Suicide Screening and Prevention in the Autism Community:

New Developments, New Perspectives

A Webinar from AUCDs Autism Special Interest Group (SIG)

Suicide in the Autistic Community: An Unseen Crisis

Sara Luterman, MFA

Association of University Centers on Disabilities

A Note on Language

- This presentation uses “identity first” language
- Identity first language puts emphasis on autism as an important and intrinsic part of who we are
- Identity first language is preferred by most autistic adults who express a preference

(Kenny L. *et al. Autism* 2016)

What Researchers Know

- 67% of adults with Asperger syndrome reported suicidal thoughts
- 35% reported having specific plans or attempting

(Cassidy S. *et al. Lancet Psychiatry* 2016)

What Researchers Know

- Autistic adults without intellectual disability (ID) are 9 times more likely to die by suicide than gen pop
- Suicide is the leading cause of death in autistic adults without ID after heart disease

(Hirovski T. *et al. British Journal of Psychiatry* 2016)

What Researchers Know

- 14% of autistic children under 16 talked about or attempted suicide in one study
- 0.5% of children from gen pop talked about or attempted suicide

(Mayes S.D. *et al.* Research in Autism Spectrum Disorders 2012)

What Researchers Know

- Being black or Hispanic and low family income increased suicide risk in autistic children
- 60% of the autistic children in the study reported being bullied
- Autistic children who reported bullying were 3 times more likely to consider or attempt suicide than autistic children who did not report bullying

(Mayes S.D. *et al.* Research in Autism Spectrum Disorders 2012)

What Researchers Don’t Know

- A lot
- Most of the scholarship around autism in the US focuses on genetics or childhood “behaviors”
- Quality of life gets overlooked and underfunded
- This has been improving, though!

Interviews with Autistic Adults

- This evidence is anecdotal
- I asked people I know in the autistic community and put out notices on social media – Not necessarily a broad or diverse group of autistic people
- The purpose is food for thought for your own research and work

Interview Questions

- What do you think could have reduced your suicidal thoughts or prevented your attempt?
- What do you want professionals and providers to know?

Causes and Prevention

“What is so hard is that this society feels that disabled people are worthless. If I had a full time job then I would feel like I was contributing more to society and wouldn't feel like such a burden. So we need to change society and the messages autistic people are sent. we need to emphasize that every life is in fact valuable. and that it is okay to take benefits.”

Causes and Prevention

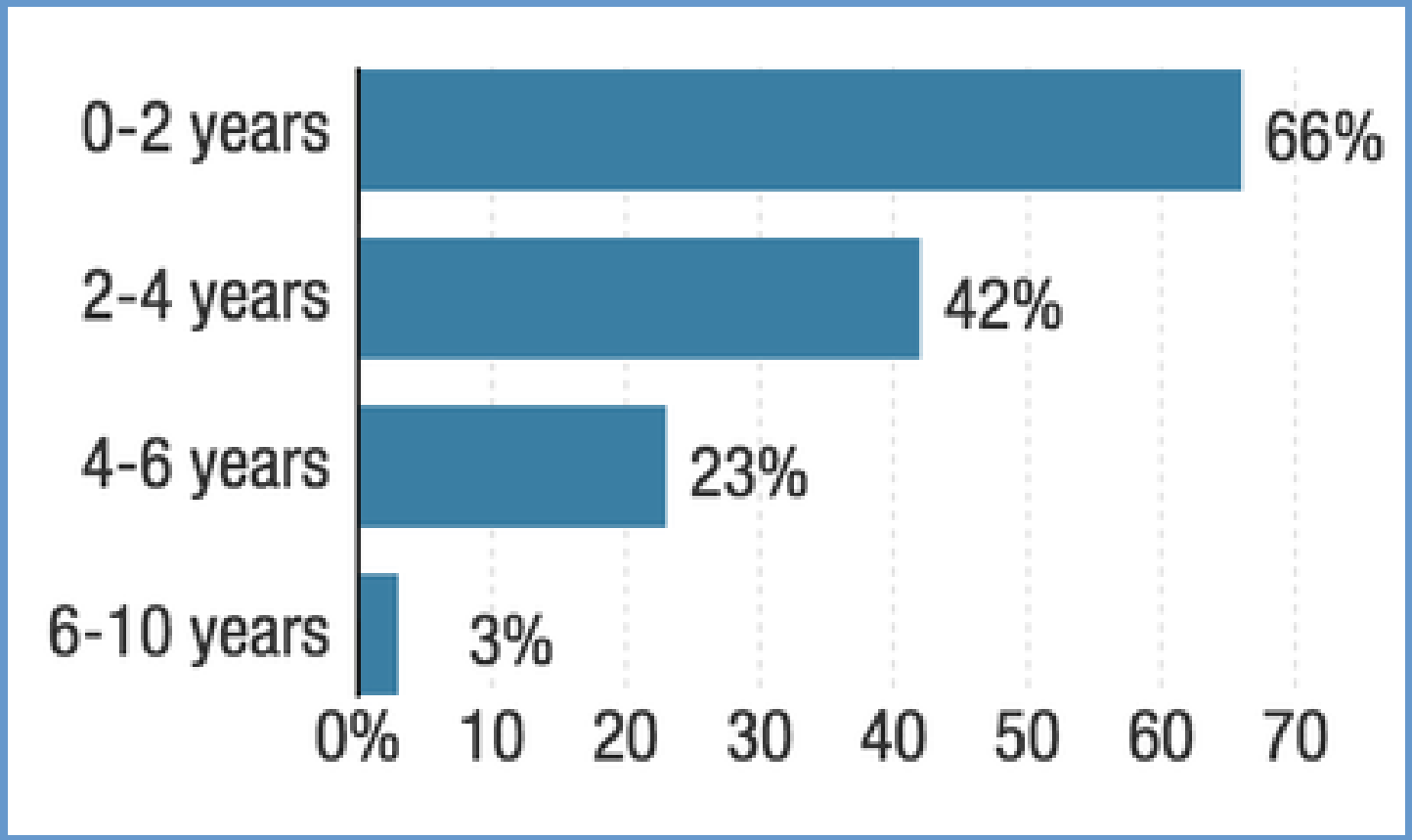
“I wish… professionals had known that a lot of my social isolation didn’t come from autism itself, but from factors like lack of social support to find things to do, where I was living in the area, and non-autistic/non-disabled people being weird about autism.”

Causes and Prevention

- Autistic young adults are significantly less likely to be employed than peers with other kinds of disabilities
- Bullying and social isolation often continue into adulthood

(Centers for Disease Control, Survey of Pathways to Diagnosis and Services 2011)

Never worked or continued education after high school



Credit: NPR; Source: National Longitudinal Transition Study-2/A.J. Drexel Autism Institute

What Does This Mean?

