these have resulted in an eclectic treatment intervention designed to meet the individual needs of IDD who have experienced PTSD. Therapy needs to be made appropriate and accessible by the therapist (Upton, 2009).

Modifications Made by the Author

An individual's treatment plan should be developed for that individual. Consequently, the mode of treatment can change from person to person, between and within sessions.The key seems to have been to watch and listen to determine if the client was receptive and perceptive to the modalities and techniques that were presented. The following text provides some examples of how traditional methods/approaches have been somewhat modified in order to meet the needs of persons with IDD.

Scheduling Appointments at Times Convenient for the Client

Some of the initial modifications involved time. Appointments were scheduled to meet the client's needs.

> Morris was depressed since the tragic loss of his father and subsequently his job. We would meet every Thursday, in the morning to help him to try and start to establish a daily routine and give him a sense of consistency.

> Thelma had left a 20 year abusive relationship and was trying to find and assert herself. She had also become involved with a man who was just interested in sexual relations and whatever he could take from her. Thelma and I would meet late in the afternoon because that is what she wanted. This woman asserted herself and needed to be listened to. Over time, Thelma requested earlier meetings because she was involved in various adventures. Once she started to see herself as valuable and being taken advantage of (which first started with a tenant of her parents) she started to develop a routine that suited her desires.

Large and small facets of therapy need to be pondered when working with persons with IDD who suffer from PTSD.

Making Efforts to Improve Communication

Make sure they understand you: Communication is a paramount facet in therapy. Simple language, simple words, small sentences can be better understood by all. Check in with the person to make sure they understand. For example, I might say: "Sometimes I talk too much. I'm kind of tired. Can you tell me what I was talking about?" Sometimes persons with IDD like

to say "yes" but that does not mean they understood. They do not want us to know they did not understand. Using the clients' words is a tenant that many counsellors have been taught.

Attempt to understand them: Attempts need to be made to search for their words and understanding. Once when scheduling an appointment, the client said she wanted to meet on the "Tuesday down." If you visually look at a calendar her meaning is clear. Another woman talked about having "two dinners." I figured out that this comment meant having "two helpings." Another example is using the term "out food" to mean "take-out or delivery."

> After Jane called and asked me to help a co-worker, she asked for paper and a pen. As she drew Figure 1, Jane asked how you draw a man on top of you. I suggested, however, that she think about this and draw what she thought. Then she drew Figure 2. Jane did not need to say much. Her pictures spoke for her.

Learn from them: As a result of some of their phrasing and attempts to express abstract concepts, people may think that some persons with IDD may be mentally ill. Doug liked to talk about lightening a lot. Once he said it originated from the ground. When I looked it up he was right. A 22 year old man once asked how long a worker in his 50s how long he had been black. A woman once told me she was "ball up." I learned that she was talking about how she felt when she got anxious. Words, phrases and colloquialisms can be used out of context. Checks need to be made to make sure that counsellors understand what people with IDD are saying. A 40 year old woman once reported that she had been "raped." I simply asked Patricia what she meant by the word, as the staff scrambled to summon their supervisor. She was upset that a male client had called her names she did not like**.** If the word rape is used literarily then she does not make sense but figuratively she makes a lot of sense.

Use repetition and different ways to present the same piece of information: It has often been said that repetition is helpful for persons with IDD to learn. Sometimes it may be that new information needs to be presented several times or that it needs to be presented in a different way.

> Brian had been in therapy for many years. He had been sexually assaulted by his brother and physically by his father and mother when he was a child. There were subsequent assaults by others in his life. Many therapists had worked with him in different ways. Once when Brian and I were meeting, I told him a story I heard of a man who had been abused as a child and some of his negative coping mechanisms (e.g., drug abuse, cutting himself) and worries (e.g., that he would abuse a child like he was abused). Many times I tried to normalize his worries and let him know that he was not alone. The story somehow connected with Brian. He started disclosing other things and became more honest with himself.

