Ontario Centre of Excellence
for Child and Youth
Mental Health

Centre d'excellence de l'Ontario
en santé mentale des
enfants et des adolescents

Bringing People and Knowledge Together to Strengthen Care.
Rassembler les gens et les connaissances pour renforcer les soins.

Evidence In-Sight request summary:

# Suicide in adolescents with developmental disabilities

Date: December 2014

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 following question(s):

- What are the best practices for supporting adolescents with developmental disabilities who are exhibiting suicidal behaviour?
- Are there particular considerations for working with this at-risk population?

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 originated from a youth suicide prevention coach supporting community mobilization efforts in youth life promotion, suicide prevention, risk management and postvention in a south western Ontario community. The community is interested in best practices for working with adolescents with developmental disabilities who exhibit suicidal behaviour. Specifically, the community is interested in whether there are additional risk factors or precipitating factors for suicidal behaviour for adolescents with developmental disabilities. The community is concerned that this population may not fully understand conversations about suicide or may become very fixated on certain thoughts and events in response to conversations about suicide. The community is looking for guidance on language use and other considerations for supporting this at-risk population, such as approaches to building safety plans.

For the purpose of this request, the youth suicide prevention coach asked the Evidence In-Sight team to research: *What are the best practices for supporting adolescents with developmental disabilities who are exhibiting suicidal behaviour? Are there particular considerations for working with this at-risk population?*

## 2. Summary of findings

While this report will address suicidal behaviour in adolescents with developmental disabilities, it is important to note that suicidal behaviour in this population is often confused with self-injurious behaviour (Menolascino, Lazer, & Stark, 1989). Unlike suicidal behaviour, self-injurious behaviour is not marked by a conscious intent to die. Young people may injure themselves for reasons other than suicide, such as to relieve stress or numbness, and adolescents with developmental disabilities are reported to commonly engage in self-injurious behaviour, perhaps due to difficulty communicating emotions or physical pain (Kitchener, Jorm, Kelly, Pappas, & Frize, 2010). For more information on non-suicidal self-injury in adolescents with developmental disabilities, please see Kitchener et al. (2010).

The following key messages emerged during the review of the literature regarding life promotion, suicide prevention and risk management for adolescents with developmental disabilities:

- While the research has come a long way in recognizing that the risk of suicide **does indeed** exist among adolescents with developmental disabilities (i.e. these youth do think about, attempt and die by suicide), the evidence base on practice in such situations is still quite limited.
- Adolescents with developmental disabilities are considered to be a vulnerable population who may be at particular risk for developing suicidal thoughts and behaviours due to underlying mental health problems. The prevalence rate of mental illness in this population is at least as high as in the general population.
- Reported rates of suicidal behaviour are lower among adolescents with developmental disabilities as compared to the general population, but this may not be the full picture. Research suggests that suicidal behaviour in youth with developmental disabilities is likely underreported and frequently overlooked due to diagnostic overshadowing.
- Risk assessment and screening for underlying mental health issues is particularly challenging as there are currently no measures developed specifically for use with this population. Assessment can be particularly problematic when supporting young people with communication challenges.
- There are many similarities between adolescents with developmental disabilities and their typically developing peers, yet signs and symptoms of suicidal behaviour and underlying mental health problems may present differently between these two populations.

- Adolescents with developmental disabilities are particularly at risk of suicidal behaviour if they have a higher IQ, an underlying mental health problem and/or have experienced recent psychosocial stressors.
- There is limited research on risk management of this issue. Regardless, the literature suggests that support must be offered to individuals at risk on a case-by-case basis, taking into consideration the unique needs of each individual and the particular context of their life situation.

## 3. Answer search strategy

- Search terms: youth, adolescent, suicide, suicidality, suicidal behaviour, developmental delay, developmental disability, intellectual disability, mental retardation, mental handicap, learning disability
- Databases searched: Google, Google Scholar, University of Ottawa Library (Scholars portal, PubMed, AMED Allied and Complementary Medicine, Mental Measurements Yearbook, PsycINFO, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) without Revisions)

## 4. Findings

Suicidal behaviour among adolescents is recognized as a major public health problem around the world. Suicide is the second leading cause of death among individuals aged 10 to 24 years old worldwide (Hawton, Saunders & O'Connor, 2012). While the literature suggests that suicide can occur across the lifespan and within every community (Lunsky, 2004) there is currently limited understanding of suicidal behaviour among individuals with developmental disabilities (Hannon & Taylor, 2013).