- Treatment and prevention of suicide in autistic people needs to take a holistic approach
- Things like poverty reduction, meaningful employment, and working on ending social isolation are key to everyone's mental health. That includes autistic people
- Acceptance and fighting stigma are also important

Barriers to Care

- Lack of providers with autism competency
- High monetary cost of mental health care
- Lack of accessible ways to ask for help – Phone calls can be difficult for autistic people
- Trauma from previous negative interactions with psychiatric and healthcare system

Barriers to Care

“The psychiatrist’s office said, ‘oh, you have Aspergers, we can’t treat you,’ and then hung up.”

Barriers to Care

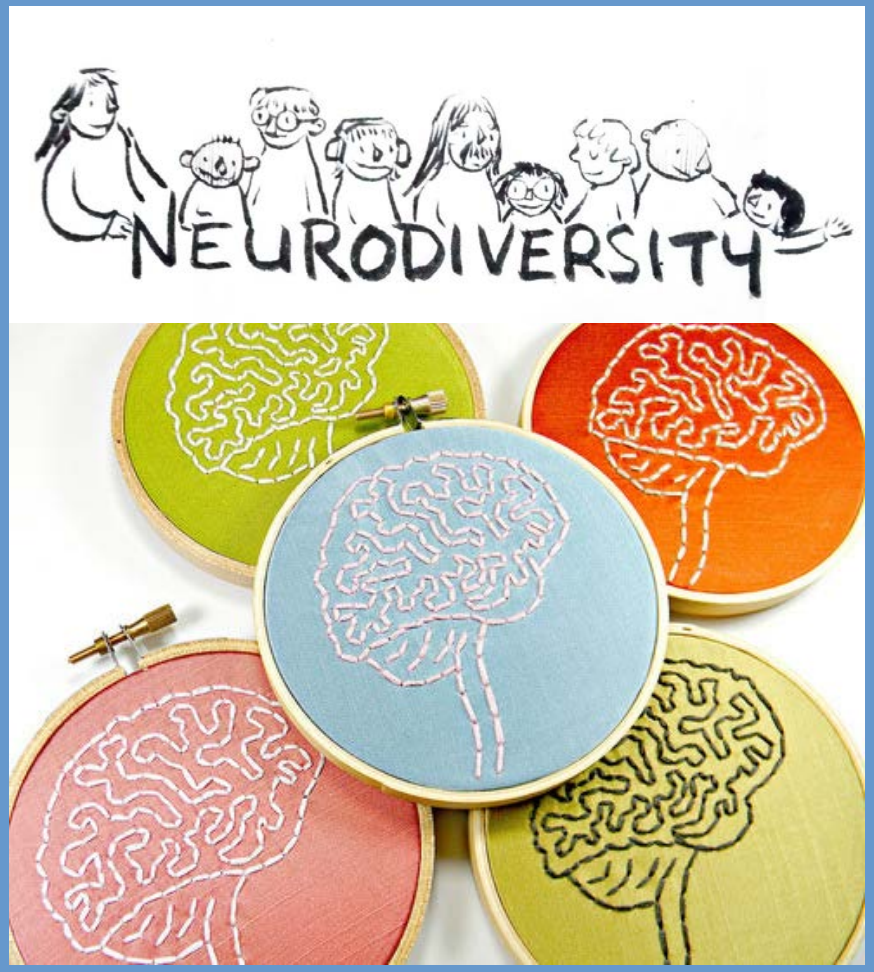
“Also there's too much emphasis on talking talking talking. Typing or texting is so much easier. The fact that I can email and text my therapist is a LIFESAVER for me, literally. I wish I could text my psychiatrist too. or text to make appointments or do it online. really why all the emphasis on talking when we've invented keyboards? I don't get it.”

What Does This Mean?

- We need more mental health professionals to have autism competency and training
- We also need more autism professionals to have mental health competency and training
- More text-based ways to ask for help, flexibility in communication style
- Opportunity for LEND programs to provide leadership

What is Autism Competency?

- Not just about knowing “clinical features”
- Your client or patient might not consider autism a problem. Understand and respect that



What is Autism Competency?

- Recognize sensory barriers – Hospitals can be “sensory hell”
- Your client might communicate and express feelings differently. That’s OK
- Awareness of Awareness and how it impacts autistic people

Autistics Talk Mental Health

"Suicide is a problem for Autistic people. A year rarely goes by without at least one fairly high-profile attempt or crisis tinged with suicidality. Suicide lurks, with the other early killers like eating disorders, along the fringes of our lives picking off acquaintances, colleagues, and friends."

- Larkin Taylor-Parker, Autistic Future

Autistics Talk Mental Health

“Do I believe in suicide prevention? Yes. But I believe in comprehensive suicide prevention. Suicide prevention must encompass both the individual and society. I believe in suicide prevention that reduces the amount of discrimination and mistreatment in the mental health care system. I believe in suicide prevention that works as more general mental health advocacy to provide stable housing and community services as opposed to institutionalization and lack of in-home settings. I believe in suicide prevention that addresses whole people and their relationships and communities and the impact society has on them.”

- Kit Mead, KPagination

Contact Information

Sara Luterman, MFA

sluterman@aucd.org

Skype: slooterman

Assessing Suicide Risk in Adolescents and Adults with Autism Spectrum Disorder

Lisa M. Horowitz, PhD, MPH
Audrey Thurm, PhD
Office of the Clinical Director
National Institute of Mental Health
Intramural Research Program

AUCDs Autism Special Interest Group Webinar
October 19, 2016

The views expressed in this presentation do not necessarily represent the views of the NIH, DHHS, or any other government agency or official. We have no financial conflicts to disclose.

