Community Mental Health Journal, Vol. 30, No. 1, February 1994

Posttraumatic Stress Disorder in Persons with Developmental Disabilities

Ruth Ryan, MD

ABSTRACT: Persons with developmental disabilities are more frequently abused physically, emotionally and sexually than nondisabled persons (Ammerman, Van-Hasselt, Herson, McGonigle, & Lubetsky, 1989; Sobsey, Gray, Pyper, & Reimer-Heck, 1991). Persons with developmental disabilities are susceptible to the full range of psychiatric disorders (Szymanski, Madow, Mallory, Menolascino, & Pace, 1991). There has been no comprehensive study of posttraumatic stress disorder (PTSD) in this population (Hudson & Pilek, 1990), a recent textbook of mental health and mental retardation does not contain index listings on this condition (Fletcher & Menolascino, 1989), and psychometric tests currently proposed for use with the retarded do not examine for this condition (Aman, Watson, Singh, Turbott, & Wilsher, 1986). In this preliminary study, descriptive data from 51 persons with developmental disabilities who met *DSM-IIIR* criteria for posttraumatic stress disorder are reported. The majority of cases were detected upon routine initial psychiatric interview and record review. Demographics, family histories, and comorbid psychiatric conditions are described. In this sample all patients who received comprehensive recommended treatment improved.

INTRODUCTION

Posttraumatic stress disorder (PTSD) is estimated to occur in 1% of the general population (Helzer, Robins, & McEvoy, 1987) and in 3.5–23.6% of persons exposed to trauma (Helzer et al 1987, Breslau, Davis, An-

Ruth Ryan, M.D., is Assistant Professor and Director, Dual Diagnosis Program (a collaboration of the Colorado State Divisions for Developmental Disabilities and Division of Mental Health with the University). Dr. Ryan is also Associate Director, Programs for Public Psychiatry, University of Colorado Health Sciences Center, Department of Psychiatry.

Address reprint requests to Ruth Ryan, M.D., Programs for Public Psychiatry, 4200 East Ninth Ave C-249–27, Denver, CO 80262.

dreski, & Peterson, 1991). *DSM-IIIR* Diagnostic criteria include (Brett, Spitzer, & Williams 1988):

1. Presence of a traumatic event (which would be considered distressing to almost anyone)
2. Persistent reexperiencing of the event
3. Persistent avoidance of stimuli associated with the traumatic event (not present before the event)
4. Persistent symptoms of hyperarousal
5. Duration at least one month

It has been suggested that PTSD is not a rare condition in the general population (Epstein, 1989), and is associated with a wide variety of other psychiatric conditions (Helzer et al, 1987; Breslau et al, 1991; Epstein, 1989).

People with developmental disabilities are more likely than nondisabled persons to be abused physically, emotionally, or sexually. Individuals victimized sexually are more likely to be victimized by multiple perpetrators (Ammerman et al, 1989; Sobsey et al, 1991). In one population of state hospital psychiatric patients more than half had been sexually abused, and of these 61% met criteria for PTSD, though none had received that diagnosis (Craine, Henson, Colliver & MacLean, 1988). In a sample of intensive case management clients, more than third had been sexually abused, yet none of these clients had been asked about abuse experiences. A family history of alcoholism predicted increased incidence of abuse. Mental health providers were urged to make routine inquiries regarding childhood abuse histories (Rose, Peabody & Strategeas, 1991). It has been established that persons with developmental disabilities are susceptible to the full range of psychiatric disorders, and that these disorders can be diagnosed using *DSM-IIIR* criteria adapted to the individual's communication style. In addition, all types of psychiatric treatment can be useful if properly selected and executed (Szymanski et al, 1991). Despite these realities there has been no systematic study of PTSD in persons with developmental disabilities (Hudson & Pilek, 1990) and standardized tests suggested for use with this population do not measure for PTSD (Aman et al, 1986). The previous literature on this topic includes a single case report (Hudson & Pilek, 1990).

