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PTSD

(Provincial Treatment System in Distress)

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Any identifying features have been changed

'I (*Dr. King*) encourage feedback and suggestions, on this issue with the hope of creating a dialogue of concern as well as solutions to rebuild a fractured system of care. We need to rediscover or perhaps discover for the first time, that '*we*' are all in this together, united by our shared humanness.'

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I first met DB in the summer of 2012. At that time she was an adult previously diagnosed as having a mild degree of intellectual disability (ID). She had accepted support from a community agency providing residential services, which pledged to provide her with compassionate, lifetime care. She accepted this with grace and gratitude, particularly given that she had previously had a less than optimal experience living in a privately run group home in the past.

DB had been diagnosed medically with having a seizure disorder and psychiatrically with Post-Traumatic Stress Disorder (PTSD). When I first met DB, she was on a long list of psychotropic and anticonvulsant medications. She expressed concern that she was lethargic throughout the day, was experiencing intermittent tremors of her hands, and had difficulty attending to tasks due to her degree of fatigue. In reviewing her documentation which accompanied our intake package, concern was expressed that she had been provided with very limited access to community integration experiences while living at her previous group home given her risk of having seizures. Her current support staff describe her as being "kind, thoughtful, and caring with respect to her relationship with her peers." Concern was expressed that DB, retrospectively and with considerable insight, termed her subjective experience when distressed as "psychosis." The relationship between her psychosis and her PTSD was dramatically illustrated by the example that seeing a condom triggered the development of a psychotic episode resulting in hospitalization. When DB was well, she was also able to confirm that she had experienced auditory and olfactory hallucinations.

During her initial psychotherapeutic sessions with a psychotherapist, she had made some gains. She described feeling more comfortable in her new place of residence, was better able to self-manage her emotions, and had developed a trusting relationship with her support staff.

A previous neurological consultation had resulted in two types of 'episodes' being identified. One was described as "emotional spasms" in which she was distraught and unable to communicate with staff throughout the spell. The attending neurologist appropriately believed that these 'episodes' may represent panic attacks. In the second type of episode, which was preceded by pain, she stared into space and was unresponsive to those around her. She also made chewing noises, appearing to attempt to speak, but the sounds were incomprehensible. These seizures were thought to represent partial complex seizures. Several years preceding my meeting her, a CT scan of her head had demonstrated medial temporal sclerosis on the right side.

DB's history included being sexually, physically, emotionally, and verbally abused by her stepfather, and during this time she disclosed her experience of abuse to a teacher. The note accompanying her apprehension by the Children's Aid Society (CAS) suggested that "she had been subjected to such severe abuse that she feared for her life." She described as "living in constant terror and was violently beaten for the slightest infraction, particularly when her stepfather was drinking heavily or when she refused to submit to sexual molestation." When she disclosed this information to her mother, "all her mother would do was yell at her stepfather and blame DB." Ultimately her stepfather was charged with a number of offences. DB subsequently, and with great courage, testified at her stepfather's trial. He was convicted of a number of sexual offences and incarcerated.

Subsequently DB became a Crown Ward of the CAS. In early adolescence she was described by an experienced therapist as being "hyper vigilant regarding her safety and most often in a state of perpetual fear and anxiety." She continued to have persistent nightmares and intrusive thoughts related to her past abuse.

Following her becoming a Crown Ward of the CAS, a behaviour therapist involved in her care described her as being “demanding, argumentative, and throwing temper tantrums when she did not get her way.” At the initial group home to which she was sent, she was described as being “attention seeking, unfocused, confused, and overwhelmed.” Over the years diagnostic impressions continued to vary considerably in the context of her challenging behaviour. Late in adolescence, a psychologist suggested that her clinical profile was “consistent with chronic and severe Post-Traumatic Stress Disorder (PTSD) in combination with a generalized anxiety disorder (GAD).” It was suggested that, "in short, all dimensions of her development had been profoundly affected by a long term history of traumatic abuse and by the impact of her distorted, dysfunctional relationship experiences."

With the assistance of a compassionate and empathic behaviour therapist, she participated in an incentive program empowering her to choose a restaurant of her choice if she did not engage in challenging behaviour for a specified period of time. A PTSD workbook had been introduced to her to help her develop emotion regulation skills. In my discussion with her, I listened to her describe a remarkable understanding of the principles of mindfulness. And with great pride she described her participation in a vocational program, suggesting that it was “active, healthy, and not a challenge.”

