Evidence In-Sight request summary:
Trauma in children and youth with dual diagnosis

Date: May 2012
The following Evidence In-Sight report involved a non-systematic search and summary of the research and grey literature. These findings are intended to inform the requesting organization, in a timely fashion, rather than providing an exhaustive search or systematic review. This report reflects the literature and evidence available at the time of writing. As new evidence emerges, knowledge on evidence-informed practices can evolve. It may be useful to re-examine and update the evidence over time and/or as new findings emerge.

Evidence In-Sight primarily presents research findings, along with consultations with experts where feasible and constructive. Since scientific research represents only one type of evidence, we encourage you to combine these findings with the expertise of practitioners and the experiences of children, youth and families to develop the best evidence-informed practices for your setting.

While this report may describe best practices or models of evidence-informed programs, Evidence In-Sight does not include direct recommendations or endorsement of a particular practice or program.

This report was researched and written to address the question(s):

- What does the research evidence say about approaches to providing trauma treatment for children and youth with dual diagnosis?

We prepared the report given the contextual information provided in our first communications (see Overview of inquiry). We are available at any time to discuss potential next steps.

We appreciate your responding to a brief satisfaction survey that the Centre will e-mail to you within two weeks. We would also like to schedule a brief phone call to assess your satisfaction with the information provided in the report. Please let us know when you would be available to schedule a 15-minute phone conversation.

Thank you for contacting Evidence In-Sight. Please do not hesitate to follow up or contact us at evidenceinsight@cheo.on.ca or by phone at 613-737-2297.
1. **Overview of inquiry**

This request is from an agency that is in the process of developing practice standards for treating trauma across all divisions and age ranges. Most of the 60 staff have training in trauma treatment, and the agency has a certified trauma specialist on staff. Although the agency has thoroughly reviewed the evidence base of their training, they are looking for further information for a population – children and youth with co-occurring mental health problems and developmental disabilities (dual diagnosis) – that is relatively under-researched.

This report is intended to answer the question: *What does the research evidence say about approaches to providing trauma treatment for children and youth with dual diagnosis?* It includes information from the published research literature as well as from some grey sources such as The National Child Traumatic Stress Network. Since the requesting agency is already very well versed in trauma services and staff have extensive training, this report may serve to only validate current practice.

2. **Summary of findings**

- Since reliable and valid instruments for assessing trauma and post-traumatic stress disorder (PTSD) in children and youth with dual diagnosis are lacking, there is no specific prevalence data.
- The evidence indicates that children with developmental disabilities are more likely to experience abuse, including neglect and emotional and sexual abuse, and they are at greater risk to suffer from its long-term effects.
- Even among typically developing children and youth, PTSD has historically been under-diagnosed. Among those with developmental disabilities, PTSD has often been misconstrued or missed entirely because the features associated with disability complicate diagnosis and obscure the effects of trauma.
- Children and youth who have experienced trauma can develop a variety of mental health problems, regardless of developmental level.
- Trauma need not be a violent or abusive event. In children with a developmental disability, life events such as a move or observing one’s siblings surpass them (i.e. leave for university) can be traumatizing.
- A shortcoming of the majority of the research on effective treatments for children and youth with trauma is that studies have typically excluded “special” populations. Organizations and practitioners that provide trauma services for children and youth with dual diagnosis including trauma may need to adapt practices from the broader literature.
- The literature is lacking in terms of specifying evidence-based practices or programs that have been through rigorous testing specifically for children and youth with dual diagnosis.
- The literature on trauma in typically developing children and youth is much more complete. Trauma-focused cognitive behavior therapy (TF-CBT) has been studied extensively with populations of children and youth without developmental disabilities and is considered the treatment of choice. The evidence for play therapy, art therapy, psychodynamic therapy, psychological debriefing, and pharmacologic therapy is incomplete and these remain promising practices.
- A review of studies on children, youth, and adults with dual diagnosis including trauma found some evidence for:
  - An interdisciplinary treatment approach
  - Caregiver training and support
  - Psychotherapy including cognitive-behavioral therapy adapted to the population
  - Limited support for Eye Movement Desensitization and Reprocessing
- Trauma-informed care is a systemic approach that merges trauma-specific diagnostic and treatment services with an overall environment and philosophy of care that is informed by awareness of trauma. Organizations may want to implement trauma-informed services across the organization because a wide range of psychiatric diagnoses are related to traumatic exposure in the past.