Overall Objectives

- Brief epidemiology of suicide risk
- Suicide risk in children and adults with ASD
- Unique challenges in screening ASD populations
- Suicide risk screening tool instrument development overview
- Take away message: Ask directly

Defining terms

- Suicidality - Any thoughts or actions related to volitionally ending one's own life
  - The whole continuum
- Manifestations along the continuum are linked
  - e.g., passive thoughts about wanting to be dead; suicide attempts with intent to die
- Significant marker of emotional distress

Tishler, 2007; Posner, 2007

Completed Suicide Worldwide

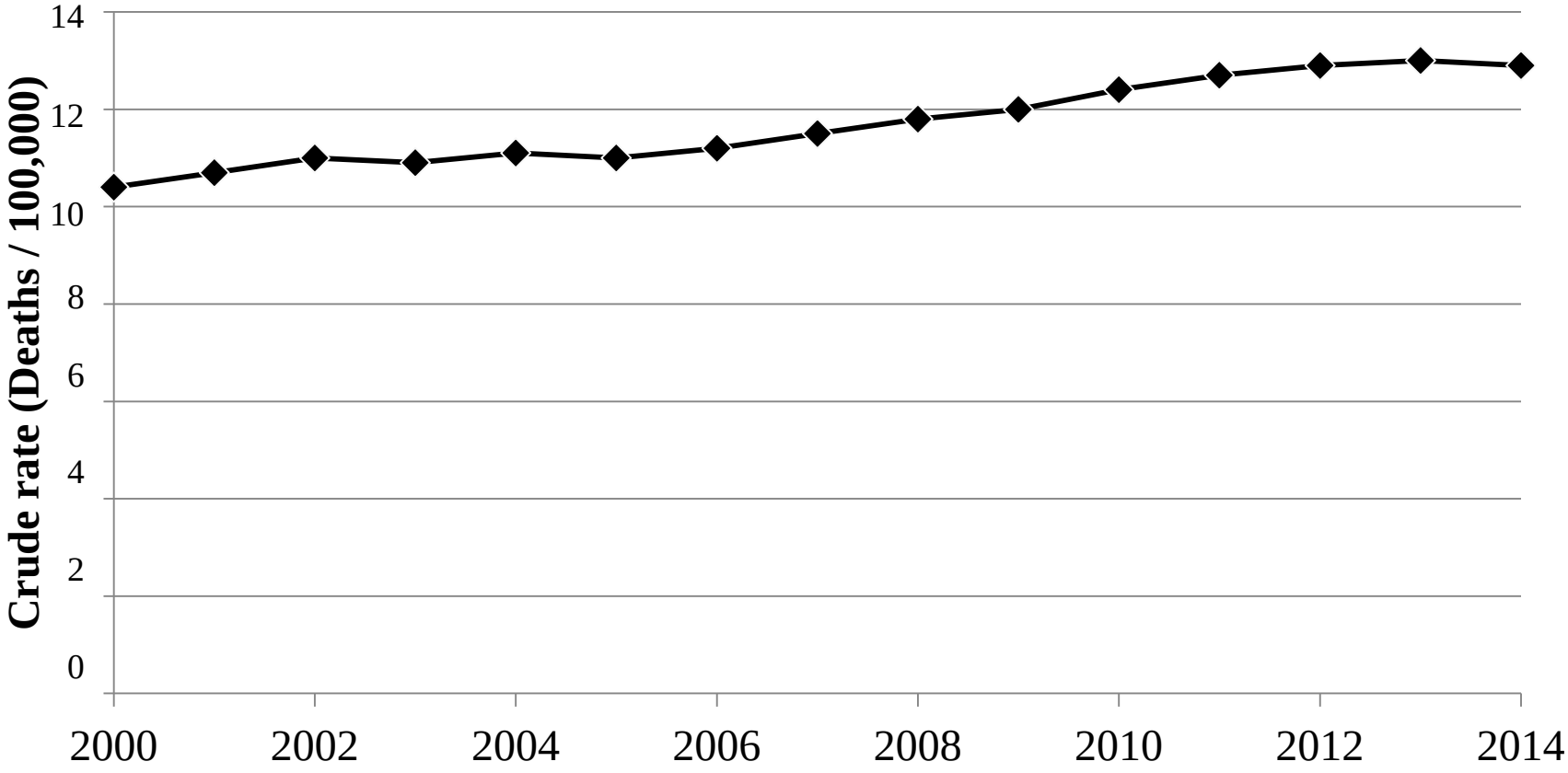
- 800,000+ deaths from suicide annually, worldwide
- Suicide rate has increased 60% in past 45 years
- 2nd leading cause of death for young people
- In 2008, global toll from suicide exceeded the number of estimated deaths by homicide (535,000) and war (182,000) combined

National Institute of Mental Health

WHO, 2014; CDC WISQARS, 2011; Varnik, 2012

Adult Suicide in the U.S.

- 10th leading cause of death in U.S.
- Over 46,000 deaths annually



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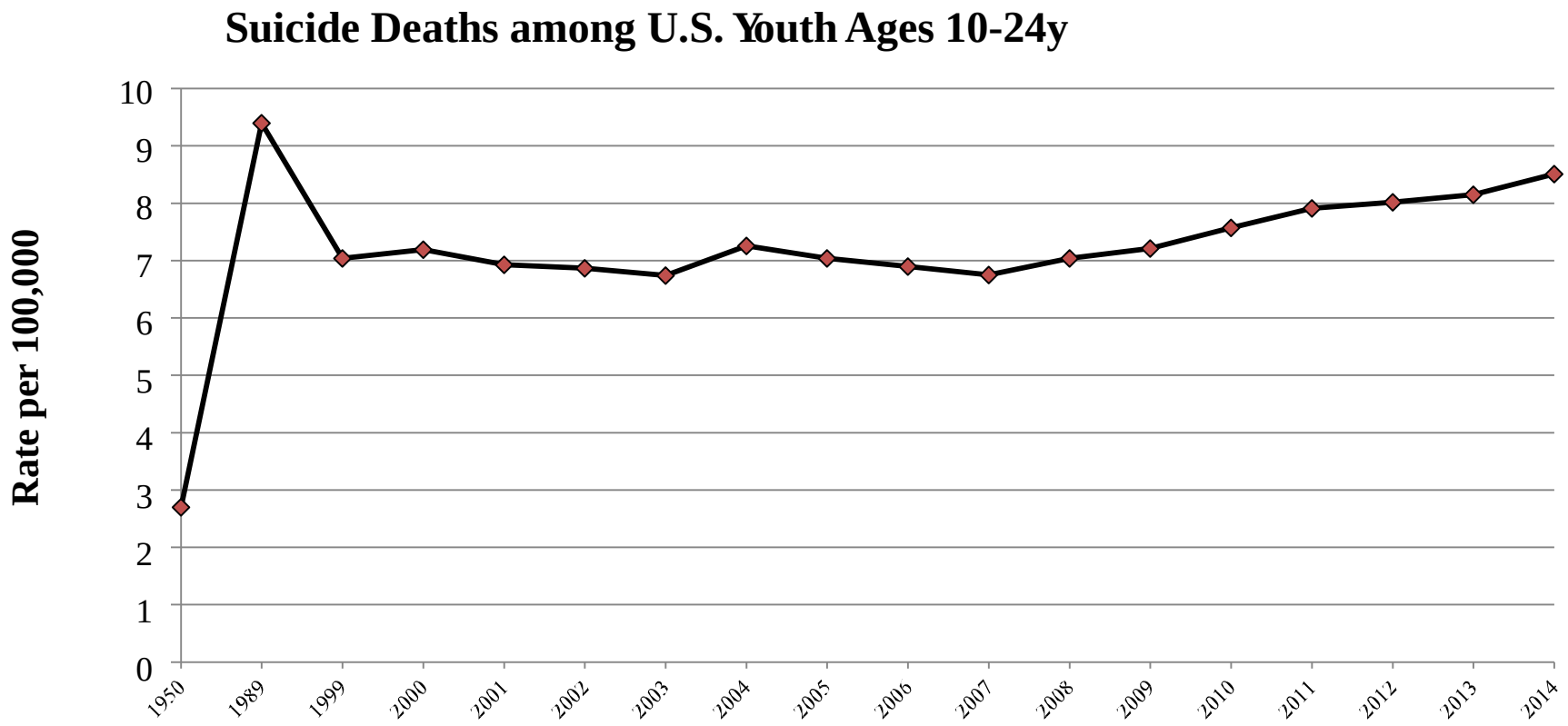
CDC WISQARS, 2016; Statistics Canada, 2016