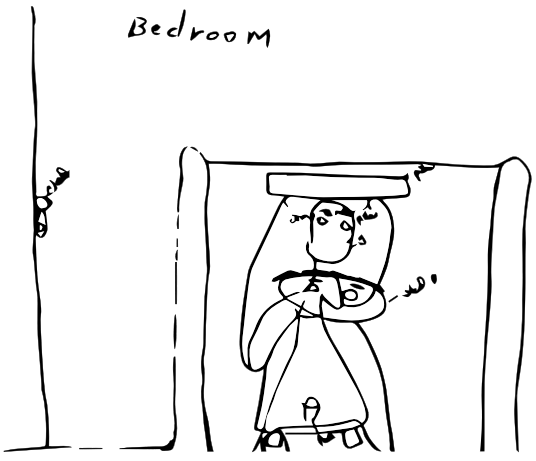

Figure 1: Jane being sexually abused by her step-father

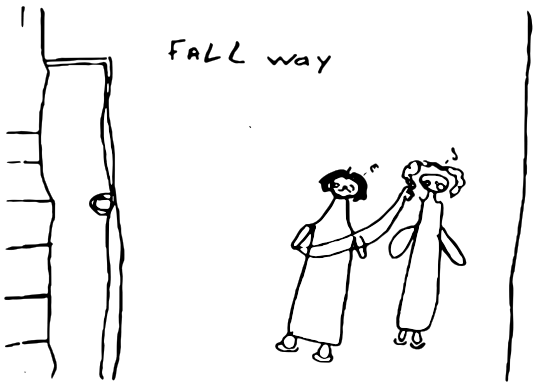

Figure 2: Jane's mother taking her by the hair and hitting her head against the wall

Provide assistance to help them understand complex situations: Over time, I have come to believe that most persons with IDD do not lie. Perhaps this is because they lack the cognitive abilities to do so. Rather, they sometimes seem to be trying to deceive themselves, or may have misunderstood something.

> Frank and I started to meet when his therapist returned to university. In Pam's (Fred's previous therapist) last report, she reported that Frank had said that his mother had died. He was offered additional sessions by Pam, but declined. About a year later, Frank returned. His worker said there were problems between Frank and his partner. At our first meeting, as we talked about the arguments with his partner, I inadvertently learned that his mother had been sick. This had been a stressor for Frank. After thinking about this conflicting information, I asked Frank to clarify for me. It turned out that he had previously assumed his mother was dead because she was motionless in a hospital bed, hooked up to all kinds of tubes and machines. Frank's mother subsequently recovered. Frank was clear about the status of his mother and so now was I.

Persons with IDD sometimes need assistance in understanding things that happen around them (e.g., what was said by the sex lady on TV, doctor, lawyer, judge, police officer, worker).

Find out how each person learns best and ask them how they would like to be helped: Communication needs to be grounded to the way the individual thinks. People learn through demonstration, visual means and/or instruction. We need to find out how each person learns best. For example, visual scales are often used to determine a person's present level of anxiety (i.e., series of faces from very anxious to neutral to happy or scaling using hand length). Most of all it is necessary to ask them what will help. Many suggestions can be offered about how to cope with a flashback but only the client can initiate one of the methods. Judy once told me that when she started to have a panic attack, she would imagine that her doll was repeating my words about breathing and saying positive messages to herself. Judy did not have a major mental health problem. At the time it sounded odd but then I realized Judy had just found a way to cope.

Cognitive Behavioural Therapy

Cognitive Behavioural Therapy (CBT) has been found to assist persons with IDD to survive with PTSD symptoms (Willner, 2004; Kroese & Thomas, 2006; King & Desaulnier, 2011). The use of CBT has seemed to work because it has concrete, black and white components. Certain people appear to think this way. Persons with IDD often operate in the here and now. That may be why *Mindfulness* (bringing one's complete attention to the present which often involves mediation) has been an effective treatment modality for this group (e.g., Singh, Wahler, Adkins, & Myers, 2003). Relaxation is not always something people learn. It has often been difficult for clients who have been abused to close their eyes whether learning how to relax in a group or individually.

> Thelma had participated in a group about coping with frustrations. When she attended a group for women who had been abused, she offered to share a relaxation CD she received in the other group (i.e., simple music or simple instructions). Not only were the other women receptive to her offer, more importantly, Thelma was using it at home. Once she had been able to practice relaxation in the comfort and security of her own home, she was willing to do it in a group. Thelma latter told me that she was participating and enjoying yoga classes.