Historically, it was suggested that lower levels of intellectual functioning protected individuals from suicidal thoughts and behaviours and children and adolescents with developmental disabilities were thought to lack the cognitive sophistication to conceptualize, plan and carry out suicidal behaviour (Kaminer, Feinstein, & Barrett, 1987). Essentially, the intellectual and adaptive limitations inherent to a developmental disability were thought to serve as a protective factor – or a buffer – against suicidal behaviour (Merrick, Merrick, Morad, & Kandel, 2006). Unfortunately, the absence of research and reported cases maintained this untested assumption for quite some time.

While limited research has been conducted on the subject, the few studies that have explored this issue contest the historical assumption that a developmental disability acts as a buffer from suicidal behaviour (Merrick, Merrick, Morad, & Kandel, 2005b). Studies conducted to date have demonstrated that young people with developmental disabilities do think about, attempt and die by suicide (Ludi et al., 2012), demonstrating that this is an issue that needs to be taken seriously and further studies are necessary. If a young person with a developmental disability is experiencing mental health difficulties, there is no compelling reason to believe that they are less vulnerable to suicidal behaviour than the general population.

The literature highlights that suicidal behaviour by adolescents with developmental disabilities is an under-recognized, yet significant problem, particularly among adolescents with underlying psychiatric disorders (Hannon & Taylor, 2013).

### 4.1 Nature of the issue

Developmental disability is present in some form in about three percent of the population (Kitchener et al., 2010; Ludi et al., 2012), yet many individuals with a developmental disability are underdiagnosed (or misdiagnosed) and underserved

(Samra et al., 2007). A variety of terms are used throughout the research to describe a developmental disability, including intellectual disability, developmental delay and mental retardation (Ludi et al., 2012). Lunsky and colleagues (2013) highlight that in Ontario, *developmental disability* is an umbrella term for a wide range of different disabilities that involve significant limitations in cognitive and adaptive functioning that are present before the individual reaches 18 years of age. These limitations are typically lifelong in nature and affect major areas of one's life activity, such as communication, mobility, learning, self-help and independent living (Kitchener et al., 2010). A developmental disability is often reflected by below-average intellectual functioning (equivalent to an IQ of 70 or below) obtained on an individually administered intelligence test (Samra, Monk, White, & Goldner, 2007). Common types of developmental disabilities include intellectual disabilities, autism spectrum disorder and fetal alcohol spectrum disorder (Lunsky et al., 2013). Developmental disability occurs along a spectrum and is typically characterized as mild, moderate, severe or profound (Ludi et al., 2012; Kitchener et al., 2010).

Young people with developmental disabilities are a particularly vulnerable population (Kitchener et al., 2010). Many individuals are exposed to psychosocial and environmental risk factors linked to suicidal behaviour, such as social rejection and stigma (Ludi et al., 2012; Montgomery County Emergency Service (MCES), 2014; Shtayermman, 2008). These individuals may recognize the potential challenges they may experience with everyday social skills, such as poor communications skills, difficulty responding to social or emotional cues, and challenges developing friendships (Shtayermman, 2008). Adolescents with developmental disabilities may also believe that they are a burden to others – a belief that may begin early in life and be further amplified later in life (MCES, 2014). The literature suggests that due to reduced protective factors (e.g. coping, effective problem-solving and help-seeking skills), individuals with developmental disabilities may be at an increased risk of being victimized (MCES, 2014).

Young people with developmental disabilities are at increased risk for developing mental health problems across the lifespan, and in turn, are at increased risk for suicidal behaviour (Lunsky et al., 2013; Ludi et al., 2012; Merrick et al., 2006; Walters et al., 1995). The prevalence rate of mental illness in this population is at least as high as in the general population although the types of mental illness differ in frequency depending on the etiology of the developmental disability (e.g. Down syndrome versus pre-natal brain trauma; Yu & Atkinson, 1993). In Ontario, *dual diagnosis* is a term reserved for individuals with a mental health problem and a developmental disability (Lunsky et al., 2013). Research indicates that a child with a developmental disability is six times more likely to have a mental health problem than a person who does not have a developmental disability (Lunsky et al., 2013; Ludi et al., 2012; Merrick et al., 2006; Walters et al., 1995). This population demonstrates higher rates of anxiety as well as more frequent and serious bouts of depression than their peers without developmental disabilities (Huntington & Bender, 1993; Lunsky, 2004; Merrick et al., 2005b).

