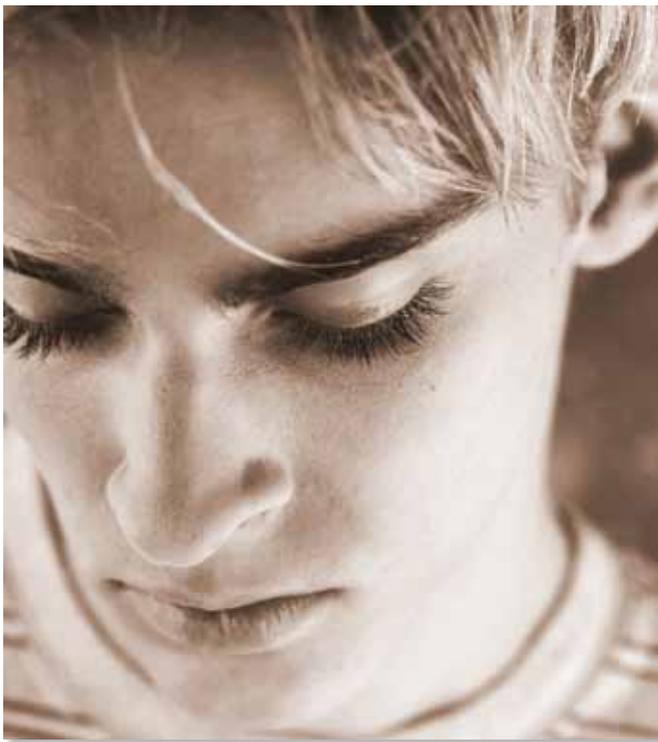


THE OTHER PUBLIC HEALTH CRISIS

With suicide rates among autism families apparently on the rise, awareness and action can save a life...

BY SALLIE BERNARD



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As more children with autism become older teens and young adults, we have yet another problem to worry about: Suicide is the second leading cause of death, after accidents, among ages 15-24 in the general population. Like autism, it strikes more often in males than females, although females have a higher rate of suicide attempts. A growing but incomplete scientific literature suggests that the rate of suicide completion and suicidal actions is higher among those with an ASD and may be harder to detect or treat by professionals used to seeing people with mental health disorders vs. neurodevelopmental disorders such as autism. The occurrence rate may be higher in families, and thus our typically developing children may be at greater risk for suicidal behaviors as well. Since suicide is largely preventable with the right interventions, awareness, education, and action, we can prevent many future tragedies in our community.

As the parent of a 25 year old son with classic autism, I have been active in autism advocacy for over 20 years. Since one of my typical sons unexpectedly took his life almost three years ago, many parents have reached out to me to share their stories. They told me of their children on the spectrum who talk of wanting to die or who showed signs of self-injurious behaviors. Many had worries about their non-ASD children, particularly daughters, who were accomplished and driven but had heightened anxiety and suicidal thoughts. A few moms related feelings of wanting to die themselves. At the local autism program I co-founded, as we enrolled increasing numbers of older teens, I noticed more participants speaking of wanting to kill themselves. When I started to research the field of suicide, I found an unusually high number of features relevant to autism.

ANOTHER EPIDEMIC

The incidence of suicide has increased 13% over the past decade. It is the 10th leading cause of death for all age groups at 12 per 100,000, but it is the second leading cause for ages 15-24 after accidents, at 10.7 deaths per 100,000 in 2011. In 2011 for the first time, suicide mortality surpassed homicides in the 15-24 age group. In 2010, this equated to 4,600 deaths for this age group in the US. In developed countries, men are nearly four times more likely to die by suicide than women, while women attempt suicide three times as often as men.

Although homicides followed by suicides tend to make the news and are horrific, the statistics show that these events are extremely rare: 98% of all suicides are a sin-

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gle, lonely act by the individual. Newtown is a horrific anomaly, reflective of a tiny minority whose suicide is driven by impulsivity and aggression both inward and outward. Contrary to stories that make the headlines, suicide in nearly all cases ends the life of a beautiful person who deserved extra care and compassion.