Youth Suicide in the U.S.

- **2nd leading cause of death** for youth aged 10-24y
- 5,504 suicide deaths in 2014



CDC WISQARS, 2016

Suicidal Behavior

- **~1.3 million adults** attempted suicide in the past year

- **~2 million adolescents** attempt suicide annually
  - 8.6% of high school students attempted suicide one or more times in the past year
  - 2.8% made an attempt resulting in medical treatment

CDC, 2015; Youth Risk Behavior Surveillance, 2015

Suicidal Ideation

- **Adults**
  - In 2013, 9.3 million adults had serious thoughts of suicide
  - 2.7 million adults made a suicide plan
- **Youth**
  - 17.7% of high school students reported “seriously considered attempting suicide” in the last year
  - 14.6% of high school students made a suicide plan in the past year

CDC, 2015; Youth Risk Behavior Surveillance, 2015

Younger Children and Suicidality

- Children under 12 yrs plan, attempt and commit suicide
  - 3rd leading cause of death for 12 year olds
  - 12% of children age 6 to 12 have suicidal thoughts

- 5-12 yr olds (underestimates)
  - 117 deaths

- 2015 Bridge et al. (U.S. data)
  - 1993-2012: suicide rate stable for children <12
  - Significant racial disparity
    - ↑ rate for black children
    - ↓ rate for white children

CDC 2015; Tishler, Reiss, & Rhodes, 2007; Natl Vital Stat Rep, 2006

High Risk Factors – General population

- **Previous attempt**
- Medical illness
- Mental illness
- Symptoms of depression, anxiety, agitation, impulsivity
- Exposure to suicide of a relative, friend or peer
- Physical/sexual abuse history
- Drug or alcohol abuse
- Lack of mental health treatment
- Suicide ideation
- Over age 60 and male
- Between the ages of 15 and 24
- Isolation
- Hopelessness

Suicide Warning Signs

These signs may mean someone is at risk for suicide. Risk is greater if a behavior is new or has increased and if it seems related to a painful event, loss, or change.

- Talking about wanting to die or to kill oneself.
- Looking for a way to kill oneself, such as searching online or buying a gun.
- Talking about feeling hopeless or having no reason to live.
- Talking about feeling trapped or in unbearable pain.
- Talking about being a burden to others.
- Increasing the use of alcohol or drugs.
- Acting anxious or agitated; behaving recklessly.
- Sleeping too little or too much.
- Withdrawing or feeling isolated.
- Showing rage or talking about seeking revenge.
- Displaying extreme mood swings.

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Suicide in ASD population

- Studies are scarce
  - Limited by small sample sizes, variations in methods
  - Focus on adults and those with Asperger Disorder

- Co-morbid psychiatric disorders (i.e. depression and anxiety), are common in ASD

- Estimated rates of **suicidal ideation and behavior** in ASD estimated to be between 11% – 66%

Balfe & Tantam, 2010; Ludi et al., 2012 Raja, Azzoni, & Frustaci, 2011; Shtayermman, 2007; Cassidy et al., 2014; Storch et al., 2013