### 4.2 Prevalence

While the reported prevalence of suicidal behaviour in adolescents with developmental disabilities is lower than that of the general population, it remains an alarming figure (Merrick et al., 2005b; Giannini et al., 2010). While recent data is sparse, results from two American studies conducted within the last two decades (Hardan & Sahl, 1999; Walters, Barrett, Knapp & Borden, 1995) found that 20 to 21% of youth with developmental disabilities engaged in suicidal behaviour. In a retrospective study of a clinically-referred sample, Hardan & Sahl (1999) reviewed the medical charts of all individuals who entered a specialized program for children and adolescents with developmental disabilities and comorbid psychiatric disorders over a 12 month period. Of the 233 patients, 47 (20%) of these individuals had a present

or past history of suicidal ideation or suicide attempts (Hardan & Sahl, 1999). In an archival chart review, Walters, Barrett, Knapp and Borden (1995) studied suicidal behaviour among 90 consecutive admissions to a specialty unit for dually diagnosed children and adolescents in a medical school-affiliated children's psychiatric hospital. A total of 19 patients (21%) presented with suicidal behaviour upon admission or during hospitalization (Walters et al., 1995). These prevalence rates are similar to that reported by Lunsky (2004) in studying 98 adults with developmental disabilities, in which one in three individuals reported that they think "life is not worth living" sometimes or a lot, suggesting that prevalence rates are similar across the ages. While the limited studies conducted to date support these prevalence rates, there is also agreement in the literature that suicidal behaviour is likely underreported in this population.

The literature suggests that suicidal behaviour occurs more frequently in inpatient settings of adolescents with developmental disabilities, perhaps as a consequence of the most severe cases being hospitalized or perhaps as a result of learned behaviour during hospitalization (Hardan & Sahl, 1999; Merrick et al., 2005b; Merrick et al., 2006). This is in keeping with what has been reported in the general population. Further research is needed to explore suicidal behaviour in adolescents with developmental disabilities in less restrictive settings, such as adolescents in special education classrooms, outpatient settings or residential treatment (Walters et al., 1995).

While adolescents with developmental disabilities differ from typically developing adolescents in many ways, the literature highlights that there are many similarities between the two populations when it comes to suicidal behaviour. For instance, adolescents with developmental disabilities use methods similar to the general population when they exhibit suicidal behaviour (Samra et al., 2007; Merrick et al., 2005b; Hardan & Sahl, 1999). The sex distribution of adolescents with developmental disabilities is also similar to trends found in the general population in that higher rates of suicidality have been reported in males (Hardan & Sahl, 1999; Merrick et al., 2005b). Suicidal ideation, threats and behaviour reported in adolescents with developmental disabilities are similar to those reported in the general population and young people with developmental disabilities are at the same risk of repeating suicidal behaviour as the general population (Walters et al., 1995; Merrick et al., 2006; Merrick et al., 2005b; Lunsky, 2004). Finally, adolescents with developmental disabilities who exhibit suicidal behaviour are also exposed to many of the same risk factors and psychosocial correlates as those in the general population, such as increased risk with the presence of a psychiatric disorder (Lunsky, 2004; Mayes, Gorman, Hillwig-Garcia, & Syed, 2013; Mikami et al., 2009; Walters et al., 1995). Thus, while it is important to consider adolescents with developmental disabilities as a unique population, it is also important to build on what we know to be similar in the general population.

**4.3 Risk factors**

There is currently limited research on intervention for suicidal behaviour in adolescents with developmental disabilities, but research to date appears to support the importance of identifying relevant risk factors for prevention (Merrick et al., 2006). While rates of suicide appear to be low in this population, there seems to be a greater number of suicide risk factors among adolescents with developmental disabilities as compared to the general population (Giannini et al., 2010). While there is no single predictor for suicide in any population, there are three variables most commonly associated with suicide risk in adolescents with developmental disabilities: higher IQ, the presence of a comorbid Axis 1 disorder (e.g. mood disorder) and recent psychosocial stressors. Further research is needed to understand how each of these risk factors are related to suicidal behaviour in adolescents with developmental disabilities, and to explore the predictive importance of each risk factor (Hardan & Sahl, 1999; Giannini et al., 2010).