The author is involved with an on site team consultation service (Ryan, Rodden & Sunada, 1991) which provides psychiatric, behavioral, and medical consultation to persons with developmental disabilities

who emit complicated behaviors. The referral base includes persons with developmental disabilities in the state of Colorado who work and live in community settings throughout the state, and have a wide variety of economic and cultural backgrounds. Treatment is community-based, though all had emitted behaviors that had precipitated hospitalizations in the past. Referrals originate from case managers, physicians, developmental disabilities and mental health professionals, families, lay staff, and consumers.

Of 310 consecutive persons seen, 51 persons met *DSMIII-R* criteria for PTSD. Almost all of the 310 persons in the referral population had suffered significant abuse or trauma, thus suggesting that approximately 16.5% of persons in this group who suffer severe trauma develop PTSD, which is similar to the data on PTSD in apparently nondisabled persons who suffered trauma (Breslau et al, 1991). Trauma in this sample most frequently included sexual abuse by multiple assailants (starting in childhood), physical abuse that was commonly the cause of the person's cognitive deficits, or life threatening neglect combined with some other active abuse or trauma. There were a few cases where the trauma did not involve abuse, including seeing a sibling die in a fire, seeing close friends drown during seizures, seeing a close friend dismembered by a train, and seeing a parent commit suicide by gunshot wound to the head. Each person in this sample suffered at least two of these types of trauma, and most had suffered more than five incidents that were confirmed. (All reports were confirmed by outside sources)

66% were women, 33% were men. Average age was 33 (in the overall 310 the average age was 36) and average degree of mental retardation was moderate range (half nonverbal), which matches that of the overall referral group. Almost all were referred for violent or disruptive behavior. PTSD was the primary diagnosis in 35 (11%) of the overall referral group, and was the only diagnosis in 11 persons (3%).

Most common prior psychiatric diagnoses were "no diagnosis" or schizophrenia. Other more common diagnoses included autism and intermittent explosive disorder. Less common prior diagnoses included affective disorders, organic personality disorders, adjustment disorders, atypical spectrum disorders, and schizoaffective disorder. One prior diagnosis each of antisocial personality disorder, borderline personality disorder, and trichotillomania had been described.

In about half of the cases the traumatic event was known to someone working with the client. In no cases had the diagnosis of PTSD been considered.

The most common comorbid psychiatric conditions diagnosed (usually revising the prior diagnosis) when PTSD was identified included major depression (19), followed by 3 cases of complicated grief reactions. Conditions seen in 1–2 persons included schizophrenia, autism, bipolar d/o type II, dissociative disorders, multiple personality disorder, Tourette's D/O, Asperger's Syndrome, kleptomania, bipolar disorder, substance abuse, panic disorder, and pedophilia.

In this sample 66% of clients also suffered with a medical illness which would be expected to exacerbate psychiatric symptoms (same as in the 310).

In the vast majority of cases the diagnosis was suspected from the individual's answers to interview questions, or when a dissociative experience occurred during the consultation interview. Videotapes were instructive as well.

Persons who are nonverbal typically reported the history and current symptoms through drawings or gestures. Verbal persons often reported the history and current symptoms through nonverbal methods, though some could provide complete verbal information as well. Information and interpretation from persons who knew the individual's style of communication well was crucial.

EXAMPLE

AB is a 21 yo woman with profound mental retardation (no spoken language) and autism (present since infancy and correctly diagnosed) who was living in a group home and working a community based enclave. She had come to Colorado from another state and records on her programming and experiences there were sparse. She was referred for evaluation of abrupt shrieking accompanied by drawing up of her legs and increased scratching at her legs and abdomen. EEG done during these episodes was unremarkable. Also described were ongoing sleep disturbance (waking up several times per night screaming), erratic appetite, hypersensitivity to any type of touch, and absence of any sexual behavior. Functional analysis of the behavior failed to disclose any gains associated with the behavior or any consistent usual precipitants (such as location or task requests) Ms. B had received meticulous trials of nonaversive behavioral programming which had emphasized ignoring the "inappropriate" behaviors and teaching her alternative behaviors with frequent positive rewards. These were ineffective. Neuroleptics increased the frequency of the episodes. In the clinic Ms. B spent most of the meeting crouched in the corners of the room with a terrified facial expression, moaning, hypervigilance, frequent self scratching, and defensive covering of her chest, lower legs, and genital area. (This is in contrast to most individuals who visit with uncomplicated autism, who are indifferent to the clinic personnel, not terrified.) A long videotape was viewed which demonstrated episodes of shrieking, drawing up of the legs, terrified unfocused facial expression, lack of recognition of familiar staff, and self scratching in several settings. The only feature that was in common in all settings was that the hot

water was running in a nearby sink, or water was running and a teakettle was heating up. It was noted that Ms. B had scars on her legs which covered the entire area below her knees. Staff indicated that they had been told by the previous program that the scars (typical of burns) were sequelae of a skin rash, however the rash identified does not cause scarring.