3. Answer search strategy

- Search tools: PsycINFO, PubMed, University of Ottawa electronic database, Google Scholar
- Search terms used: developmental delay; developmental disability: child; youth; adolescent; trauma; PTSD: post traumatic stress disorder: autism; retardation

4. Findings

Dual diagnosis usually refers to the co-existence of both developmental disabilities and mental health problems in the same individual. It is under-researched compared to the evidence base on effective interventions for children and youth that only have developmental disabilities or mental health problems, and pediatric dual diagnosis has been studied even less than adult dual diagnosis. There is very little in terms of an evidence base specific to trauma in children and youth with dual diagnosis, and the field would greatly benefit from further research – including program evaluations that are built into practice contexts in Ontario. A separate report on pediatric dual diagnosis is available from the Centre of Excellence upon request. This current report only examines trauma within the mental health aspect of dual diagnosis.

Terminologies vary internationally and change over time. The DSM-IV refers to this population by the term “mental retardation” but increasingly the preferred term is intellectual disability (Bradley, 2012). Other terms or disability concepts include learning disability and developmental disability. For the purposes of this report the term developmental disability is used as it is the current phrase of choice in Canada. While this specific question is about trauma in children with dual diagnosis, we provide a brief overview of trauma and dual diagnosis as well.

4.1 Trauma in children and youth

Children and adolescents develop in a contextual environment, and that context is primarily social and emotional (Wekerle, 2011). Traumatic exposure, whether a one-off event or ongoing episodes, can have transient effects and result in no apparent harm or they can cause significant psychological harm. Children and youth who have experienced trauma may develop a variety of mental health problems: anxiety disorders including post-traumatic stress disorder, depressive disorders, externalizing conditions, suicidal ideation or behavior, substance abuse, and complicated grief. Reactions can be immediate or can arise weeks or months later. Many children and adolescents who have been exposed to trauma show a loss of trust in adults and fear of the event recurring (Wethington et al., 2008).

The evidence base on effective interventions for typically developing children and youth in need of treatment for trauma-induced conditions is relatively well developed and includes several evidence-based, manualized intervention programs. Cognitive-behavioral therapy (CBT), both individual and group, has the strongest research evidence for effectiveness for decreasing psychological harm among symptomatic children and youth, (Wethington et al., 2008), including Trauma Focused CBT (TF-CBT). TF-CBT is listed in multiple repositories of evidence-based practices and has been studied extensively, with generally good outcomes for children and youth. While there has been research on the effectiveness of play therapy, art therapy, psychodynamic therapy, psychological debriefing, or pharmacologic therapy, the evidence is incomplete and these remain promising practices.
A shortcoming of the majority of the research on effective treatments for children and youth with trauma is that studies have typically excluded “special” populations such as those with psychotic disorders, who were a danger to themselves or others, or those with developmental delays.

### 4.2 Developmental disabilities and trauma

Statistics on the incidence of psychological problems in general among children and youth with developmental disabilities indicate that co-occurring problems are a significant issue and occur more frequently in this population than in children and youth who are not developmentally disabled (National Child Traumatic Stress Network, 2004). In the United States the 2008-2010 statistical tables of crimes against people with disabilities, derived from the National Crime Victimization Survey, found that individuals aged 12-15 with a disability had a rate of violent victimization at least twice that of persons without disabilities (Harrell, 2011). Note that disability for this survey is defined as a sensory, physical, mental, or emotional limitation, so the pool of disabilities is broader than intellectual, neurological, and mental. Nonetheless, it indicates that rates of violence against persons with disabilities are higher than in people without disabilities.