*Higher IQ*

While research findings are somewhat inconclusive as to whether there is a clear association between suicidal behaviour and IQ, a number of studies have found that higher levels of intellectual and adaptive functioning can be associated with suicidal behaviour in adolescents with developmental disabilities (Ludi et al., 2012; Hannon & Taylor, 2013). For example, Carlson, Asarnow and Orbach (1994) found that the average IQ of a sample of suicidal adolescents with developmental disabilities was over 12 points higher than that of their non-suicidal counterparts, a finding that has been replicated in other studies (Walters et al., 1995; Hardan & Sahl, 1999). While suicidal behaviour has been documented to occur among adolescents of all levels of intellectual functioning, it has been found to occur most frequently among individuals with mild developmental disability, marked by an IQ between 50 and 75 (Hurley, 2006; Giannini et al., 2010; Shtayermman, 2008;). Research suggests that suicidal behaviour is extremely rare in adolescents with severe or profound developmental disabilities (Merrick, Merrick, Lunsky, & Kandel, 2005a; Hardan & Sahl, 1999; Walters et al., 1995; Kaminer et al., 1987). These observations may have contributed to the historical belief that one's developmental disability could serve as a protective factor from suicide (Hardan & Sahl, 1999). It is important to remember that although higher IQ has been reported as a risk factor, suicidal behaviour can and does still occur among adolescents of all levels of intellectual functioning.

*Comorbid Axis 1 disorder*

Several authors have highlighted that adolescents with developmental disabilities are at increased risk for suicidal behaviour if they also have a comorbid Axis 1 disorder (Ludi et al., 2012; Huggins, Grant, O'Malley, & Streissguth, 2008). For example, Hardan and Sahl (1999) found that suicidality was more often encountered in individuals diagnosed with oppositional defiant disorder, depressive disorders and post-traumatic stress disorder. In a sample of adolescents with developmental disabilities, Carlson and colleagues (1994) found that 67% of a suicidal group and none of a nonsuicidal group met the criteria for a mood disorder. This strong association between suicidality and affective disorders is also present in the general population (Hardan & Sahl, 1999). In adolescents with developmental disabilities, depression is the most common mental disorder (Better Outcomes, New Delivery (BOND), 2013; Kitchener et al., 2010; Hannon & Taylor, 2013; Hurley, 2006) and a young person's risk for suicidal behaviour increases with a history of hospitalization for mental health issues (Walters et al., 1995; Merrick et al., 2006).

*Recent psychosocial stressors*

While the exact relationship of psychosocial stressors to suicidal ideation and behaviour is still unclear, there is agreement within the literature that certain stressors may place an adolescent with a developmental disability at greater risk of suicidal behaviour. Stressors that may increase the risk for suicidal behaviour in adolescents with developmental disabilities include:

- a history of abuse, neglect or trauma (Hannon & Taylor, 2013; Lunsky, 2004; Ludi et al., 2012; Walters et al., 1995; Merrick et al., 2006; Huggins et al., 2008)
- significant familial loss such as death, adoption or out-of-home placement (Ludi et al., 2012; Lunsky, 2004; Walters et al., 1995)
- family conflict or instability including depression, psychosis, suicidality or alcoholism in the family (Walters et al., 1995; Merrick et al., 2006)
- unstable or low family and social support (Ludi et al., 2012; Lunsky, 2004; Merrick et al., 2006; Huggins et al., 2008)

- greater stress, loneliness and isolation (Ludi et al., 2012; Lunsky, 2004; Merrick et al., 2006)
- personal relationship conflicts such as peer rejection, bullying and victimization (Ludi et al., 2012; Mikami et al., 2009; Shtayermman, 2007; Mayes et al., 2013)

Many of these stressors have been shown to serve as a precipitating life event or trigger for suicidal behaviour, a trend that is similar in the general population (Hurley, 2006). Essentially, stressful life events combined with a lack of supports can lead someone to feel isolated and hopeless, which may lead to suicidal behaviour (Lunsky, 2004).