The emotional toll of a suicide is hard to adequately convey. Not only has a promising life ended early, but there are up to 32 closely affected survivors on average. Over seven percent of Americans know someone who died from suicide in the past year. Prevention is critical.

AUTISM FAMILIES AND RISK

Recent evidence consistently points to a higher rate of suicidal behavior (SB), defined as suicidal actions and completions, among those with an autism spectrum disorder. These studies, all published within the past two years, looked at specific populations such as psychiatric or emergency room patients, or had limited control groups and thus need broader confirmation, including methods that can determine how much of an increase exists and why. The studies suggest that suicidal thoughts and acts cut across autism severity, and don't just affect the Asperger's subgroup. Several authors recommend that those with an ASD be routinely screened for suicidal thoughts and actions.

A number of studies over the years have suggested a higher rate of mental health problems in the immediate family members of a person with autism. These problems include anxiety and depression, both of which are predisposing factors for SB. Although anecdotal only, internet blogs have regular mentions of suicidal thoughts among siblings of an ASD person.

AUTISM IS DISTINCT FROM SUICIDE

Suicidal behavior is its own discrete disorder. Other conditions like depression or anxiety disorder may be associated with a predisposition to suicide, but suicide is a distinct neurobiological entity with its own core features,



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The reasons for the increased rate of SB in ASDs might be categorized into five areas: predisposing co-morbid conditions, biological overlaps, conditions of the social environment, conditions of the person, and barriers to treatment.

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complex biology and multifactorial etiology. Only a small percentage of those with a predisposing condition will develop SB. This also seems to be the case with ASD, with only a small percentage of those on the spectrum developing SB. It is unclear if the conditions co-morbid with autism, like depression or anxiety, are responsible for any increased risk, rather than the underlying cause of the autism itself.

Certainly, the primary behavioral symptoms defining autism do not include inwardly directed violence or harm, and autism itself is not a mental health disorder. A psychiatric disorder *per se* is not a prerequisite for SB, as shown by data from other countries, particularly in Asia, where most suicides are not associated with mental health disorders. Brain injuries, certain drugs and abuse of distilled alcohol can also lead to SB, outside of any pre-existing mental health condition. Thus, having ASD doesn't mean someone will become suicidal. Other factors must be present.

WHY THE INCREASED RISK?

The reasons for the increased rate of SB in ASDs might be categorized into five areas: predisposing co-morbid conditions, biological overlaps, conditions of the social environment, conditions of the person, and barriers to treatment.

As noted above, co-morbid conditions like anxiety and depression can predispose to SB. So can ADHD, impulsivity, aggression, conduct problems, sleep disturbance, and self-injurious behavior which are common in ASDs. For example, a recent study in *Pediatrics* found 49%, 31% and 36% of 12-17 year olds with autism had anxiety, depression and conduct problems respectively. The more conditions a person has, the greater the propensity for SB. These conditions are often treated with medications such as SSRIs and antipsychotics which themselves can increase SB in a vulnerable subgroup.

A new study using a Danish registry found a higher rate of suicide among siblings of those with an ASD who

were highly creative in the writing field, and posit that this might be due to an epigenetically-driven propensity to larger brain asymmetry in language centers in these families.

The social environment has an impact on SB risk. Factors which might be present to a higher degree in those with an ASD are stressful family life, for example, from divorce or financial strain from job loss, especially for the mother; childhood abuse, which may be higher in ASD families; difficulties at work or school, like low employment opportunities or expulsion from school; and bullying, which is rampant.

Common conditions of a person with autism which have been shown to increase risk or lower protective barriers in the non-ASD population include poor diet leading to nutritional imbalance, lack of daily exercise, weak social networks and social isolation, feelings of hopelessness, chronic physical illness, fewer and less developed coping skills in problem solving and conflict resolution, and difficulties in self-assessment of internal problems and help-seeking. For example, a new study by Christina Nicolaidis and colleagues found that ASD adults scored significantly lower than matched controls on these statements:

- ▶ I can judge when changes in my health mean I should visit a healthcare provider.
- ▶ I can do something to make myself feel better when I feel sad, discouraged, or depressed.
- ▶ I can get emotional support (such as listening or talking over my problems) from friends, family, or other resources.