Estimates of prevalence of mental illness in individuals (age not specified but most likely adult samples) with a developmental disability have repeatedly found in the range of 30-40 percent of these people have a diagnosed psychiatric disorder. The most frequently occurring relationship is with aggressive behaviors and major depressive disorder, but individuals with development disability might exhibit any of the full range of psychiatric disorders (Fletcher et al., 2007). However, since reliable and valid instruments for assessing PTSD in this population are lacking, there is no specific prevalence data on PTSD among people with developmental disabilities, including children and youth (Mevissen & de Jongh, 2010).

The evidence indicates that children with developmental disabilities are more likely to experience abuse, including neglect and emotional and sexual abuse, and they are at greater risk to suffer from its long-term effects (Berney & Allington-Smith, 2010). Extrapolations from existing research suggest that the high level of self-injurious behavior among people with developmental disabilities is likely a function of exposure to trauma at lower developmental levels, regardless of chronological age (Fletcher et al., 2007). Similarly, symptoms such as the tendency to “act out” rather than “think through” when distressed can be a function of, or be exacerbated by, traumatic exposure. Some researchers have questioned the extent and quality of evidence that individuals with developmental disabilities are at greater risk of experiencing traumatic events or their being more susceptible to suffering from trauma (Newman et al., 2000). Although the Newman article is systematic, it is older than other references and we err on the side of caution and note that the burden of evidence leans toward individuals with developmental disabilities being at heightened risk of suffering from trauma.

Abuse and neglect have profound effects on brain development, and in a feedback loop people with developmental disabilities are more likely to be exposed to trauma while exposure to trauma makes developmental delays more likely (National Child Traumatic Stress Network, 2004). Individual client variables affect the degree of risk of suffering from trauma, but in general developmental disabilities heighten sensitivity to traumatic events or maltreatment because:

- Limited resources the individual has available make it more difficult to cope with normal life stressors.
• These children are often difficult to raise and may place a high level of strain on the family, which increases vulnerability to abuse in the home.
• Poor judgment and lack of self-protective skills make these children more vulnerable to abuse in the community.
• For higher functioning clients, an additional stressor is awareness of their intellectual deficits. Grief and loss issues may be associated with their functioning problems.
• Communication and processing problems may make it harder to get help for mental health issues, and to interact in therapy.

Trauma need not be a violent or abusive event. Developmental changes such as being surpassed by siblings who learn to drive cars, go to college, and marry and leave home can be traumatizing to some individuals (Fletcher et al., 2007). A move can be particularly traumatizing, especially when it is engineered by others and the individual finds themselves in a strange environment. These sorts of traumatic events may not be recognized, known, or reported by caregivers.

Even among typically developing children and youth, PTSD has historically been under-diagnosed (Fletcher et al., 2007). Among those with developmental disabilities, PTSD has often been misconstrued or missed entirely, usually because the features associated with disability complicate diagnosis and can obscure the effects of trauma. Common referral problems such as non-compliance, self-injury, aggression, outbursts of anger, and irritability may be manifestations of PTSD and they require explicit evaluation and intervention that is intended to help the child, youth, and family cope with and recover from the trauma.

4.3 Treatments that (might) work

Basic practice recommendations
The National Child Traumatic Stress Network in the United States suggests simple practice modifications to typical assessment and therapy to help meet the needs of children and youth with co-occurring mental health issues and developmental disabilities (National Child Traumatic Stress Network, 2004):
• Given communication challenges, involve a wide range of caregivers in both the assessment and treatment process. These should include parents/guardians and school and daycare personnel. Caregivers can communicate about changes they have observed in behavior, and report any life events that might ordinarily seem benign (i.e. moving) but that the practitioner knows can be traumatizing to this population.
• Since children and youth may not report trauma themselves, practitioners and caregivers should be trained to identify behavioral changes that may be associated with trauma.
• Basic communication adjustments should be made such as slowing down speech, using simple language, presenting one concept at a time, using concrete concepts and terms, supplementing with drawing and play materials, and making ongoing adaptations.