**4.4 Risk assessment**

Diagnosing underlying mental health issues in adolescents with developmental disabilities is challenging (Menolascino et al., 1989). There is a tendency to under-diagnose psychiatric disorders in this population due to a phenomenon referred to as *diagnostic overshadowing* (Merrick et al., 2005b, Bradley & Lofchy, 2005). Diagnostic overshadowing refers to the tendency of clinicians to attribute psychopathology to cognitive deficiency rather than to a diagnosable psychiatric disorder (Reiss, Levitan & Szyszko, 1982, as cited in Hardan & Sahl, 1999). Essentially, this means that suicidal behaviour may be overlooked if clinicians presume that the presenting problem is a result of the young person's developmental disability rather than a secondary mental health problem, such as depression (Hannon & Taylor, 2013; Kitchener et al., 2010; Hurley, 2006).

Developmental disabilities and mental health problems are often difficult to tease apart. Family members and professionals alike often find it challenging to determine whether the behaviour they are observing is due to the developmental disability, a mental health problem or both (Lunsky et al., 2013). For example, it can be difficult to diagnose depression in someone with a learning disability because some of the symptoms of depression experienced by the general population can be a part of the 'usual' behaviour or presentation of someone with a learning disability (BOND, 2013; Kitchener et al., 2010). The existing research suggests that care must be taken to avoid diagnostic overshadowing (Mayes et al., 2013) by obtaining as much information as possible regarding an adolescent's baseline personality, affect, behaviour, capacity and skill level in order to accurately assess changes or divergence in the young person (Ludi et al., 2012; BOND, 2013; Kitchener et al., 2010; Menolascino et al., 1989).

It has been argued that all young people with developmental disabilities should be routinely assessed for suicidality, especially when symptoms of depression or other mental health problems are identified (Mayes et al., 2013; Hardan & Sahl, 1999).

*Screening measures*

Direct suicide screening can rapidly and effectively detect suicide risk and facilitate further clinical evaluation and management (Chehil & Kutcher, 2012). Unfortunately, there are currently no available measures that screen for suicide risk that are designed specifically for individuals with developmental disabilities (Ludi et al., 2012). Similarly, there is as yet no 'gold standard' diagnostic tool for depression for use among adolescents with developmental disabilities (McBrien, 2003; Hannon & Taylor, 2013).

A number of challenges have been identified when using existing screening measures with adolescents with developmental disabilities (McBrien, 2003). For instance, many assessment tools rely on an individual's ability to communicate effectively (Shtayermman, 2008). Unfortunately, many adolescents with developmental disabilities are

often unable to express symptoms or convey through language the true level of their current or past distress due to their limited communication skills (Kitchener et al., 2010; McBrien, 2003; Huggins et al., 2008; Carlson et al., 1994). This also means that it is difficult for clinicians to gain a clear idea of whether a young person with a developmental disability understands death or the concept of killing themselves (Hardan & Sahl, 1999). For example, in one study, Carlson and colleagues (1994) found that 27% of a sample of adolescents with developmental disabilities believed that their own deaths would not be permanent.

Most existing screening measures also require abstract thought (i.e. remembering past events and thoughts), which may present a challenge for those with developmental disabilities (Huggins et al., 2008) who sometimes tend to be more oriented to the present time and place (Ludi et al., 2012). Most existing screening measures also require the individual to read to themselves, which is problematic as many adolescents with developmental disabilities experience limitations in reading capacity and tend to read and comprehend at an elementary grade level (Ludi et al., 2012). Even if a screening measure is read out loud (few are intended to be conducted in this way), it may include complex sentences and vocabulary and elaborate response formats such as four or more response options or changes in response formats (Ludi et al., 2012). This has led some researchers to suggest the use of simplified verbal self-reports using short 'yes' or 'no' answers (Ludi et al., 2012; Huggins et al., 2008). However, others have noted that adolescents with developmental disabilities may have a tendency to acquiesce, to please those in authority and to give the 'right' answer in a screening interview (Salvatore, n.d.). For example, a young person with a developmental disability may say 'yes' when in fact the true answer is 'no' or vice versa. The literature emphasizes that it is important to avoid leading questions wherever possible and be clear with adolescents with developmental disabilities that you want to hear how they are really feeling (BOND, 2013; Kitchener et al., 2010).

While there is no 'gold standard' for screening measures for use with adolescents with developmental disabilities, there is agreement within the literature that existing screening measures can often be used with minor accommodations for adolescents with mild levels of developmental disability, as these individuals often have a fairly typical clinical presentation when it comes to suicidal ideation and behaviour (Hurley, 2006; Huggins et al., 2008). However, further research is needed to determine appropriate screening measures for adolescents with more severe developmental disabilities.