On the brighter side, some features of autism can be protective. People with ASD tend to be rule-based, and a strong cultural, philosophical or religious foundation against taking one's life and being safe can act as a buffer. Some with an ASD are less sensitive to socially-construct-

ed norms, so may feel less stigmatized by admitting to mental health issues and thus more likely to seek help. Additionally, people with an ASD are less prone to abuse alcohol and drugs.

TREATMENT BARRIERS

Barriers to accessing mental health treatment seem to be more common for autism than even the general population. A recent study by Kalb et al found children with autism appearing at emergency rooms in crisis from mental health problems because their insurance plans limit coverage for mental health or for autism. The Nicolaidis study cited above also found that adults with an ASD were over twice as likely to not receive mental healthcare or counseling when needed, or to have visited the emergency department for treatment in the past 12 months.

The standard practice for encountering someone with suicidal thoughts is to have them see a professional, but we have few professionals who are trained to provide this type of therapy for someone with autism. The standard practice presumes that suicidal thoughts can be ascertained, but these may present differently in an ASD person or be hidden due to lack of verbal skills or ability to describe internal states.

The widely publicized study on wandering and elopement in autism found a high number of intentional escapes. Some of these escapes can seem deliberately self-injurious, like jumping off buildings, diving into ponds on frigid winter days or running into traffic. Even those who verbally express suicidal thoughts are often ignored. I've encountered a number of teens who say they want to die who are either not being treated at all or are receiving minimal treatment. Their words are sometimes taken as attention-seeking or perseverative speech. In typical siblings, suicidal thoughts may be unaddressed because of focus on the child with autism, or the sibling may hide these thoughts so as not to draw family focus away from his or her disabled sibling, believing his or her needs are less important.

SUICIDAL BEHAVIOR AND ASD OVERLAP

The biological overlap between ASD and SB is surprising. Examples, not exhaustive, include:

- ▶ exposure to infections like influenza and *Toxoplasma gondii* during pregnancy and infancy
- ▶ exposure to metals
- ▶ immune differences and activated microglia
- ▶ altered neurotransmitter systems like serotonin, dopamine, GABA and glutamate
- ▶ disruption in synaptic communication (WNT, connexins, cadherins)
- ▶ alterations in fatty acid metabolism such as cholesterol
- ▶ low vitamin D levels
- ▶ gluten sensitivity

WHAT WE CAN DO

Suicide is largely preventable. There are evidence-based steps to reducing risk all along the "suicide continuum," from predisposing factors to ideation to action. Xenobiotic exposures in pregnancy and infancy can be minimized. Powerful drugs can be avoided with safer approaches or monitored more closely. Recognizing and removing dysregulating conditions can strengthen protective factors: better sleep, less GI pain, more outdoor exercise, balanced nutrition, and practicing mindfulness and calming. With proper family and school supports, stresses can be reduced, including bullying. More emphasis on ASD approaches that build social relationships and foster community-based settings can reduce social isolation. We should prioritize social skills training and