In describing her periods of psychosis, she indicated that she felt that “her skin was being pricked by needles.” She also stated that at times “I see things that aren’t there.” She had insight regarding the fact that, retrospectively, these things were not likely based on reality. In further discussing her subjective experiences, she described the sensation of “jabbing feeling into my throat or my throat closing.” She also indicated that in the past she had dreamed of “goblins, skeletons, bats, bombs, her mother and stepfather, and her brother.” And in describing her experience at her former group home, she stated “the staff made fun of me and asked if I was crazy.” She also revealed that she was embarrassed in her relationships with peers, as she felt like “I had a disease that they could catch.”

She repeatedly experienced flashbacks represented by “a picture of my stepfather hurting me.” She described “it is like seeing it happen in your brain really fast and then it goes away.” At the mid-point of our discussion she abruptly sat up in her seat and re-enacted a scene in which she described with great emotion her stepfather grabbing her by the throat, throwing her against the wall, and threatening that he was going to murder her. She was reminded by the behaviour therapist that she had spontaneously reported “at times I step out for a minute and then come back.” Remarkably, despite this past trauma, she was future oriented, stating she would like to work in a nature oriented setting.

Diagnostically, I believed that DB had ‘Complex PTSD,’ a term first used by Dr. R. Herman in her book Trauma and Recovery in 1997. I was concerned regarding the presence of adverse effects secondary to prescribed medication. I made what I considered appropriate recommendations arising from the diagnosis and related concerns. She very cooperatively agreed with these recommendations, agreeing to work in partnership with her team, whom she had come to trust. Complex PTSD is characterized by chronic and debilitating difficulties in numerous areas of emotional and interpersonal functioning. *[Complex post-traumatic stress disorder also known as "multiple interrelated post traumatic stress disorder" or Developmental Trauma Disorder is a psychological injury that results from protracted exposure to prolonged social and/or interpersonal trauma in the context of either captivity or entrapment (a situation lacking a viable escape route for the victim), which results in the lack or loss of control, helplessness, and deformations of identity and sense of self.*]
http://en.wikipedia.org/wiki/Complex_PTSD or see also
http://www.ptsd.va.gov/professional/pages/complex-ptsd.asp

When reviewing DB’s status several months later, I noted that the prescription of an antidepressant had increased her energy level. She talked proudly about participating in therapy with her behaviour therapist and enjoying music and laughter. She also stated that she shared the residence with “family” in her new group home.

When reviewed again, we continued to taper previously prescribed, traditional antipsychotics, which were producing extrapyramidal adverse effects (Parkinson-like tremor, drooling, and cogwheel rigidity). Although she was very proud of ongoing gains with respect to her involvement in community activities, DB described a very frightening experience in which she had been left alone in a room at a Day Program with a male. She indicated that her panic attacks, traumatic nightmares, and flashbacks, however, had resolved.

The following winter DB very articulately indicated that she was feeling well subjectively. She had responded to an antacid, had noted a positive change in her mood in response to an increase in her newer antidepressant, and with the practice of her non-pharmacological self-regulation tools (the PTSD Workbook in particular), DB felt it was time to discontinue her originally prescribed traditional antidepressant. She had been able to drive past her former place of residence, which in the past had been a trigger for symptoms of her PTSD, stating that “I have left that all behind.”

In the spring she experienced a brief relapse with respect to her PTSD. She embraced this as a learning experience. This perspective allowed her to acknowledge the value of being adherent to prescribed medication. She suggested that when she did not take her medication, she made “thinking mistakes.” She had written a list of personal victories, which she had framed and mounted in her bedroom. She was now “working on staying alone.” She spoke with great pride regarding the positive strides she had made with respect to her recovery program.

In the late spring she experienced an extended grand mal seizure (seven minutes in duration), which resulted in an admission to her small local hospital. Her grand mal seizure was attributed to the fact that she had been nonadherent to her medication for several days, DB believing the medications were poisoned as part of her delusional thought content.

In the late spring she began to refuse her medication again, was eating and drinking little, and sleeping very poorly. She was expressing paranoid delusions. After an assessment by a mental health nurse and an emergency room physician in a local hospital, she was the subject of an Application for Psychiatric Assessment (Form 1). The emergency room physician appropriately attempted to refer her to a regional hospital with a well-equipped Schedule 1 psychiatric unit. She was refused admission to this hospital because she had an intellectual disability, which was a violation of her constitutional rights. Instead, she was admitted to the psychiatric unit of a very small hospital further away from her hometown.