PTSD was strongly suspected, however further information was needed. Ms. B's mother immediately provided evidence she had collected that documented abuse by scalding (dipping Ms. B's feet in scalding water) and sexual abuse which had occurred at age 5. Ms. B's mother had been told that trauma does not affect people with profound mental retardation or autism, and thus her findings "didn't matter."

Ms. B was suffering with dissociative events/flashbacks of being scalded and sexually abused which were triggered by hearing water running and being heated. Treatment included medication to reduce the frequency of dissociation (carbamezepine), tapering and discontinuation of beta blockers and neuroleptics, systematic desensitization to water (she had only allowed sponge baths for years, which observers had attributed to "her autism"), retraining staff to reduce the number of dissociations and assisting Ms. B in reorienting when dissociated (rather than ignoring her) and ultimately to teach Ms. B ways to help herself when becoming frightened. Meticulous medical evaluation did not disclose any complicating medical problems.

Family psychiatric histories were unknown in most cases. There were 15 cases with a family history of untreated alcoholism in at least one parent. The rest had family histories of affective disorders, mental retardation, dementias, and others. In two cases there was a murder of one family member by another family member.

TREATMENT

A six point protocol has been developed, based on current work in treatment of PTSD in nondisabled individuals (Epstein, 1989; Pitman, Van Der Kolk, Orr & Greenberg, 1990; Silver, Sanberg & Hales, 1990), the specific medication contraindications which apply to persons with developmental disabilities, and the data on the large number of persons with psychiatrically significant medical problems:

1. Judicious use of medications. Medications are used to treat concurrent psychiatric conditions, such as depression, anxiety, constant dissociations (which must be carefully distinguished from seizure phenomena), or compulsive self mutilation, utilizing such agents as fluoxetine, nortriptyline, carbamezepine, or naltrexone. Sedation is not considered treatment and is not recommended.
2. Identification and treatment of medical problems. It was observed that in this group any physical discomfort or medical problem was associated with treatment resistance and increased frequency of dissociation.
3. Minimization of iatrogenic complications. 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 neuroleptics, and depression and nightmares with treatment with certain beta blockers. Neuroleptics are of special concern in PTSD in that many individuals suffered abuse in settings while receiving neuroleptics. 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."

4. Psychotherapy. It is recommended that individuals receive psychotherapy utilizing their preferred method of communication for the purpose of processing trauma and grief issues, as well as for assisting themselves in finding ways to feel safe in their lives.
5. Habilitative changes to control dissociative triggers. It is recommended that the person's environment be continuously assessed for olfactory, visual, tactile, or auditory triggers of dissociation. In one case the individual was doing well until a staff member posted a photograph of a nude child who was the same age as the individual was when he was first raped. Another person became terrified and violent when his sister wore the same perfume as the mother who sexually abused him. Another common trigger can be unsupervised contact with previous abusers, even if abuse is no longer occurring. There is obviously no absolute rule for handling this type of situation, however it is important that any ongoing contact with previous abusers be strongly re-evaluated. Any ongoing abuse must be stopped. It has been observed that if an agency allows this contact to go on, regardless of the pretense, the individual's trust in the system is damaged (as is the individual). We have observed that some individuals may initially test the agency's resolve to see if there will actually be follow through with protecting them, however overall results of separation have been positive.
6. Education and support for staff. It is recommended that staff receive practical education in PTSD, as well as a reliable ongoing support and emergency backup system.

Each of the persons reported were deteriorating at the time of the initial evaluation. It was observed that if any of the parts of the

protocol are omitted, the individual's improvement is marginal at best. The full protocol has thus far been implemented in 23 cases (who do not differ demographically from the partially treated group). Criteria of change include self report of sense of well-being, frequency and intensity of psychiatric symptomatology, frequency of incidents of violence to self or others, and functioning at work and in relationships. All who received the full protocol improved by these measures.