*Informant reports*

Given the challenges inherent in using existing screening measures with adolescents with developmental disabilities, suicide risk assessments often rely heavily on third-party or informant reports (Kitchener et al., 2010; Menolascino et al., 1989). Most clinicians turn to parents, caregivers, friends, teachers, service providers and other key individuals in the adolescent's life in order to get a clear picture (Huggins et al., 2008). Collaborating with others and surveying the individual's environment for evidence allows those supporting the individual at risk to collect as much information as possible to ensure their assessment of the situation is accurate in order to offer the right type of help (Kitchener et al., 2010).

While an adolescent's parent or caregiver is commonly considered the most reliable primary data source (Ludi et al., 2012), informant reports are not without challenges. Third-party informants may not always be aware of an adolescent's suicidal ideation or behaviour, perhaps because not all adolescents who feel suicidal voice it to their caregivers and warning signs can be harder to distinguish (Lunsky, 2004; Ludi et al., 2012; Merrick et al., 2006). Finally, informant

reports are also subject to bias (McBrien, 2003). While speaking with third-party informants is an important part of conducting a suicide risk assessment, information from an informant cannot replace the perspective of the adolescent at risk – both perspectives need to be taken into account (Merrick et al., 2006).

*Indicators*

Warning signs for suicidal behaviour can appear differently in adolescents with developmental disabilities as compared to those without. For example, the young person with a developmental disability may regress in their functional skills or they may demonstrate outward behaviours that differ from their usual temperament and signal distress (Ludi et al., 2012). Stereotypic and repetitive behaviours also tend to increase in frequency with an agitated or irritable mood, which may be an indicator of an underlying issue of concern (Ludi et al., 2012). In addition, suicidal intent or the wish to die may present in a more atypical manner in this population. For example, the research reports instances where adolescents with developmental disabilities bit electrical wires, swallowed coins or refused to eat – more atypical manifestations than hanging or cutting as one might see in the general population (Ludi et al., 2012). Similarly, depression may manifest in atypical ways in adolescents with developmental disabilities (McBrien, 2003).

Some key indicators that a young person with a developmental disability may be at risk of suicide include:

- threatening to hurt or kill oneself (Kitchener et al., 2010)
- seeking access to pills, weapons or other means (Kitchener et al., 2010)
- talking, drawing or writing about death, dying or suicide (Kitchener et al., 2010)
- seeming preoccupied with the deaths of family members and friends, funerals or violent TV shows/movies (Kitchener et al., 2010)
- demonstrating rage, anger or revenge (Kitchener et al., 2010; Menolascino et al., 1989)
- acting recklessly or engaging in risk activities, seemingly without thinking (Kitchener et al., 2010)
- increasing alcohol or drug use (Kitchener et al., 2010)
- withdrawing from friends, family or society (Kitchener et al., 2010; Menolascino et al., 1989)
- demonstrating dramatic changes in mood, such as significant anxiety, agitation, sadness or depression (Kitchener et al., 2010; Merrick et al., 2005b)
- sleeping all the time or being unable to sleep (Kitchener et al., 2010)
- expressing no reason for living or no sense of purpose in life (Kitchener et al., 2010)

Adolescents at risk of suicide may show one or more of these signs, and some may show other signs not listed here. As with the general population, it is important to explore all self-threatening statements and behaviour in a young person with a developmental disability, and wherever possible, limit access to lethal means such as guns and pills (Ludi et al., 2012).

*Considerations for assessing risk*

Suicidal thoughts and behaviours in adolescents with a developmental disability should always be taken seriously and fully investigated (BOND, 2013; Kitchener et al., 2010). As with typically developing adolescents, the literature suggests that if you suspect that an adolescent with a developmental disability may be at risk of suicide, let the young person know that you are concerned about them and want to help (Kitchener et al., 2010). Do not avoid using the word *suicide*.

Instead, ask direct, to-the-point questions such as “Are you thinking about suicide?” or “Are you thinking about killing yourself?” (BOND, 2013; Kitchener et al., 2010).