State of the treatment evidence - PTSD
The literature is lacking in terms of specifying evidence-based practices or programs that have been through rigorous testing specifically for children and youth with dual diagnosis. The literature on trauma in typically developing children and youth is much more complete, for instance trauma-focused cognitive behavior therapy (TF-CBT) has been studied extensively with populations of children and youth without developmental disabilities. It may be the case that, given the
lack of specific recommendations, agencies and practitioners need to adapt common modalities to special populations. The state of the evidence is lacking and there are no empirically based treatment methods specifically for PTSD for children and youth with dual diagnosis.

We identified only one systematic review of the literature relevant to this topic, and it is specifically about PTSD and includes adults as well as children and youth. PTSD is one outcome of psychological trauma and diagnosis is considered to capture only a minority of the clinically significant post-traumatic stress outcomes (Bradley et al, 2012). Nonetheless, PTSD provides a structured context in which to consider how trauma and dual diagnosis interact.

The review by Mevissen and de Jongh (2009) identified 18 studies from 1992-2008 with sufficient methodological rigor to satisfy their review standards. In general, studies on PTSD in people with developmental disabilities are very rare and their strength of evidence is low. Nonetheless, PTSD is considered a problem in this population because developmental level has a major impact on individuals’ ability to cope with traumatic events and the severity of PTSD symptoms is negatively associated with intelligence level.

Of the 18 identified studies, only nine concern treatment, and the majority of these studies were conducted with adult populations. Mevissen and de Jongh’s review found several articles with preliminary evidence for:

- An interdisciplinary treatment approach, with interdisciplinary team support, including making certain that a formal medical evaluation has been conducted to rule out frequently occurring medical conditions that can cause particular symptoms. Additionally, changes in environment and personal contacts and attention to developmental issues with a view to eliminating frightening cues (Bradley et al., 2012).
- Caregiver training and support, to increase understanding of symptoms of PTSD and to teach appropriate responses.
- Psychotherapy, as clinical evidence suggests that individuals respond well to a broad range of therapeutic modalities and that there is no reason for not using psychotherapeutic methods that have been established for other disorders. This includes therapies such as TF-CBT and CBT in general that have good evidence for effectiveness in the general population. Case reports also report positive treatment effects from psychodynamic therapy.
- Eye Movement Desensitization and Reprocessing (EMDR) as a specific treatment. EMDR is for clients with PTSD and involves asking the client to hold in mind a disturbing image, an associated negative cognition, and bodily sensations associated with a traumatic memory, all while tracking the clinician’s moving finger in front of his or her own visual field. The intent over time is to facilitate a reduction of distressing aspects of memory and to introduce more adaptive cognitions (Chemtob et al., 2000).

**Promising practices**

Given how little this topic has been studied and that poor methodological status of the existing evidence, Mevissen and de Jongh suggest that is may be necessary to profit from findings on PTSD treatment in general population, for instance the strong evidence for the effectiveness of trauma-focused CBT and EMDR. TF-CBT has been implemented successfully within organizations in Ontario for children and youth, and linkages are available.
One cautionary note from Mevissen and de Jongh is that claims on the efficacy of CBT in people with developmental disabilities may not be well-founded because intervention techniques might not be delivered with fidelity to cognitive best practice. Practitioners grounded in applied behavioral analysis (ABA) might be more likely to use treatment techniques that, while called cognitive-behavioral, are actually more similar to ABA. Although ABA is an evidence-based technique for working with people with developmental disabilities, we identified no studies of ABA particular to trauma or PTSD.