Partaking in arts and crafts and writing in journals can be therapeutic. These activities can provide others way to express how a person is feeling, what they are thinking about and how they are dealing with a traumatic experience. Below are descriptions of several individuals who have been helped by such techniques.

> Moe had been raised on a farm by various family members. He often walked around the unit with twigs and other things stuffed into his orifices. Later, Moe disclosed that this was to protect him from others putting things into him. See Figure 3 for a picture Moe drew when asked to draw a picture of himself.

> Nadia would not talk to anyone she saw as an authority figure. She did like cats. I compiled a series of cat books and pictures. Nadia would only talk about the pictures. We then tried a tape recorder because Nadia said that she did not like the sound of her voice. Nadia would record all

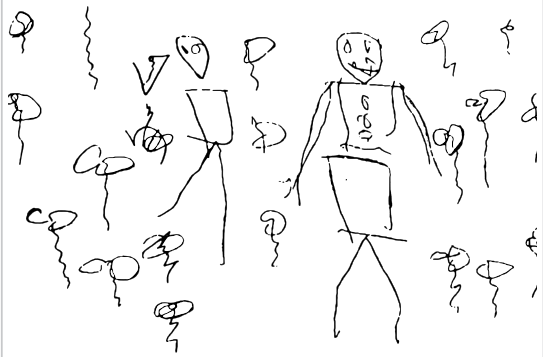

Figure 3: Moe's picture of himself which seemed to indicate that there were different components to components to himself – some more evolved than others

her concerns and worries on the recorder, while I was out of the room. Then I would talk after listening to her message.

When John first came for assistance, he was in his mid 50s, his father had recently died and he was not able to find another job. John had never received services for IDD. His father did not want that for his son. As part of his first psychological assessment, he drew a picture of himself and his mother. He looked like a "blob" but she had definition. After several years of therapy, regarding his grief and figuring out who he was as a person, John again drew a picture of himself. Both he and I were astounded at the change in his depiction of himself. He had hair, glasses, eyes, hands, a belt and so much more. Shortly after that, John told me he did not have anything to talk about. John agreed that he no longer needed to meet but desired to pursue some of the Service Coordinator's suggestions about activities.

One of Martha's favorite endeavours was to write letters. The letters were to public transit (she had been on probation for hitting a driver with her cane), public housing and about people she was mad at. Like many other persons with IDD she had an extensive abuse history. The most constructive way we found for her to express her distrust and anger was to write letters. She would dictate and I would write. (Martha had developed Parkinson's disease.) The letters never went anywhere other than my file. Sometimes she would ask about a letter because she wanted to continue it. At times, I thought she was going to have them delivered but she never left with one. When Martha was in her late 50s she had a afall and broke her arm extensively. She needed to go to a Long Term Care (LTC) facility to recover. It was very difficult for her not being able to take care of herself. Once Martha moved into LTC, we ceased to meet because of transportation issues. A few months later, her sister said that she would bring Martha in. Martha had been getting into a number of verbal altercations with people at her new home. We met monthly for about a year. When her sister suddenly passed, her nephew continued to bring Martha in periodically. She continued to write letters that went into her file and I never heard from anyone about further problems at her residence.

Caroll also liked to "write" in her journal. I could not read what was written in her journal. It was possible that as a result of physical abuse (and sexual) by her father, Caroll was not able to read and write. What mattered was that Caroll said it helped her to feel better when she was anxious.

Solution Focused Brief Therapy

Solution Focused Brief Therapy has been found to help persons with IDD who are struggling with the problem of a loss (Stoddart, McDonnell, Temple, & Mustata, 2001). Using this form of therapy taught me that not everyone wants to solve their problems. What appeared to be the difficulty to me was not necessarily the conundrum to the client. One component that has been helpful in understanding the difficulty a person with IDD has been experiencing is "the miracle question." Learning what the individual's life would look like if I had magic has been miraculous.

Jack had been referred because he was setting fires at the workshop. The assumption had been made that he was having conflicts with co-workers. When I asked him "if I could wave a magic wand, what would be different," Jack said that his father would no longer be at home. I learned that Jack's father had been sexually abusing him and his two sisters.

Psychoeducation

The clients I have worked with have taught me a lot. However, sometimes I am expected to teach them. Psychoeducation has turned out to be a large component, whether it was teaching someone about sexuality, social norms, the court system, consequences for actions and the process for getting gender reassignment surgery or how to deal with anxiety attacks.