Over the course of two weeks she remained unwell in hospital. She shared paranoid thoughts and delusions when visited by her support staff. She expressed a profound sense of hopelessness. She required considerable encouragement to eat and drink, often with no success. Despite this, in the early summer she was discharged to her group home. Within days she was again nonadherent to her medication, liquids, or food. She had attempted to harm herself with a knife. She had delusional beliefs that specks of dirt on the floor were drugs placed in her room by others. She had visual hallucinations of bugs and hair growing out of her mouth. With a sense of hopelessness, she suggested “I don’t care anymore. It doesn’t matter. I am never going to get better. I have been at the hospital so many times I might as well live there.” When I met her next, she was clearly demonstrating paranoid delusions. She was concerned that spiders had infested her room. She responded with compulsive cleaning of her bedroom. She was concerned that her pillows had been tampered with by staff and that laser beams were directed through the window of her bedroom. She continued to be noncompliant with medication.

I felt again that she was at significant risk of harm to herself. Therefore I again placed her on a Form 1. Then I called the regional hospital responsible for psychiatric care for individuals who live in the city in which she resided. A resident on-call agreed to assess her in an Emergency Room. The police force from her region refused to transport her from my office to this hospital suggesting that they did not transport individuals in the community to the hospital unless they were actively violent. The Staff Sergeant explained to me poignantly “we only transport if we apprehend and detain.” When I contacted a city police service, they did agree to safely escort her to an Emergency Room, but only to an emergency room many miles from her home. Despite speaking to clinical and administrative staff members at this hospital, no commitment was made to transfer this young lady following an assessment in the local Emergency Room to the regional hospital where she had previously received treatment. Instead, she was restrained, placed in handcuffs by police officers, and transferred to the local hospital’s Emergency Room. She was subsequently admitted to the psychiatric unit there.

While she remained on the psychiatric service at this hospital, I discussed her care with her attending psychiatrist. The behaviour therapist, who was intimately involved with this young lady’s community based care, had visited her often in hospital. Her notes documented the persistent evidence of paranoid delusions and ideas of reference. There had been no change in the dose of the atypical antipsychotic prescribed to her. The presence of an elated mood, pressure of speech, loosening of association, and distractibility failed to result in a second diagnosis of a hypomanic phase of a Schizoaffective Disorder (occurring comorbidly with her Complex PTSD). Alterations in her medication regimen were suggested by me and reviewed by her attending psychiatrist, but not implemented. After a five-week stay in this hospital, which was termed a period of “containment” rather than treatment, she was discharged back to her group home. Within a week she again threatened self-harm and was nonadherent to medication. She presented to the Emergency Room of her local hospital. After completing a Form 1, the emergency room physician attempted to contact four hospitals.

(1) A small local hospital, which had a small psychiatric unit to which DB was originally admitted, had no bed occupancy.

(2) The regional hospital indicated they would not accept her once again because of her ID.

(3) The hospital miles from her home where she primarily was admitted did again admit her, but refused to transfer her to a tertiary care hospital in the region of her residence.

(4) The tertiary care hospital in the geographical catchment area where this young lady resided refused to see her unless she was in a Schedule 1 facility in a regional hospital for two weeks.

After a three-day stay in hospital, she was discharged. Two weeks later, she was yet again the subject of a Form 1. On this occasion she was admitted to the regional hospital which had denied her admission on two previous occasions. During this admission all of her medications except her anticonvulsants were discontinued. The psychiatrist stated that her symptoms were behavioural. He did not offer a psychiatric diagnosis. His opinion was that her presentation "was all behaviour." (Reiss, Levitan & Szyszko, 1982) She was discharged with no antidepressant or antipsychotic medication. She was referred on an outpatient basis to the tertiary care hospital. Confused and experiencing complete and utter mistrust for the system which had traumatized her and her trust in the individuals around her, she refused to provide consent to allow anyone to attend this meeting with her.

DB remains psychotic, refusing to attend psychiatric appointments. Efforts to systemically challenge the decision making process at the regional health care facility have failed to evoke change to-date. A concerned advocate has joined a subcommittee of a regional mental health planning authority, with the determination and commitment to pursue systemic solutions to these issues. Such advocacy requires a commitment to listening, watching carefully, and acknowledging what is heard and taking appropriate action (King, 2003). Douglas Biklen (*2000*) reminds us that "*experiences at the margins can inform and possibly transform meanings at the dominant center of society*" (see p.444).

In response to this tragedy, a family member of another client has volunteered to serve on the Local Health Integration Network subcommittee to bring forth these issues to the hospitals involved with the hope of enacting change and improvements in the local service system. As well, the primary supporting agency has embraced a trauma-informed-culture in DB’s group home. As mentioned above, any suggestions for improving the health system are welcomed by Dr. King at robertking.med@gmail.com

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Dr. Robert King is consultant psychiatrist to Terrace Residential Youth Services, in Stittsville, Ontario, as well as Kenora Community Living and the Brighton & Quinte West Family Health Team. He will be forever grateful for the lessons learned during the completion of his psychiatric residency in the Department of Psychiatry at the University of Western Ontario in the 1990s.