Suicide in ASD populations

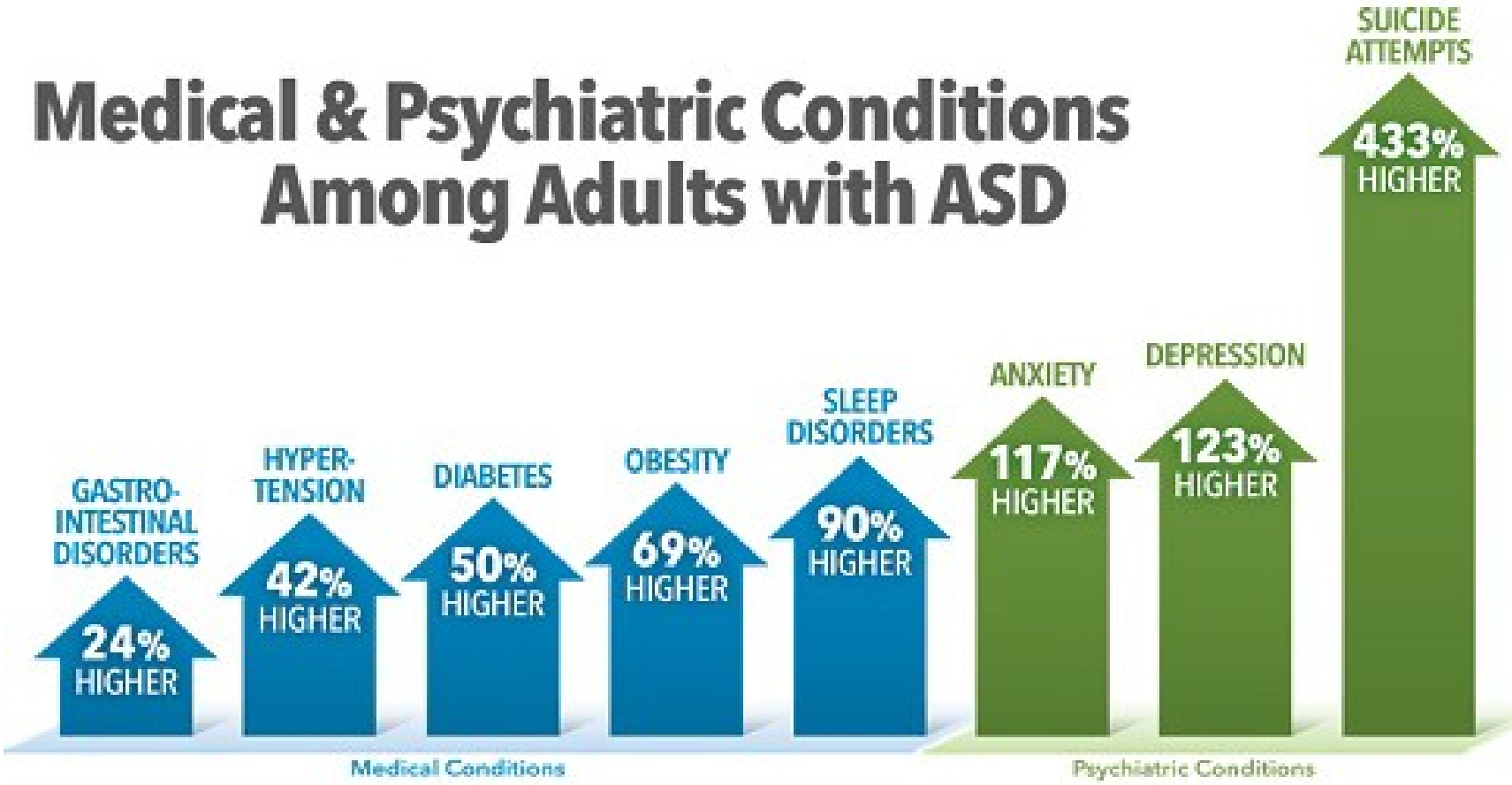


Image courtesy Lisa Croen, Kaiser Permanente Division of Research

National Institute of Mental Health

Mayes, 2013; Richa, 2014

High Risk Factors for ASD population

- Higher IQ
  - IQ scores higher in suicidal youth than non-suicidal youth
  - Young people with ASD without comorbid ID at higher risk
  - Findings inconclusive
- Comorbid Axis I disorders
  - Psychiatric disorders correlated with elevated suicidal ideation and behavior.
- Potential psychosocial stressors for those with suicidal ideation
  - Less family and social support
  - Greater rejection, stress, and isolation
  - Poor problem solving skills
  - Difficulties with perspective taking

Carlson et al, 1994; Coulter 1980; Harris 2006; Hannon & Taylor, 2013; Ludi et al., 2012; Walters, 1995

Underdetection

- Majority of those who commit suicide have contact with a medical professional within 3 months of killing themselves
  - 80% of adolescents contact within 3 months
  - Frequently present with somatic complaints
- Majority of attempters unrecognized by medical professionals
- Majority of practice settings do not screen for socio-behavioral health risks
- **ASD population**: suicidal behavior may be overlooked due to diagnostic overshadowing

Blum, 1996; Clark, 1993; Frankenfield, 2000; Gairin, 2003; Hannon & Taylor, 2013; Pan, 2009; Rhodes 2013

What are valid questions that nurses/physicians can use to screen pediatric medical patients for suicide risk?

Ask Suicide-Screening Questions (ASQ)

- 3 pediatric EDs
  - Children's National Medical Center, Washington, DC
  - Children's Hospital Boston, Boston, MA
  - Nationwide Children's Hospital, Columbus, OH

- September 2008 to January 2011

- 524 pediatric ED patients
  - 344 medical/surgical, 180 psychiatric
  - 57% female, 50% white, 53% privately insured
  - 10 to 21 years (mean=15.2 years; SD = 2.6y)

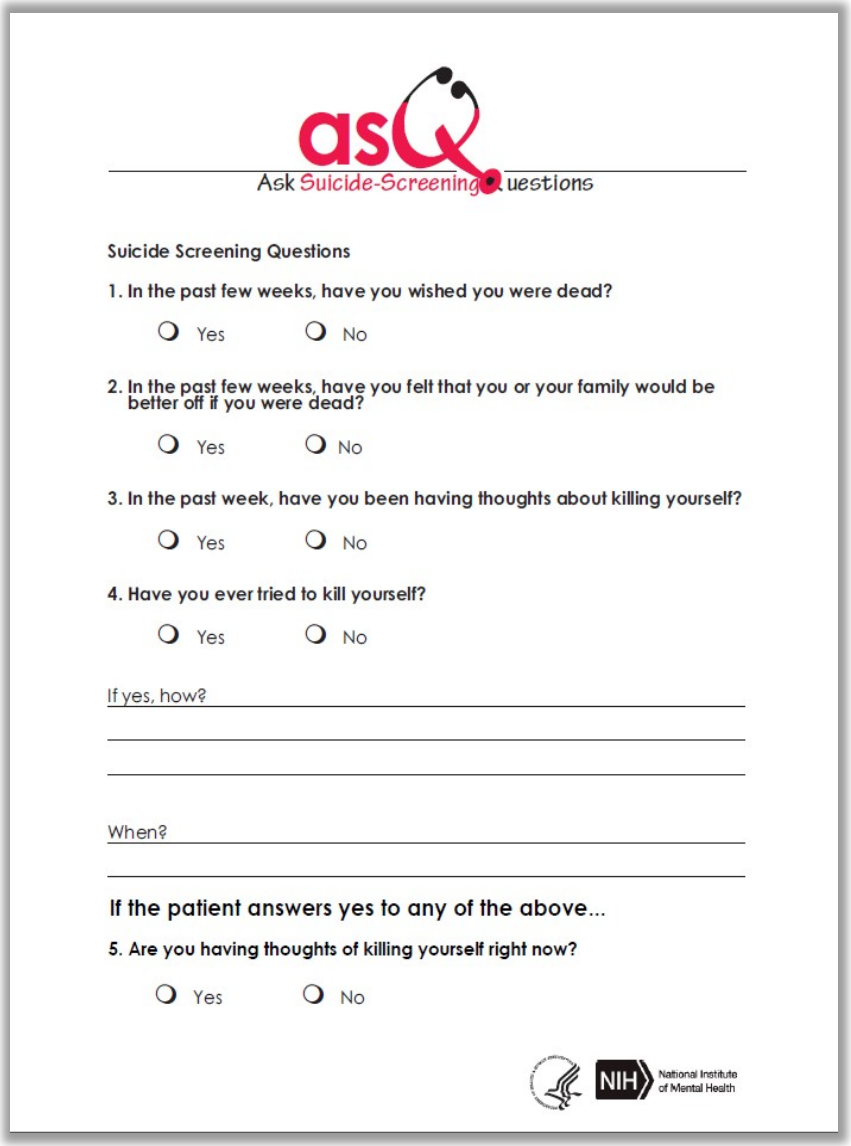
Horowitz et al. (2012) *Arch Pediatr Adolsc Med*

