Chapter 14
Preventing Suicide in Youth with Intellectual and Neurodevelopmental Disorders: Lessons Learned and Policy Recommendations

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Suicidality in Intellectual and Neurodevelopmental Disabilities

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by social communication deficits and the presence of repetitive and restricted behaviors. Based on tracking of 8-year-old children within 11 communities in the USA, 1 in 54 children was identified with ASD in 2016 by the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network (Maenner et al., 2020). Mayes et al. (2013) found that 14% of youth with ASD were endorsed by mothers as experiencing suicidal thoughts and behaviors whereas only 0.5% of neurotypical children were rated by mothers as having these same concerns. Baer et al. (2020) reported that 41.8% of parents registered with the Interactive Autism Network (IAN) noted that their child or dependent adult (25 years or younger) had displayed suicidal behaviors. Furthermore, the most commonly reported age of onset for both passive and active suicidal ideation was 8 years old or younger. Children as young as 5 years old were reported by their parents as having tried to end their life. Within the IAN sample, 3.5% had attempted suicide.

Several ASD symptoms overlap with known suicide risk factors. Further, ASD is associated with many comorbid mental health conditions. Research has explored the influence of impaired social communication and cognitive flexibility, social isolation, bullying, high rates of psychiatric comorbidities (e.g., depression, anxiety, ADHD, trauma), impulsivity, deficits in understanding the temporal sequencing and durability of events, masking/camouflaging, and alexithymia on suicidal behavior

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(Baer et al., 2020; Cassidy, et al., 2020; Joshi et al., 2010; Mayes et al., 2013; Richa, et al., 2014; Storch et al., 2013). Conversely, the psychiatric hospitalization of youth due to their suicidal behavior may lead to the identification of intellectual and neurodevelopmental disorders (INDs) by their treatment team. In some medical settings, consults for neurodevelopmental evaluations of psychiatrically hospitalized youth may be completed to aide in establishing immediate safety and treatment planning for at-risk youth.

Intellectual disability (ID), which often accompanies ASD, does not have a protective effect against suicide. Horowitz et al. (2018) studied children between the ages of 10 and 18 with ASD, a quarter of whom had mild ID. They found that 63% of parents indicated that their child "talks about death or suicide" for a "period lasting several days." "Frequent periods" of talking about death or suicide were reported in 22% of the sample. Their analyses further explored rates of suicidal ideation among children within three ranges of intellectual ability reporting 25.4% in those with an IQ above 85, 20% in those with IQ below 70, and 15.4% for those with IQs between 70 and 85.

Another source of data that sheds light on the prevalence of suicide attempts and deaths is the Ohio Department of Developmental Disabilities (ODODD) which tracks these outcomes among its more than 95,000 consumers aged 10 to 60. From 2015 through 2019, ODODD reported that 15 individuals with developmental disabilities died by suicide, 8 of whom had a diagnosis of ASD. Of these eight individuals, all were male, 50% were 21 or younger, and 25% had ID. Between 2012 and 2019, there were 182 suicide attempts. Of those making attempts, 40% did not have an intellectual disability, 35% had mild ID, 6% had moderate ID, and 0.6% had severe ID; 56% of these consumers had at least one comorbid mental health condition, and 44% had made a prior attempt (Internal ODODD data retrieved 2020). These findings, pulled from a large population data set, provide strong foundational information about suicidality in persons with INDs. It corroborates the occurrence of suicide attempts in children as young as age 10, with a preponderance of reported attempts and deaths by suicide occurring in individuals who are under the age of 30.

Collectively, these data substantiate the urgent need to ensure universal suicide screening inclusive of children and adolescents with INDs. However, there are few evidence-based tools available to researchers and clinicians that can be used with individuals with INDs. Frequently, individuals with INDs are excluded from research studies despite the possibility of inclusion with minimal adaptation (Feldman et al., 2014). There are adverse consequences to excluding individuals with INDs from research studies designed to establish the effectiveness of instruments and intervention particularly as it relates to suicide risk. The generalizability of current tools and interventions which have been validated on neurotypical samples is unknown, leaving parents and providers relying on observation and intuition, rather than science. Excluding individuals with ID from research efforts is problematic and potentially harmful despite the well-intended goal of preventing harm among those with ID. Although including individuals with neurodevelopmental disabilities in research requires heightened engagement, creativity, and patience, doing so results in findings and recommended practices that are generalizable to a broader spectrum of youth (Carlson, 2013).