The Ontario Association on Developmental Disabilities (OADD) Research Special Interest Group (RSIG) is inviting proposals for presentations and posters for its annual research conference, to be held **Friday, April 11th, 2014 at the Ambassador Conference Resort, Kingston, Ontario**.

RSIG was formed to provide an opportunity for researchers, professionals, and other interested individuals, working in the field of developmental disabilities to exchange research, ideas, resources, and concerns. We welcome research from all disciplines and areas of research related to developmental disabilities. We accept both quantitative and qualitative research.

We are excited to be able to offer on-line submissions this year. T**he deadline for abstract submissions is January 17th, 2014.** In order to submit an abstract for either a poster presentation or oral presentation, please go to: **http://www.oadd.org/RSIG_Abstract_Submission_785.html**

Awards: The Ontario Association on Developmental Disabilities (OADD) Research Special Interest Group (RSIG) is inviting submissions and nominations for a number of **awards** that will be distributed at the annual research conference. The deadline for submissions for all **awards** is **Friday, January 31st. Please see attached documents for more information.**

Conference theme: We have incorporated a theme to this year's conference: "Embracing Community-University Partnerships: Building Bridges towards Practice", which highlights the need to make our research findings accessible to policy makers, individuals who work with persons with disabilities, as well as family members. *Oral presentation submissions related to this theme are encouraged, but not necessary.*

For more information about RSIG and OADD, please visit our website at: www.oadd.org. Click on the RSIG tab to get more specific information regarding the April 11th research day. If you have any questions about the conference or the abstract submission process, please contact us at oadd.rsig@gmail,com

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Resources

If you would like a single copy of any article listed below for self education purposes, please email Maria Gitta at mgitta@uwo.ca

Please take a moment to look at this very important new knowledge translation site for Developmental Disabilities. **H-CARDD** www.hcardd.ca has just released health information on the largest research cohort (66,000 individuals) in North America, if not the world. While the data is Ontario based, the findings are applicable to other similar jurisdictions. Further research is currently underway to look at specific groups including women and dual diagnosis. Keep this link for regular reference.

http://www.choosingwisely.org/ An initiative of the ABIM Foundation, ***Choosing Wisely*** is focused on encouraging physicians, patients and other health care stakeholders to think and talk about medical tests and procedures that may be unnecessary, and in some instances can cause harm.

As part of its “Choosing Wisely” campaign, the American Psychiatric Association has released a list of “Five Things Physicians and Patients Should Question.”

The APA list contains the following five recommendations:

1. Don’t prescribe antipsychotic medications to patients for any indication without appropriate initial evaluation and appropriate ongoing monitoring.
2. Don’t routinely prescribe two or more antipsychotic medications concurrently.
3. Don’t prescribe antipsychotic medications as a first-line intervention to treat behavioral and psychological symptoms of dementia.
4. Don’t routinely prescribe antipsychotic medications as a first-line intervention for insomnia in adults.
5. Don’t routinely prescribe antipsychotic medications as a first-line intervention for children and adolescents for any diagnosis other than psychotic disorders.

Hospital Admissions That Should Not Happen: Admissions for Ambulatory Care Sensitive Conditions for People with Learning Disabilities in England
Gyles Glover, Felicity Evison, 45 pages
http://www.improvinghealthandlives.org.uk/publications

PRACTICE **Interviewing adults with intellectual disabilities**.
This is an article on people with intellectual disabilities and the criminal justice system
Gisli H Gudjonsson, & Theresa Joyce 10.5042/amhid.2011.0108

Advances in Mental Health and Intellectual Disabilities Volume 5 Issue 2 March 2011 © Pier Professional Ltd

Preventative Health Care Screening Guidelines for People Aging with Intellectual and Other Developmental Disabilities: A Report from the Commissioner's Task Force on Aging Subcommittee on Health, Prevention and Geriatric Assessment, February 2009 ***Please visit www.omr.state.ny.us for timely revisions to this document***

http://www.bmj.com/content/347/bmj.f7033

Feature Pharmaceuticals: Polypharmacy: a necessary evil

BMJ 2013; 347 doi: http://dx.doi.org/10.1136/bmj.f7033 (Published 28 November 2013)
Cite this as: BMJ 2013;347:f7033

http://www.cfp.ca/content/59/12/1282.full
From ABCs to GRADE
Canadian Task Force on Preventive Health Care's new rating system for clinical practice guidelines

http://jama.jamanetwork.com/journal.aspx
Viewpoint | December 5, 2013 FREE ONLINE FIRST
Enhancing Physicians' Use of Clinical Guidelines
Peter Pronovost proposes five strategies that developers of guidelines could implement to enhance physicians' use of guideline recommendations.

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