Adapted Dialectical Behavior Therapy for Special Populations (DBT-SP) is an intervention with preliminary evidence for efficacy in reducing symptoms of trauma in children with developmental disabilities (de Arellano et al., 2008). As a treatment it is intended to address the general symptoms of trauma rather than being a method to process a specific trauma. It has been specifically adapted to meet the needs of children (8-12 years) with impaired cognitive functioning and who otherwise might have difficulty processing complex verbal and visual information. In essence, the intervention is delivered using the standard streams of focused individual therapy, group skills training, and whole treatment team involvement. At this time it only appears that DBT-SP has been tested in a single pilot study (see Charlton & Dykstra, 2011). Clinical indications suggest that the adaptations are effective for working with children with dual diagnosis and trauma, but the modifications have not been fully tested to demonstrate their effectiveness (de Arellano et al., 2008).

Overall, the research base on trauma treatment options for children and youth with dual diagnosis is very poor. There are no evidence-based programs, little in terms of best practices recommendations, and it appears that this particular topic has not received the same amount of attention that trauma in general has.

### 4.4 Trauma-informed services

Misperceptions and misunderstandings have contributed to under-recognition of vulnerability to trauma in children and youth with developmental disabilities (Bradley et al., 2012). Misconceptions include beliefs that people with developmental disabilities:

- Are “protected” by their intellectual limitations so do not get traumatized
- Do not experience trauma because they do not understand the trauma
- Are not amenable to treatment because of their limited communication skills

Although childhood trauma may be central to psychiatric conditions and to the healing needs of children and youth, it seldom is addressed or viewed as a central issue in the treatment within public mental health settings. Many children and youth may have histories of severe interpersonal violence and multiple adverse childhood experiences, but recognition of the trauma underlying their behaviors and diagnoses often does not occur (Jennings, 2008). Intervention settings pose a risk of further traumatizing children and youth via invasive interventions and ignorance of stressors and triggers.

Creating trauma-informed systems requires increasing knowledge about trauma by integrating information focused on trauma into systems, increasing skills for identifying and triaging traumatized children, and promoting strong collaborations between systems and disciplines (Ko & Sprague, 2007). Trauma-informed care is a philosophy of service to improve patient safety and dignity within psychiatric hospital settings and community clinics. It is a systemic approach that merges trauma-specific diagnostic and treatment services with an overall environment and philosophy of care that
is informed by awareness of trauma. Among other factors, it incorporates policy positioning, workforce requirements, client engagement, clinical practice guidelines, organizational policies, monitoring and evaluation, universal trauma screening, and specific evidence-informed trauma intervention (Jennings, 2008). The essential assumption is that all clients are potentially suffering from trauma and that trauma is an important treatment need, so every element of the agency – from intake to discharge – should be deliberately structured to minimize the risk of further traumatization and to facilitate recovery.

One reason that an agency may want to consider having a trauma-informed system of care across the organization is that a wide range of psychiatric diagnoses are related to past trauma. Psychiatric diagnoses that have been related to past trauma include borderline personality disorder, schizophrenia, depression, anxiety, eating disorders, psychosis, dissociative disorder, addictions, and somatoform conditions. As children and adolescents, trauma-related behaviors and coping mechanisms can lead to misdiagnoses such as attention deficit hyperactivity disorder, oppositional defiant disorder, conduct disorder, substance use disorders, bipolar disorder, bipolar depression, borderline personality disorder, and major depression (Jennings, 2008).

Many individuals who present with the conditions listed above develop extreme coping strategies in childhood and adolescence to manage the impacts of traumatic stress, including suicidality, substance abuse, self-harming, aggression, and in adulthood re-enactments such as abusive relationships. Although childhood trauma may be core to their mental health condition, screening and assessment or treatment for trauma is often lacking (Jennings, 2008). Although many children in mental health services have histories of traumatic experience, recognition of the trauma underlying their behaviors and diagnoses may not occur, and this is reflected by the large gap between diagnoses of PTSD compared to actual rates of exposure to trauma.

4.5 Assessment and evaluation considerations
A common message in the literature is that not only is the topic of trauma in children with dual diagnosis under-studied, including effective interventions, but the field lacks psychometrically sound measures (Wigham et al., 2011). The lack of measures intended for the population compromises the methodology of studies, making it difficult to draw firm conclusions. Furthermore, since reliable and valid instruments for assessing PTSD in this population are completely lacking, it is not possible to obtain prevalence data (Mevisson & de Jongh, 2009).