Some young people with developmental disabilities may have difficulty answering risk assessment questions and some may not understand the term *suicide* (BOND, 2013; Kitchener et al., 2010). Instead, recommendations highlighted in the literature suggest the following:

- Use simple, concrete terms wherever possible and avoid words with double meanings (Huggins et al., 2008). For example, use words such as ‘kill yourself’ or ‘make yourself die’ (BOND, 2013; Kitchener et al., 2010).
- If possible, consider using visual aids when appropriate, and ask any supportive individuals if the young person has a preferred or augmentative method of communicating (Kitchener et al., 2010).
- Regularly check that the young person understands by asking them to explain in their own words what they have heard, rather than just relying on simple verbal affirmation (Huggins et al., 2008).

Suicidal gestures among adolescents with developmental disabilities are often confused with self-injurious behaviour because the behaviour may not have any lethal potential, leading clinicians to believe that the individual did not intend to die (Menolascino et al., 1989; Kitchener et al., 2010). The seriousness of a young person’s behaviour may not always link with their level of intention to die. By nature of their developmental disability, a young person may have an impaired ability to cognitively link cause and effect and/or may experience unpredictable impulsivity (Huggins et al., 2008). Given this, it is important to take the time to ask the individual to explain what their intent was. If the person committing the act considers the behaviour to be life-threatening, it should be understood as a suicidal gesture regardless of the outcome (Menolascino et al., 1989; Kitchener et al., 2010).

**4.5 Risk management**

Very little research has been conducted on risk management of suicidal behaviour and treatment of underlying mental health concerns in adolescents with developmental disabilities. While no large-scale studies have examined treatment approaches for suicidal behaviour specifically (Merrick et al., 2006), the most common treatment modalities for suicidal behaviour in adolescents with developmental disabilities discussed in the research include:

- short-term hospitalization to prevent death by suicide and to analyze underlying mental health disorders (Menolascino et al., 1989; Huggins et al., 2008)
- outpatient individual, family and group counselling to teach the individual new ways of coping (Menolascino et al., 1989; Merrick et al., 2006; Huggins et al., 2008)
- psychoactive medications to treat more entrenched psychiatric disorders such as depression (Menolascino et al., 1989; Merrick et al., 2006; Huggins et al., 2008)

Psychiatric hospitalization is currently the standard treatment approach for adolescents with developmental disabilities who exhibit suicidal behaviour (Salvatore, n.d.) though further evaluation is needed on the outcomes of this approach. While inpatient psychiatric care may ensure a young person’s short-term safety and stabilization, it appears to compound subsequent risk, in that there is a high level of danger immediately following the adolescent’s discharge (Crawford, 2004, as cited in Salvatore, n.d.). Further research is needed on risk management and treatment approaches.

*Individualized approach*

While a standard suicide intervention involves reducing risk factors and enhancing protective factors (Huggins et al., 2008), it is important to take into consideration that each young person with a developmental disability will have specific challenges and risk factors, as well as different levels of symptomatology and functioning (Shtayermman, 2007). Each individual will also present with different protective factors that may impact therapeutic relationships and treatment outcomes. The current literature highlights the need for clinical assessment and intervention approaches to be unique and tailored to each individual adolescent (Hannon & Taylor, 2013).

Given this, individuals supporting an adolescent at risk should consider the individual's risk factors for suicide and intervene in relation to these factors (Merrick et al., 2006; Huggins et al., 2008). For example, an adolescent with a developmental disability at risk of suicide may benefit from improved family or social support, reduced stress and/or increased social opportunities and daily activities (Lunsky, 2004; Ludi et al., 2012). In addition, Shtayermman (2007) suggests that adolescents with developmental disabilities at risk of suicide are likely to need support surrounding peer victimization and stigma associated with developmental disabilities. Other individuals may need grief counselling, including appropriate bereavement services and support with understanding loss (Hurley, 2006; Ludi et al., 2012). As with the general population, it is important to address what is underlying the suicidal ideation or behaviour (Menolascino et al., 1989) and in order to do so, one must treat each adolescent in an individual way. Understanding the function of suicidal behaviour for each individual is critical (Merrick et al., 2006).