DISCUSSION

Individuals with developmental disabilities who have suffered trauma may develop PTSD. It is possible to diagnose PTSD in these individuals using *DSM-IIIR* criteria. In the majority of cases the diagnosis can be suspected from routine questions on psychiatric interviewing (of the individual and those who know the person well). In this sample an unexpectedly high percentage (all) of clients who received comprehensive treatment improved significantly.

In the partially treated cases the most commonly unused recommendations were those for implementation of psychotherapy and for medical evaluation and adequate treatment.

EXAMPLE

CD was a 45 yo woman referred for evaluation of abrupt running away which was associated with screaming, sweating, and fearful facial expression. Another behavior of concern was abrupt episodes of running up to any man she saw and aggressively fondling them.

Ms. D's staff had become frustrated with her. Standard "ignore, redirect, substitute" strategies had not been effective. Functional analysis revealed paradoxical results, that is, the behaviors appeared to have the function of self-sabotage.

Social history revealed that Ms. D's father and brothers had tied her to a metal bed and sexually tortured and raped her throughout her childhood, while mother served refreshments. When she was removed from the home by a high official of the state agency the family was barred from seeing her in the subsequent setting, however found other ways to harass her. At the time of the evaluation Ms. D was still having unsupervised visits with mother. Manner was depressed, hypervigilant, angry, and fearful. Sleep was characterized by both frequent nightmares and early morning awakening. Flashbacks were observed during the interview, where she appeared frightened and unfocused and ran out of the meeting. To the examiner that followed her she described (by pointing and gesturing) that she felt like she was being beaten and penetrated. The trigger was when the door was closed to the meeting room. This was noted to be one of many consistent triggers for this individual.

Ms. D also met criteria for major depression, had an unusual rash on her face, and enlargement at the base of her neck. Staff mobilized immediately to change her program completely. She was seen at intake and rejected by five psychotherapists, but was accepted by a therapist with extensive experience in developmental disabilities and art therapy. The primary physician (a trainee) agreed to the antidepressant and checking thyroid function studies, but refused the rest of the recommendations, based on issues of cost containment just described in a recent grand rounds in the trainee's department. Thyroid studies were abnormal and supplementation was started. Ms. D's mother was not permitted to contact her, and when Ms. D wanted to "say" something to her mother she was assisted to make a phone call (supervised and discontinued if mother became abusive; Ms. D only needed to be shown this once, and subsequently would do this on her own), dictate a letter, or draw a picture. Despite all of these interventions, Ms. D only improved to where she was no longer in a perpetual state of emergency. Several medical questions remained unanswered. Another letter and several phone calls were made to the primary physician, who replied that it was the program's policy not to do "extensive" workups on "the retarded" (the workup, in this case, was several blood and urine tests, and to get useful results would require a day in the hospital). A subsequent letter from the supervising attending indicated that regardless of the clinical indications, they would not take the risk of offending the nurses at the private hospital by admitting a person with Ms. D's behavior to their ward. An alternative was arranged, an additional autoimmune disorder was identified and treated, and a subsequent communication from the primary physician expressed offense at the additional treatment of "my patient."

After this final step Ms. D improved rapidly. She now works nearly a full work week (deciding how many hours to work is in her program), has developed some friendships, and the symptoms of depression, episodes of running off and accosting men have remitted. The art therapy initially revealed self-figures that were frightened, naked, and seen from the back. Now she draws figures from the front, fully clothed, with happy confident facial expressions and gestures.

Psychotherapy was usually denied with a recital of common myths regarding persons with developmental disabilities. Examples of these myths include: persons who do not use speech cannot be treated in individual psychotherapy, persons with developmental disabilities do not really suffer after trauma, mentally retarded persons "forget" trauma, or persons with developmental disabilities are not capable of emotional insight.

"Reasons" given for refusal to provide medical workups or adequate treatment of suspect medical conditions included the significance of the physician's "gatekeeper" role in cost containment, and insistence that basic medical care would not make any difference in the quality of life for a mentally retarded person.