> Even though Raquel's favorite TV show was Law and Order, she still wanted to review the court process when she had to testify as a witness, to her sexual assault. As she went through each step, she requested to review what was next. Frequently, she would ask how long it had been – not since she reported or when her abuser was arrested, but since he first started hurting her.

> When Lela decided that she wanted to go through gender reassignment surgery, we often used pictures of the surgical process and aftercare. It was important that she knew what she was consenting to. Lela had encountered a life of sexual, physical and emotional abuse. It was more important to Lela that she completely understood. With the assistance of a resourceful student, at Lela's request, she was presented with resulting surgical pictures – clear-cut positive and undesirable outcomes.

Pharmacology

Pharmacology has been found to be useful in providing positive results for insomnia, depression, suicidal ideation and panic attacks when psychotherapy was in process. In some respects, without pharmacology, for some individuals psychotherapy would not be possible.

> For example, one man was experiencing heart palpitations. During medical examinations, it was determined that he did have some minor heart concerns. Due to his presenting symptomatology, the physician suggested that the underlying concern might be that he was having panic attacks. The client was prescribed medication for panic attacks. His therapy involved work related to his abuse history, information on coping with stress, panic attacks and catastrophic thinking (e.g., Bourne, 2005). In addition he attended a group about coping with frustrations. The client subsequently reported fewer panic attacks. He did not feel the need to use the medication prescribed but it was reassuring to know he had it. Fewer late night calls that he had been to the hospital with heart palpitations were made.

Components of the different models have often been utilized as if they were like tools in a doctor's bag. Tried-and-true techniques are for enhancing the therapeutic interventions (Carrell, 2001). Home renovators have often said you cannot do a job right without the right tools.

Critical Incident Stress Debriefing

With regards to Critical Incident Stress Debriefing, it is often hard for first responders to talk about their feelings. Consequently, thoughts are discussed. Often persons who have IDD have been taught to not express their emotions. Sometimes they need assistance to connect with their emotions. This may be especially true of those traumatized. People sometimes try to protect themselves by not being in tune with their internal states (Price & Herting, 2012). Consequently, it has proven to be helpful to start with a new client by talking about their thoughts and interests before delving into their concerns and worries. Often, I have used pictures from newspapers or magazines to explore and teach about emotions.

> Mona was adopted (later rescinded) by a couple who fostered a number of children. When a foster brother, several years older, sexually assaulted her, Mona was sent to an institution. At this institution she encountered some men who were institutionalized because they had sexually offended against women and children in the community. Mona became a victim several times again. Over the years of working together, I realized that she had disassociated not only from her feelings but also from her body. We began to simply work on reconnecting her to herself (e.g., "How does your head feel? Your stomach? Your knee? Is the coffee hot? How hot? How did it feel as going down?"). She suffered from recurrent urinary tract infections (UTIs) and "headaches." During these times, Mona would become aggressive to her housemates and the staff. This would often result in her being admitted to a psychiatric ward. (That is where it was learned that she was having reoccurring UTIs.) Through the efforts of

her staff to work in combination with the hospital staff, her psychiatrist and myself, Mona went from almost monthly admissions to two years without an admission.

Symbolic Interactive Therapy

Symbolic Interactive Therapy (SIT) involves the use of objects to represent something else (Caton, 1988).

When Doug and I met we would often started off with a sand tray. I quickly learned from Doug that the number of objects in the tray determined how much work we were going to get done. If visually, his placement of objects appeared rather chaotic or organized and purposeful, I was able to glean insight into his internal thinking.