In terms of clinical diagnosis, there is a psychiatric diagnostic instrument available, the Diagnostic Manual – Intellectual Disabilities (see http://www.dmid.org/). It is intended as an adaption of the DSM-IV, specifically meant to help make a diagnosis of mental illness in people with developmental disabilities. As it is psychiatric in focus, it may not be relevant to this current request, but the broader information contained in the manual may be useful in determining treatment options for children and youth with dual diagnosis.

In addition to the lack of assessment instruments, children and youth with a dual diagnosis may “present” differently than typical functioning children. The role of developmental level may complicate diagnostic clarity in determining symptomology, and determining what the traumatic stressor is (Fletcher et al., 2007). Diagnostic overshadowing, where symptoms are put down to the developmental disability rather than the mental health concern, and compromised
communication skills between therapist and client can interfere with accurate assessment (Wigham et al., 2011). Ultimately, reliable case identification facilitates effective service delivery. The basic circumstances that are not deemed traumatic within the general population can be very traumatizing for people with developmental disabilities (Bradley et al., 2012), so a trauma-informed organizational approach to services for children and youth with developmental disabilities may enhance practitioner awareness and assessment.

5. Next steps and other resources

For more information on trauma-informed service from an agency in Ontario, see the KidsLINK resources page at: http://kidslinkcares.com/for-professionals/trauma-informed-resources/. The Centre can also provide a connection to an Ontario-based practitioner with expertise in trauma-informed services.

For a fact sheet on traumatic stress and children with developmental disabilities, see the National Child Traumatic Stress Network. While most of the overall content is geared to children and youth who do not have disabilities, there are a few relevant resources: http://www.nctsnet.org/sites/default/files/assets/pdfs/traumatic_stress_developmental_disabilities_final.pdf (or http://kidslinkcares.com/wp-content/uploads/2012/03/traumatic_stress_developmental_disabilities_final.pdf)

The research evidence on the prevalence and risks of mental illness, and in particular trauma, in children and youth with developmental disabilities is incomplete and this report cannot make any strong conclusions or recommendations. Nonetheless, the evidence indicates that trauma exposure is a relevant problem and clinicians should systematically assess the lifetime exposure to a variety of events in clients. Although exposure to a traumatic life event in itself is not indicative of a mental health problem, specific symptoms should be assessed to better determine if they are indicative of trauma rather than being symptoms of the disability (Newman et al., 2000).

The field needs evidence-informed and evidence-based treatment methods for this population. As little evidence is currently available, one consideration for agencies is to use evaluations of their own current programs to gain a better understanding of what is working in practice. One example would be to implement an adapted version of TF-CBT, and conduct a program evaluation of process and outcome factors.

Knowing what works and receiving training on an evidence-informed practice or program is not sufficient to actually achieve the outcomes that previous evaluations indicate are possible. A program that has been shown to improve mental health outcomes for children and youth but that is poorly implemented will not achieve successful outcomes (Fixsen et al, 2005). In order for a program to be evidence-informed, it needs to be applied with fidelity to the design and it needs to be implemented using supportive “drivers” related to staff competency, organizational leadership and organizational capacity. These drivers include assessing and monitoring the outcomes of your practice using evaluation or performance measurement frameworks, which are particularly important when there is insufficient evidence in the literature to guide clinical decisions. Choosing a practice is an initial step toward implementation, but the implementation drivers are essential to ensure that the program reaches appropriate clients, that outcomes are successful and that clinical staff members are successful in their work.
The Ontario Centre of Excellence for Child and Youth Mental Health has a number of resources and services available to support agencies with implementation, evaluation, knowledge mobilization, youth engagement and family engagement. For more information, visit:

http://www.excellenceforchildandyouy.ca/what-we-do or check out the Centre’s resource hub at http://www.excellenceforchildandyouy.ca/resource-hub.

For general mental health information, including links to resources for families:

http://www.ementalhealth.ca
References