ASQ Study (con't)

- Administered 17 candidate items:
  - "Have you ever felt hopeless, like things would never get better?"
  - "Do you feel like you might as well give up because you can't make things better for yourself?"
- Administered gold standard: Suicidal Ideation Questionnaire (SIQ; Reynolds, 1987)
- Examined the least number of items with sound psychometrics
- Positive responses received psychiatric consultation

Results

- 98/524 (18.7%) screened positive for suicide risk
  - 14/344 (4%) medical/surgical chief complaints
  - 84/180 (47%) psychiatric chief complaints
- Feasible
  - Less than 2 minutes to administer
  - Non-disruptive to ED workflow
- Acceptable
  - Parents/Guardians gave permission for screening
  - Over 95% of patients were in favor of screening
- ASQ is now available in the public domain



asQ

Ask Suicide-Screening Questions

Suicide Screening Questions

1. In the past few weeks, have you wished you were dead?

Yes No

2. In the past few weeks, have you felt that you or your family would be better off if you were dead?

Yes No

3. In the past week, have you been having thoughts about killing yourself?

Yes No

4. Have you ever tried to kill yourself?

Yes No

If yes, how?

When?

If the patient answers yes to any of the above...

5. Are you having thoughts of killing yourself right now?

Yes No

NIH National Institute of Mental Health

Sensitivity: 96.9% (95% CI, 91.3-99.4)

Specificity: 87.6% (95% CI, 84.0-90.5)

Negative predictive values:

-Medical/surgical patients: 99.7% (95% CI, 98.2-99.9)

-Psychiatric patients: 96.9% (95% CI, 89.3-99.6)

What happens when a patient screens positive?

- Doctor will review patient's answers and initially discuss the ASQ results with the patient **alone**
  - **Brief suicide safety assessment** to determine if more extensive psychiatric evaluation is necessary
  - Inform patient that results will be discussed with parent

- Next steps are dependent upon screening setting (i.e. ED, inpatient unit, primary care)

“What about screening people with ASD?”

-Dr. Rachel Greenbaum

NIH National Institute of Mental Health

Screening for Suicide Risk in Patients with ASD

- Patients presenting with suicidal thoughts present a high anxiety situation for clinicians

- **There are currently no standardized tools developed to screen for suicide risk in individuals with ASD**

Suicide in IDD populations

Review Article

Suicide Risk in Youth with Intellectual Disabilities: The Challenges of Screening

Erica Ludi, BS,* Elizabeth D. Ballard, MA,† Rachel Greenbaum, PhD,‡ Maryland Pao, MD,* Jeffrey Bridge, PhD,§ William Reynolds, PhD,‖ Lisa Horowitz, PhD, MPH*

ABSTRACT: Children and adolescents with intellectual disabilities (IDs), often diagnosed with comorbid psychiatric disorders, are a vulnerable population who may be at risk for developing suicidal thoughts and behaviors. Previous research has demonstrated that direct suicide screening can rapidly and effectively detect suicide risk and facilitate further clinical evaluation and management. Currently, there are no measures that screen for suicide risk designed specifically for individuals with ID. A review of the literature was conducted to (1) estimate the prevalence of suicidal thoughts, behaviors, and deaths by suicide in children and adolescents with ID; (2) describe associations between youth with ID and suicide risk; and (3) identify the limitations of commonly used suicide screening measures developed for non-ID youth. The literature review confirms that suicide risk exists in this population; youth with ID think about, attempt, and die by suicide. Standardized suicide risk screening is challenged by the lack of measures developed for this population. A summary of the findings is followed by a discussion of the practical clinical considerations surrounding the assessment of suicide risk in youth with ID.

*(J Dev Behav Pediatr 33:*431–440, 2012) **Index terms:** youth suicide, intellectual disability, developmental delay, suicide screening, assessment.

Ludi, 2012

Limitations to Screening for Suicide Risk in Patients with ASD and/or IDD

- Reading comprehension levels
  - 6th grade reading level
- Receptive language skills
  - Long sentences and polysyllabic words
  - Self-report measures not intended to be read aloud
- Complex response formats
  - Participants asked to choose between 4 or more response options
- Abstract thinking
  - Assessment requires recollection of discrete past events
  - Memory skill deficits may inhibit retrieval of past thoughts and behaviors
  - IDD patients more oriented toward present time and space
- Informant component
  - Observations of behavioral changes or functional regression more reliable than self-report

Ludi et al. 2012

Answering a Need

- **Previously validated scales may not be applicable**

- **Clinicians require validated, standardized tools to assist in assessment of suicide risk**
  - To detect patients at risk who might not otherwise be identified
  - To secure from imminent harm
  - To assist with identification of who requires mental health follow-up and treatment

Pilot Study

Future directions

- Begin instrument development study at ADDIRC sites in order to create a screening instrument designed for and tested with an ASD/IDD population

Instrument Development Study

- Collaboration with the Autism Developmental Disorders Inpatient Research Collaborative (ADDIRC)

- Sample: clients enrolled in the ADDIRC
  - Ages 12+
  - Diagnosed with ASD with and without ID
  - Currently accessing inpatient psychiatric treatment

Summary

- Individuals with ASD at risk for suicide may go undetected
- Clinicians require tools to guide them in assessing suicide risk
- Interventions designed to treat suicidal ideation and behavior in the ASD population are needed

Thank you

- **Surrey Place Center**
  - Rachel Greenbaum, PhD and Laura Weinheimer
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  - Jeffrey Bridge, PhD