Joseph was said to function in the moderate range of developmental disability. He had watched his mother being abused. At a young age his younger, half brother cut him deeply with a knife. There were also sexual assaults in his history. Joseph was extremely vulnerable in the community (e.g., when going into an alley with a street worker, talking to strangers and making "friends"). Contact with his family was minimal. One of his difficulties was that he often expressed his difficulties through actions (e.g., aggressive altercations with his staff, "running away," talking about jumping off a bridge, touching pregnant women's stomachs). At times, Joseph had some difficulty finding the right words to express himself. When his beloved grandmother (in many ways Joseph saw her as his mother) suddenly died, Joseph was not invited by his mother and brother to attend the funeral. Consequently, Joseph and I had a funeral for her. Using a small box, female figure, tree forms, other female and male symbols, a cloth, kleenex and a bigger box we conducted Joseph's grandmother's funeral and burial service. In discussions about difficulties with his family, Joseph often recounted about the time he was not allowed to attend his grandmother's funeral. With pride he would talk about the funeral we held. This seemed to of assisted Joseph during a difficult time. During another difficult time (e.g., several changes in workers, moving three times in two months, changing workshops), Joseph used his words and not his actions to deal with the chaos and upset he was experiencing. At that time, Joseph was also coming for therapy less often. He had found his way to coping with upsets in his life in a satisfying way.

Relapse Prevention

The relapse prevention model is often used in the areas of addiction and sexual offending. Components of this model have been used with some clients in order to assist them in obtaining a more fulfilling life. The model was used as if it were a template to prevent clients from again getting involved in an abusive relationship.

Diana had been isolated, physically and sexually assaulted by her father. One of her worst memories was of her father assaulting her much loved dog and killing the pet in the process. We had met during a women's sexuality education group. Privately she told me of her father. She was firm that I was to be the one to work with her. Diana had been in physically abusive relationships with "boyfriends" in the past and while we worked together. In unison, we developed a plan so that she would know when she was looking for in an appropriate partner. For example, if she was feeling lonely or feeling left out and desperate for a boyfriend, or vulnerable, the time was not right to make a decision. We also discussed what qualities the "right kind of guy" should have. For example, the right person should always make her feel good about herself, listen to her, take her places, have the same dreams for the future. We also discussed the steps she needed to take when she began to slide – for example, call friends, spend time with her family, sing, listen to music, call me. It took time, but Diana found someone who did not mistreat her. It was impressive to watch her blossom in this relationship (e.g., she began to trust others, no longer bathed with her clothes on, and she allowed him to touch her).

Discussion

Through my work with individuals who have IDD, I never wanted to think that I was: "some clinician[s] [who] listened but did not hear" (King & Desaulnier, 2011, p. 48). Most of the time, progress tended to be slower than in the general population. However, looking for simple gains and reflecting that back to the client can keep one focused. The Emotional Problems Scales (EPS) (Prout & Strohmer, 1993) is an instrument that has been used. At times, this was possible to administer. At other times, it was difficult because the client's issue(s) already had been identified and the

situation was urgent. Consequently, it has been difficult to administer on a consistent basis. Nevertheless, this measure has been found to be a great tool to understand a client more fully by allowing thoughts to be expressed that had not come up. The EPS has also proven fruitful in stimulating discussion. This tool will continue to be utilized with the hope that some of the modifications outlined will be validated.

The variations sketched are not intended to be prescriptive. Rather they are attempts to try to give some ideas next time a therapist is feeling "stuck." Sometimes the therapist and the person who has IDD are both stuck. Willner (2004) noted that it is important for therapist not to infer that a client is not capable of benefiting from therapy when they do not perform as we had anticipated. Sometimes it is us. We need to think and communicate like they do.

It is hoped some of these tools will service others well. If so, you may find that the client will return – not only because of the exceptional assistance provided but also because the person with IDD needs further assistance. Sometimes only components of trauma can be addressed. "Women often seek out therapy or help when the adaptations begin to lose their effectiveness" (Haskell, 2003, p. 23). "Men in general are known for being reluctant to seek health services. Men often deny their vulnerabilities and feel they must portray the illusion of strength" (Wilken, 2008, p. 16). In addition, it is proposed that possibly the internal resources of a person with IDD will only allow so much upheaval at one time. At other times, a person with IDD may seek further assistance because another trauma, difficulty or life experience (e.g., death of a loved one, loss of a job, a relationship break-up, legal charges) has arisen. Consequently, this work needs to continue and further modification made to meet the needs of those we are servicing.

Key Messages From This Article

People who have a developmental disability: You have rights. Respect should be shown to you. Workers need to make changes that help you get the help you need. Thank you for teaching me.

Policymakers: Providing psychotherapy to people who have a disability can take longer than provision to those who do not. Respect the work that people do and give them time to do their work well and right.

Acknowledgements

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