*Ongoing support for adolescents with developmental disabilities*

Following a crisis, stable behaviour is often incorrectly viewed as a rationale for removing support as it may seem as though the young person doesn't need it anymore (Menolascino et al., 1989). Removing support can serve as a trigger for further suicidal behaviour, as it may leave the adolescent with a developmental disability feeling emotionally alone and needing to fend for themselves (Menolascino et al., 1989). Particularly for individuals receiving inpatient care, it is critical to establish a long-term plan for ongoing support upon discharge from the clinical setting. Often this means that major changes need to be made to the amount of support that a young person receives as they may require increased support to regain or maintain stable emotional adjustment (Menolascino et al., 1989). For some, this may mean exploring group living settings with more interpersonal structure and more onsite support, but it will depend on the individual and how much emotional support they require (Menolascino et al., 1989).

*Language considerations for risk management*

As with assessing risk in the young developmentally disabled population, it is important to continue to modify intervention protocols to accommodate various challenges that may be experienced by this population (e.g. communication; Huggins et al., 2008). Due to the difficulty that these individuals have with processing abstract information, a direct counselling approach is needed (Menolascino et al., 1989). Individuals supporting adolescents with developmental disabilities need to pay careful attention to their language use and choice of words (Huggins et al., 2008). Kitchener and colleagues (2010) highlight the following suggestions when working with adolescents with developmental disabilities:

- Keep conversations simple and free of jargon, and ask one short and specific question or request at a time.
- Speak clearly, slowly, and calmly, in a normal tone of voice, using non-threatening language (including body language).

- Listen carefully and be patient, providing the young person with ample time to respond. Offer to repeat if necessary.
- If you have difficulty understanding the young person, ask whether they have family or a support worker that you can contact. They may carry contact details for such an individual in their wallet or purse.
- Don't assume that an individual's ability to express themselves is an indication of what they understand and vice versa.
- Above all, ensure the privacy, dignity and respect of the young person.

## 5. Next steps and other resources

Suicidal behaviour in adolescents with developmental disabilities remains an understudied phenomenon (Hardal & Sahl, 1999). There is widespread agreement that suicide is overlooked in adolescents with developmental disabilities (Kaminer et al., 1987; Merrick et al., 2005b). In fact, in many cases, adolescents with developmental disabilities have been excluded from research on suicidal behaviour (Ludi et al., 2012; Hardan & Sahl, 1999).

Research to date has determined that adolescents with developmental disabilities do think about, attempt and die by suicide. The limited studies that have been conducted to date have explored the correlation between developmental disabilities and underlying psychiatric conditions but research does not yet paint a clear picture of the extent of the problem or the best practices in prevention, risk management and postvention of suicidal behaviour among adolescents with developmental disabilities. More research needs to be conducted in order to fully understand the nuances between this population and the general population (Hannon & Taylor, 2013; Walters et al., 1995). There is consensus on the risk factors that contribute to the development of suicidal behaviour in adolescents with developmental disabilities, but limited investigations into them, so further research is needed (Hardan & Sahl, 1999; Giannini et al., 2010).

The limited research available consists for the most part of chart review studies and case reports (Ludi et al., 2012; Merrick et al., 2005b; Hardan & Sahl, 1999), and is based primarily on inpatient samples (Lunsky, 2004). This means that individuals not yet receiving support for suicidal behaviour – and perhaps those at most risk – are not captured in existing research. Existing chart review studies are also limited in that they omit non-lethal attempts that remain unobserved by others, as well as suicidal thoughts unless they are reported to clinical staff and then documented (Hardan & Sahl, 1999). Studies conducted to date also tend to be based on small sample sizes, yet they still play an important role in directing future research (Giannini et al., 2010; Hannon & Taylor, 2013).

The clinical implications of this paucity of research are alarming: there is not yet a clear sense of how to best support this population at risk. More than ever, it is essential to evaluate the work that is done with this population in order to determine best practices.

There also seems to be a lack of capacity across the country in the number of mental health professionals who have training in, and a comfort with treating individuals with dual diagnosis. Attention to the mental health human resources and training needs required to address the needs of individuals with dual diagnosis is an issue that many jurisdictions are struggling with (Byrne, Hurley & James, 2007). This requires further attention.

For information on strategies and helpful considerations for supporting adolescents with developmental disabilities: https://mhfa.com.au/sites/mhfa.com.au/files/2nd-Edn-ID-MHFA-Manual-Sept-2012-small.pdf
This resource was adapted from the Mental Health First Aid Manual (2nd edition, Kitchener, Jorm & Kelly, 2010) to consider the specific needs and difficulties of individuals with developmental disabilities.

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

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

http://www.ementalhealth.ca

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