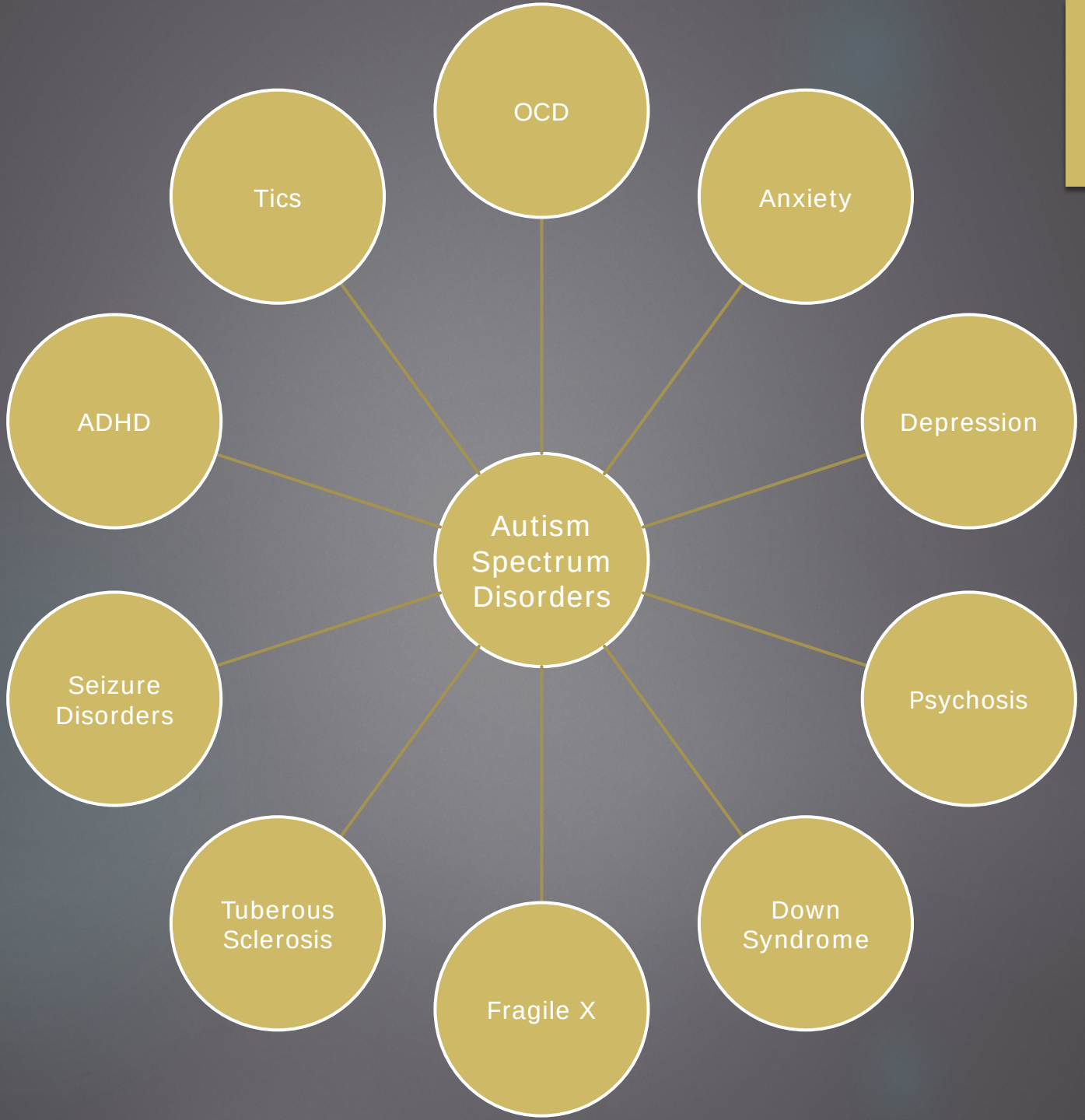
Lisa M. Horowitz, PhD
HorowitzL@Mail.NIH.gov

Audrey Thurm, PhD
athurm@mail.nih.gov

PROMOTING MENTAL HEALTH AND PREVENTING SUICIDE IN THE AUTISM COMMUNITY

JULIE T. STECK, PH.D., HSPP
CRG/CHILDREN'S RESOURCE GROUP
INDIANAPOLIS, IN

AN INDIVIDUAL WITH A DEVELOPMENTAL DISORDER IS AT HIGHER RISK FOR ANY OTHER DEVELOPMENTAL DISORDER AND/OR PSYCHIATRIC (MENTAL HEALTH) DISORDERS


OCD
Tics
Anxiety
ADHD
Depression
Autism Spectrum Disorders
Seizure Disorders
Psychosis
Tuberous Sclerosis
Down Syndrome
Fragile X

STELLA—CASE STUDY

- *10 year-old-female*
- *Preschool teachers described her as a "puzzle"*
- *Highly verbal*
- *"Quirky"*
- *Poor fine and gross motor skills*
- *Specific and intense interests*

STELLA -- CONTINUED

- ***Death of mother at age 8***
- ***Frequent moves***
- ***Significant difficulty with math, spelling and writing***
- ***Cries frequently in school and goes to school counselor***
- ***Graded diagnoses of ASD confirmed with ADOS-2***

STELLA – BUT IS THERE MORE

- ***Further evaluation revealed:***

Significant visual-spatial-organizational difficulties

Deficits in math, decoding for reading, spelling

and written expression

Significant anxiety

Symptoms of depression

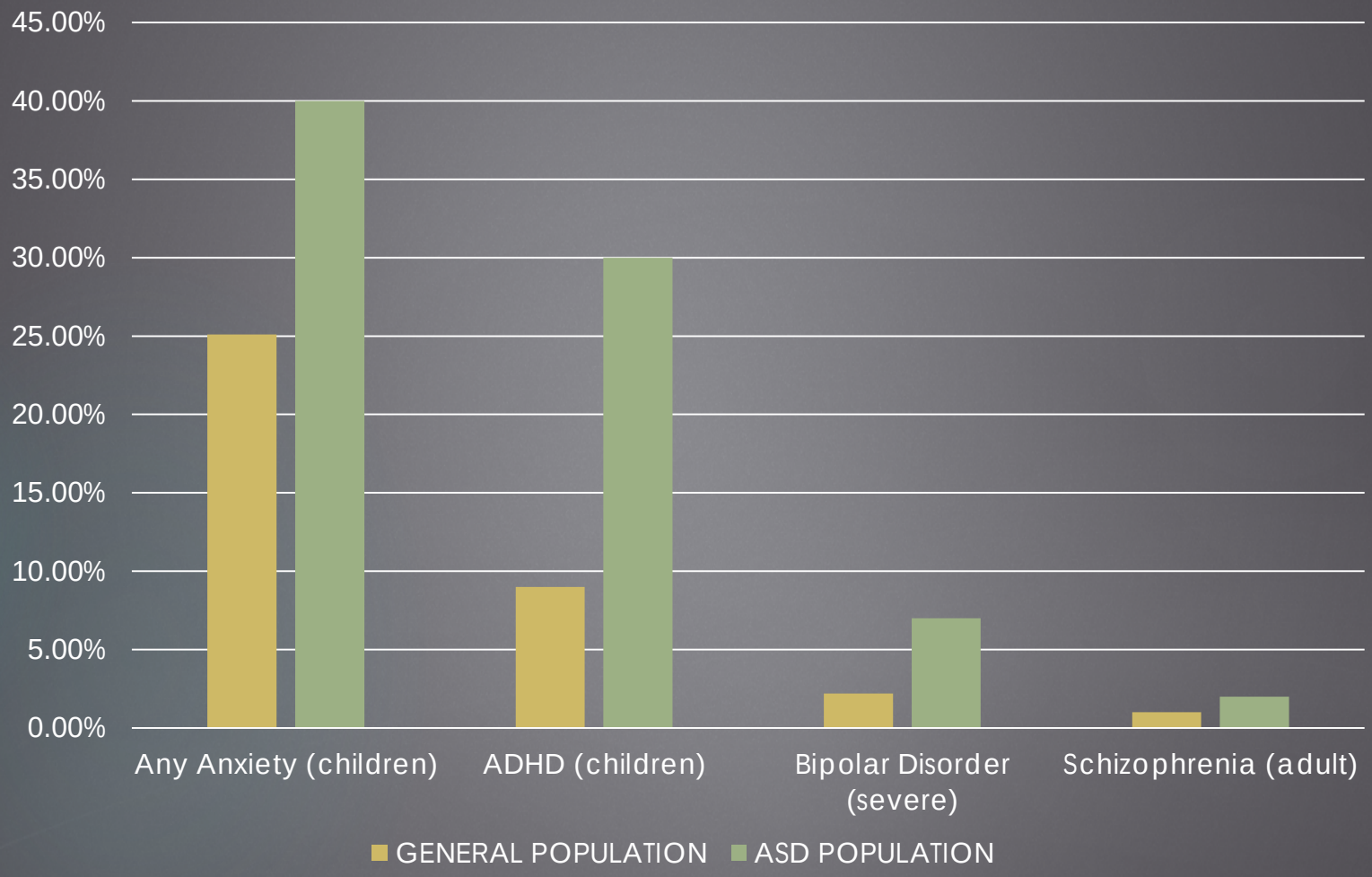
Attention Deficit Hyperactivity Disorder, Predominantly Inattentive Presentation