Lessons Learned in Suicide Prevention in Youth with INDs

Due to the lack of validated suicide screening tools and interventions, clinical providers often struggle with how to appropriately complete these essential responsibilities with patients with INDs. This section outlines suicide prevention efforts for individuals with INDs conducted at Nationwide Children's Hospital (NCH), a large pediatric hospital in the Midwest. It can serve as a road map for other healthcare organizations and further the conversation regarding best practices in suicide prevention for youth with INDs. One gap identified with respect to suicide prevention was the consistent use of a validated suicide risk screening tool. Across numerous internal planning discussions regarding the design of suicide prevention policies at NCH, the validity of conducting universal screening with the Ask Suicide-Screening Questions (ASQ; Horowitz et al., 2012) tool for children presenting for either neurodevelopmental assessment or treatment for ASD was debated. Decisions were made at the unit level to design protocols that best matched their service line. At the NCH Child Development Center, a center which focuses on the assessment of ASD and other INDs as well as treatment for individuals with INDs, and NCH Center for Autism Spectrum Disorder, which focuses on treatment for youth with ASD, we have implemented broad suicide screening of all patients 10 years old and above. Exceptions to this screening may be made when the clinician determines that the screening would be developmentally inappropriate (e.g., a verbal IQ lower than 70). Our experiences have confirmed the value of suicide prevention policies that are inclusive of children with ASD and other INDs. Universal suicide screening was launched for children presenting to these NCH centers in July 2019. Through the second week of February 2021, 1410 ASQs were completed at the Child Development Center; approximately 15.2% had a positive screen (a "yes" to any of four initial suicide-specific questions), and 0.57% had a positive screen on Question 5, asking if the child had present thoughts of killing themselves following a positive response to one of the first four items. At the NCH Center for Autism Spectrum Disorder outpatient treatment program, 400 ASQs were completed during the same time period; approximately 35.7% had a positive screen, and 3.0% were positive on Question 5 (Internal NCH data retrieved on Feb. 17, 2021).

Considerations in Screening, Risk Assessment, and Safety Planning: Illustrative Vignettes

Enhanced screening, risk assessment, and safety planning have become the standard of care across the behavioral health service line at NCH over the several years including for youth with ASD and other INDs. Use of a program-wide screener (e.g., ASQ) for suicidal thoughts and behaviors has been critical in identifying individuals at risk for suicidal behaviors and engaging in appropriate safety planning for them. Along with the utility of the ASQ, we have found through continuous quality improvement efforts that clinical best practices have emerged. We share some of

these cases to highlight the nuances in assessment and management of suicidality as well as recommendations for safe and effective care with this population.

Several consistent observations have guided adaptations. As we have administered the ASQ to children with INDs, it has become apparent that some patients struggle with understanding timeframes such as "within the past few weeks" and "in the past week" on the ASQ. In the case of a 12-year-old male diagnosed with ASD, without language and intellectual delays, and ADHD receiving psychiatric care at our clinic, when asked if he had thoughts of killing himself in the last week, he responded "yes." Furthermore, when asked if he had ever tried to kill himself, he responded "yes" and then stated that the attempt had occurred at school during the past week. His caregivers expressed shock at this revelation as no recent incident report was sent by school; however, they described similar past incidents that had been reported to them by school staff. Collateral information from the school clarified that such an incident had occurred several months ago and the school team had verbally de-escalated the patient to safety. This case highlights that children within this population may struggle with the abstract concept of time; in response, clinicians have offered specific dates to help anchor the timeline for patients in these situations.

We have also encountered other cases at our clinic where patients' understanding of the intent of the ASQ questions limited their utility. In another case, a 14-year-old male who presented to our clinic for evaluation of ASD, and who was later diagnosed with ASD without language or intellectual delays, struggled with the phrase "better off" in Question 2 ("In the past few weeks, have you felt that you or your family would be better off if you were dead?") of the ASQ. In response to the question, he stated, "what do you mean 'off,' like turning a computer 'off?'." The clinician again attempted to ask the question verbatim, and the patient continued to be confused. Finally, the clinician rephrased the question by replacing "better off" with "happier," the patient seemed to understand the meaning of the question at that point, and the patient was able to provide an answer.

Recommendations for Screening, Risk Assessment, and Safety Planning

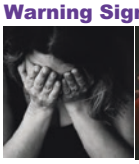
We offer several recommendations to address these challenges. As the phrasing of screening questions appears to be understood by most individuals with INDs, clinicians should continue to ask screening questions verbatim, consistent with initial validation studies and administration guidance (see Mournet et al., this volume). However, in some cases it will become evident that the patient does not understand the intent of the question. In those cases, clinicians should not abandon the screening, but rather, they should be prepared to modify the question(s) to complete a screening of the patient while assessing for adequate comprehension of each question's intended meaning.

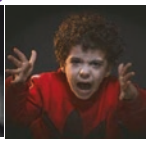
When assessing for suicidality in children with ASD and ID, the heterogeneity of self-injurious behaviors must also be considered. Hunsche et al. (2020) highlight that self-injurious behavior in children with ASD does not always indicate the presence of suicidal intent. In our practice at the Child Development Center and Center for Autism Spectrum Disorder, visual supports have proven useful in clarifying the underlying function and intent of the self-injurious behaviors. Additionally, these visual supports benefit safety planning as they allow for strong individualization of the safety plan and collaborative patient engagement in the safety planning process.