RECOMMENDATIONS

It is recommended that mental health professionals routinely include questions regarding trauma, abuse, sleep problems, dissociative phenomena, and self-image. This, in conjunction with record review and

staff observations, may detect the majority of cases of PTSD in this population.

A possible program of treatment is outlined above.

This sample is drawn from a referral population and may not accurately represent the general population of persons with developmental disabilities. A similar study is underway with institutionalized persons with mostly severe to profound disabilities, with similar preliminary results. More work is needed in a number of areas. Increased understanding of the incidence and frequency of this condition in the overall population of persons with developmental disabilities must be determined. A biological marker would be a useful finding. Work differentiating those who suffer trauma and do not develop PTSD from those who do may be useful in identifying preventive measures. A closer examination of forces which interfere with comprehensive treatment and promote apparent acting out on the part of caregivers may be of utility. More systematic testing of treatment modalities is needed, with better standardized outcome measures.

REFERENCES

Aman, M.G., Watson, J.E., Singh, N.N., Turbott, S.H., & Wilsher, C.P.(1986). Psychometric and Demographic Characteristics of the Psychopathology Instrument for Mentally Retarded Adults. *Psychopharmacology Bulletin, 22,* 1072–1076.

Ammerman, R.T., VanHasselt, V.B., Herson, M., McGonigle, J.J., & Lubetsky, M.J. (1989). Abuse and Neglect in Psychiatrically Hospitalized Multihandicapped Children. *Child Abuse and Neglect, 13,* 335–43.

Breslau, N., Davis, G.C., Andreski, P., & Peterson, E. (1991). Traumatic Events and Posttraumatic Stress Disorder in an Urban Population of Young Adults. *Archives of General Psychiatry, 48,* 216–222.

Brett, E.A., Spitzer, R.L., & Williams, J.B.(1988). *DSM-III-R* criteria for posttraumatic stress disorder. *American Journal of Psychiatry, 145,* 1232–1236.

Craine, L.S., Henson, C.E., Colliver, J.A., & MacLean, D.G.(1988). Prevalence of a History of Sexual Abuse Among Female Psychiatric Patients at a State Hospital. *Hospital and Community Psychiatry, 39,* 300–304.

Epstein, R.S.(1989). Posttraumatic Stress Disorder: A Review of Diagnostic and Treatment Issues. *Psychiatric Annals, 19,* 556–563.

Fletcher, R., & Menolascino, F. (1989) eds, *Mental Retardation and Mental Illness.* Lexington Books.

Helzer, J.E., Robins, L.N., & McEvoy, L.(1987). Post-Traumatic Stress Disorder in the General Population. *The New England Journal of Medicine, 317,* 1630–1634.

Hudson, C.J., & Pilek, E. (1990). PTSD in the Retarded. *Hospital and Community Psychiatry, 41,* 97.

Pitman, R.K., van der Kolk, B.A., Orr, S.P., & Greenberg, M.S.(1990). Naloxone-Reversible Analgesic Response to Combat-Related Stimuli in Posttraumatic Stress Disorder. *Archives of General Psychiatry, 47,* 541–544.

Rose, S.M., Peabody, C.G., & Stratigeas, B. (1991). Undetected Abuse Among Intensive Case Management Clients. *Hospital and Community Psychiatry, 42,* 499–503.

Ryan, R.M., Rodden, P.J., & Sunada, K.(1991). A Model for Interdisciplinary On-Site Evaluation of People Who Have "Dual Diagnosis." *The NADD Newsletter, 8,* 1–4.

Silver, J.M., Sandberg, D.P., & Hales, R.E.(1990). New Approaches in the Pharmacotherapy of Posttraumatic Stress Disorder. *Journal of Clinical Psychiatry, 51,* 33–38.

Sobsey, D., Gray, S., Pyper, D., & Reimer-Heck, B. (1991). *Disability, Sexuality, and Abuse, An Annotated Biobiolgraphy.* Paul A. Brookes Publishing Company, Inc.

Szymanski, L., Madow, L., Mallory, G., Menolascino, F., Pace, L., & Eidelman, S. (1991). *Report of the APA Task force on Services to Adults With Mental Retardation and Developmental Disabilities.* American Psychiatric Press.