8 CRITICAL MEASURES TO COUNTER SUICIDE

- 1 **PAY ATTENTION** Never minimize or trivialize words or actions indicating suicidal thoughts. Ignoring them won't make them go away. Additionally, monitor any changes in behavior, and be aware that such changes can follow head injuries including concussion. Be extra vigilant should your child receive a sports or other injury involving even a mild concussion.
- 2 **TALK ABOUT IT** Be open and frank with both your ASD and typical children when talking about suicidal thoughts and feelings of depression and anxiety. Don't be afraid to enlist help, from a healthcare professional, pastor, educator, therapist, etc.
- 3 **PREVENT BULLYING** Monitor your child's school or workplace and engage with teachers or employers to ensure any bullying is recognized and eliminated.
- 4 **REDUCE SOCIAL ISOLATION** Build social relationships, access community-based activities, and prioritize social skills and peer mentoring.
- 5 **PROMOTE HEALTHY LIFESTYLES** Good nutrition, daily exercise, regular sleep, and mindfulness practice go a long way in regulating mood and behaviors. Implement self-empowerment and self-awareness programs which enable your child to better handle life stressors. Meaningful, consistent work also acts as a buffer. Also, be alert for signs of alcohol and drug abuse and be prepared to seek professional assistance if needed.
- 6 **MONITOR MEDICATION SIDE EFFECTS** Some medications used for behavioral or mood problems can increase suicidal ideation. Maintain close dialogue with the prescribing physician if any worrisome symptoms appear.
- 7 **PLACE BARRIERS ON LETHAL MEANS** If you have concerns or are entering a crisis situation, keep firearms and sharp objects under lock and key. Be aware of any poisons—including medications—in your home that need to be secured. Lock upper story windows and engage child locks on car doors. Remove or prevent access to ropes and cords.
- 8 **ACT QUICKLY** If you recognize suicidal tendencies in an individual with or without an ASD diagnosis, reach out to a professional immediately. Monitor your child closely and constantly until he or she is seen by a professional.

peer mentoring. Opening employment and volunteering opportunities with the requisite support can reduce employer-employee conflict, joblessness and lack of meaningful work. Guidance from family, trusted professionals and religious advisors throughout childhood and adulthood on safety, self-advocacy and wellness serves as a foundation against self-harming tendencies.

Young adults with ASD or their typical siblings who are going to college can access an effective mental health wellness program through Active Minds (See *Find Out More*). This student-run organization is present at hundreds of college campuses. Vulnerable students can engage their college counseling center when arriving on campus so that support systems can be put in place to reduce the likelihood of crisis.

Above all, indications of suicidal thoughts or actions need to be paid attention to and addressed immediately. Ignoring these (“if I don't pay attention to them, they'll go away”), making light of them (“you're just saying that to make me feel bad”), or arguing against them (“you don't really want to do that, do you?”) have been found to be ineffective. Acknowledge that these thoughts and feelings exist. Action should be as strong for the person with autism as with the typical sibling. Don't minimize the sibling situation by saying their problems are not as bad as autism. Have frank discussions with all children. It's a myth that talking about suicide or directly asking someone if they are thinking of suicide increases the chances of it happening. Rather, direct talk can diffuse a building crisis and enable the person to get professional help.

Evidence-based practice is to recognize the signs and refer the person quickly to a professional. Even though many more people (about 2 million Americans per year) have suicidal thoughts than ever act on them, addressing these thoughts quickly leads to prevention. The vast majority of people who survive a suicide attempt regret the action and want to live: they were in a crisis mode that clouded their judgment, and 90% of attempters never try again. Intervention makes a difference. A good model to follow is QPR (Question, Persuade, Refer), which includes a GateKeeper Instructors program for suicide prevention meant for ordinary citizens.

It's important to seek out clinicians who have expertise in autism whenever possible. This implies an urgent need to expand the number of trained experts, from psychologists to counselors to medical personnel. It also gives one more reason to press for health insurance reform so that ASD is adequately covered.

If someone appears especially vulnerable or in crisis, limiting access to lethal means (firearms, poisons) can go a long way toward prevention, as can continuous monitoring. The top crisis hotline in the US is 1-800-273-TALK (8255) from the National Suicide Prevention Lifeline, or visit their website to chat. Other countries have their own hotlines. An alternative is to hand-deliver the person in crisis to a professional center. Suicide is everybody's business and any positive action can save a life. ◀

FIND OUT MORE

- ▶ **Active Minds** activeminds.org
- ▶ **QPR** qprinstitute.com
- ▶ **National Suicide Prevention Lifeline** suicidepreventionlifeline.org