The case of "Sarah," a 13-year-old female, illustrates the use of visuals and assessment of self-injurious behaviors. Sarah is diagnosed with mild ID and has a history of two previous self-aborted suicide attempts; she presented for treatment of panic attacks, recurrent suicidal ideation, and non-suicidal self-injurious behaviors (NSSIB). She had a history of multiple hospitalizations in the past due to her complex clinical presentation. Sarah struggled to verbally report intent behind NSSIB as compared to suicidal ideation. Clinicians utilized concrete visual supports to assess her motivation behind the self-injurious behaviors, including identifying a graveyard as a symbol to depict end of life when clarifying suicidal intent. From the beginning, the safety plan was identified as belonging to Sarah, so she had choice and control of its content. She was able to choose her preferred color and font for the text of the plan. Color associations and thermometers previously learned in cognitive behavioral therapy to describe emotions were included. Pictures Sarah chose from Google Images of the precursor behaviors were also placed in the "Warning Signs" section along with a few descriptive words and pictures she chose to illustrate preferred activities. Personal interests were also included in her plan. Additionally, due to Sarah's struggles with self-awareness and decreased self-monitoring capacity, specific need for close adult supervision and monitoring was discussed with caregivers. As the safety plan is considered to be a "living document," it continued to be modified during treatment. As other triggers, drivers for suicidal behavior, and coping strategies were identified in later visits, they were incorporated in her plan. In order to fully include individuals with INDs in the process of screening, assessment, and safety planning, visual supports are useful. Figure 14.1 provides examples of how visual supports can be utilized.

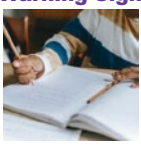
There are instances when a patient's level of cognitive ability interferes with understanding the questions as intended and the ASQ is deemed to be "developmentally inappropriate." For individuals with INDs who are unable to complete the ASQ or other suicide risk screeners, alternative safety screening methods are recommended. For example, individuals with less impaired communication may be able to engage in a conversation with the clinician which will allow for clarification and frequent perception checking. Individuals with more impaired communication abilities may take part in a conversation with the clinician with an informed caregiver who is familiar with their language abilities as part of the conversation.

Warning Signs:


Sad


Yelling

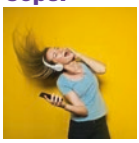
Warning Signs At School:


Having to Write


Math Class

Things I Can Do to Cope:


Play Basketball


Listen to Music

Things I can Do to Cope At School:


Paint


Take Deep Breaths

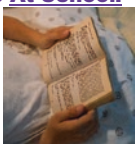
People or Things to Distract Me:


Playground


Play Soccer with Joe

Things to Distract Me At School:


Count to 10


Read a Book

People I can Ask for Help From:


Dad and Maria

Adult at School I can Ask for Help:

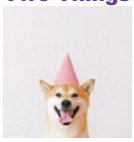

Mr. Jack


Mrs. Smith

Who I Can Call for Help:

Mom XXX-XXX-XXXX
Dr. Alex XXX-XXX-XXXX
911
County Crisis Line: XXX-XXX-XXXX
Text: 741-741

Two Things That Are Very Important to Me and Worth Living For:


Max


Game

Fig. 14.1 Examples of a safety plan utilizing visual cues (pictures). A safety plan should be created in collaboration with the patient and can be modified during treatment. (pexels.com)

Future Directions and Policy Implications

Additional research is needed to validate existing tools and provide clinical guidance in the pediatric IND populations. The vignettes and discussion illustrate how two centers at NCH used clinical discretion and creativity to meaningfully adapt existing tools for the pediatric IND populations. More guidance in this area will be important for clinicians and families.

There are several ways in which work in this area can be advanced. In order to create appropriate tools for this population, funding agencies should support the inclusion of individuals with INDs in population-based research on suicide prevention. Research should be conducted to identify needed modifications to screening processes, to assess the effectiveness of safety planning, and to clarify other necessary treatment components to serve the unique needs of patients with suicidality and ASD/INDs. Licensing and accrediting bodies should consider mandating universal screening for youth age 10 and up. It is further recommended that the credentialing and licensing authorities for the various health professions review and consider requiring, or otherwise prioritizing, training on suicide prevention, risk assessment, and safety planning for specialty populations, including ASD/INDs. As The Joint Commission (2016) requirement has pushed institutions to incorporate standardized implementation of screening measures, institutions like NCH have recognized the need for formal training on assessment and management of suicidality in this high-risk population, with special focus on implementation of existing tools using a developmental approach.

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