WHAT DOES THIS CASE TELL US?

- ***Diagnosis of ASD is often delayed or more tentative in females***
- ***ASD often a "yes/no" question***
- ***ASD often accompanied by specific learning disorders which contribute to difficulties in school***
- ***Further mental health conditions not assessed***
- ***Intervention must be multi-modal and across settings***

The rate of virtually every psychiatric condition is greater in the population of those with ASD than in the general population

CO-MORBIDITY RATES IN ASD



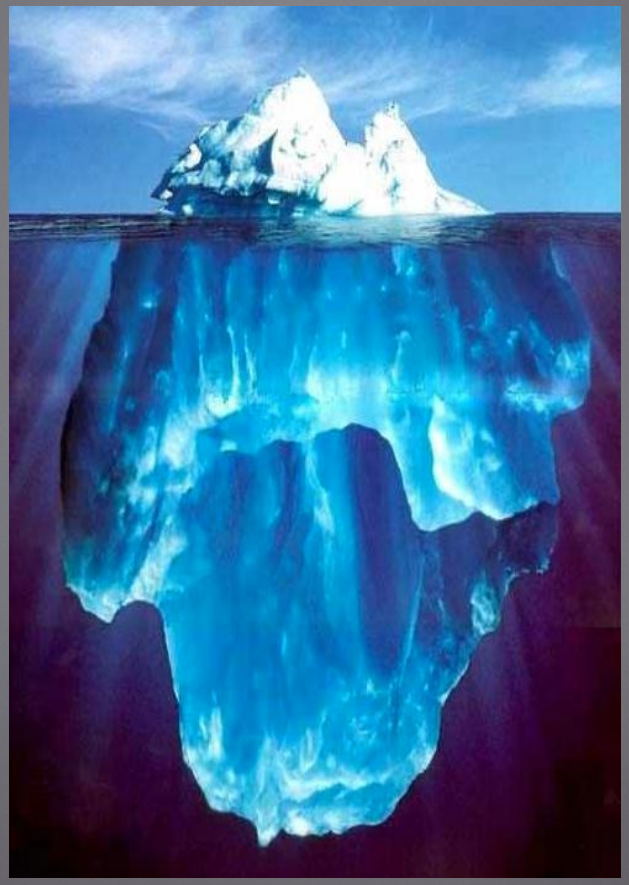
NEWER AREAS OF CONCERN AND INVESTIGATION

- ***Gender and sexual identity issues***
- ***Internet addiction***
- ***Internet pornography addiction***

The increased incidence of mental health conditions in individuals with ASD appears to be due to:

- *The experience of having ASD*
- *Common genetic pathways for ASD, ADHD, depression, bipolar disorder and schizophrenia*

ASD IS OFTEN THE TIP OF THE ICEBERG



OR IT CAN BE THE BASE OF THE ICEBERG DEPENDING ON THE DIAGNOSING PROFESSIONAL'S OREINTATION

PREVENTION

- ***Increase awareness of mental health conditions that co-exist with ASD—***
- ***Increase awareness of suicidal ideation and risks in those with ASD***
- ***Educate mental health professionals about ASD and co-existing conditions***

INTERVENTION AND TREATMENT

- ***Intervention starts with diagnosis***
- ***Diagnosis includes looking at co-existing conditions (ASD should not be a yes/no question)***
- ***Individual and family education about the condition(s) are critical***
- ***Consideration of medication to treat co-existing conditions***

TREATMENT AND INTERVENTION

- ***Ongoing monitoring for other co-existing conditions***
- ***Therapeutic intervention with an individual knowledgeable of ASD***
- ***Environmental adjustments to improve home, work, school settings***
- ***Keep the individual with ASD connected with family, church, friends, or other supports***

THERAPEUTIC CONSIDERATIONS

Research based therapies in individuals with ASD:

- ***Cognitive-Behavior Therapy (CBT) modified for ASD***
- ***Mindfulness-Based Therapy modified for ASD***

THERAPEUTIC CONSIDERATIONS

- *Therapist must attempt to see the world through the other person's eyes*
- *Talk less and listen more*
- *Those with ASD do not typically want the therapist to be too positive*
- *Ask about time spent online and the nature of the content*
- *Participation in therapy by a family member or other supportive adult with a signed consent for communication*

THERAPEUTIC CONSIDERATIONS

- ***Mental health providers need to ask about suicidal thinking on a regular basis—if you don't ask, you won't know***
- ***When suicidal thinking is present, it is important to build a safety plan and increase frequency of appointments***
- ***Decrease immediate stresses and develop a long-term plan***
- ***Medical provider and therapist must communicate***

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Questions?

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ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
RESEARCH, EDUCATION, SERVICE

Thank you

To Our Presenters

- **Sara Luterman, MFA**
- **Lisa M. Horowitz, PhD, MPH**
- **Audrey Thurm, Ph.D.**
- **Julie Steck, Ph.D., HSPP**

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And to the Maternal and Child Health Bureau which has funded this project