1 FEDERAL COMMISSION ON SCHOOL SAFETY

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21 Reporter By: Michael Farkas

22

Page 2

I N D E X

SPEAKERS:

PAGE NO.

SECRETARY BETSY DEVOS 3

SECRETARY ALEX AZAR 4

ATTORNEY GENERAL JEFF SESSIONS 7

SECRETARY KIRSTJEN NIELSEN 10

SHERYL KATAOKA, M.D. 14

GABRIELLE A. CARLSON, M.D. 23

MARK OLFSON, M.D. 33

QUESTION AND ANSWER SESSION 43

JENNIFER MATHIS 56

DORIS FULLER 66

SONJA TRAINOR 75

JOHN VERDI 85

QUESTION AND ANSWER SESSION 95

CLOSING STATEMENTS

SECRETARY AZAR 108

SECRETARY BETSY DEVOS 109

SECRETARY NIELSEN 110

ASSISTANT ATTORNEY GENERAL WILLIAMS 111

1 P R O C E E D I N G

2 SECRETARY DEVOS: Good morning everyone. I'd
3 like to welcome everyone to this Federal Commission on
4 School Safety Meeting.
5 This is our second full commission meeting.
6 In late June we met and considered the impact of cyber
7 bullying and youth consumption of violent entertainment
8 upon students, as well as the affects of media coverage
9 of mass shootings.
10 The purpose of our meetings has been to hear
11 from experts and others about best practices and
12 recommendations for keeping students safe at school.
13 As I've noted in the past, the commission was
14 established by President Trump in March of this year,
15 in response to the tragedy at Margery Stoneman Douglas
16 High School, in Parkland, Florida.
17 Unfortunately, we are all too aware that this
18 was not an isolated incident. And so, we continue to
19 press ahead to see what is working in local communities
20 across the nation.
21 The commission continues its work of gathering
22 information from students, parents, teachers and school

1 counselors, professionals and others.

2 We do that through commission meetings, such

3 as this, field visits, listening sessions and feedback

4 we receive through our email address, safetynet.gov.

5 We will continue to solicit and gather

6 information from professionals here and across the

7 country. We know that there is no one-size fits all

8 plan, no standardized approach, when it comes to school

9 safety.

10 Every school and every community is different.

11 That's why the commission will make recommendations,

12 not issuing mandates.

13 These recommendations will address a range of

14 issues including character developments, emergency and

15 crisis training, best practices and school building

16 designs and campus security and the effect that various

17 forms of entertainment may have of violence, among

18 others.

19 This important work continues today with our

20 expert panels. I look forward to hearing from each of

21 our speakers, and the knowledge from speaking more to

22 my fellow commissioners, secretaries and all the

1 speakers. Thank you.
2 SECRETARY AZAR: Great. Thank you very
3 much, Secretary DeVos.
4 And, good morning, speakers and fellow
5 commissioners. And good morning to all those in the
6 audience.
7 I am very pleased to be hosting this meeting
8 today. This is the first and only commission meeting
9 to be hosted by The Department of Health and Human
10 Services.
11 And it will cover some very critical issues
12 related to the health and safety of students in our
13 schools.
14 In particular, we're here to focus on the
15 question of our children's mental health. Many
16 children struggle with what are known as serious
17 emotional disturbances, which are severe mental health
18 challenges that interfere with their daily lives.
19 Despite having diagnosable disorders that can
20 be treated, many do not receive adequate care.
21 Addressing this public health crisis requires a
22 concerted multi-dimensional approach.

1 In particular, improving access to high-
2 quality behavior health treatment, including early
3 identification and intervention for children, youth and
4 their families, is one of HHS's core missions. Half of
5 adult mental illness begins before the age of 14, and
6 three-fourths of it begins before age 24.
7 In addition, while suicide is most common
8 among older adults, suicide is now the second leading
9 cause of death among youth age 15 to 24, after
10 unintentional injury.
11 Compared with their peers, people within this
12 age group with mental disorders are more likely to
13 experience homelessness, be arrested, drop out of
14 school and be underemployed.
15 Mental health disorders produce more
16 disability within this age group than any other chronic
17 health condition. Therefore, meeting the behavioral
18 health needs of our young people is essential.
19 The topic for the HHS Commission Meeting today
20 is curating a healthier and safer approach, issues of
21 mental health and counseling for our young people.
22 Today, we will be hearing from seven different

1 speakers, who will share their expertise and knowledge
2 on three topics, integrating behavioral health services
3 in the schools, the use of psychotropic medications for
4 children and confidentiality issues related to HIPPA
5 and FERPA.
6 Remarks from our speakers today will help
7 shape the Commission's final report. I want to
8 acknowledge my fellow Commissioners' commitment to this
9 initiative and thank Secretary Devos for her
10 leadership.
11 As Commissioners, we have an extremely
12 important job to do and we are taking our roles very
13 seriously. Ensuring a healthier and safer school
14 environment is of the utmost importance and we all play
15 a critical role in this process.
16 I want to thank all of the speakers who have
17 come here today, to share your knowledge and expertise
18 with us about these very critical and important
19 matters. We look forward to hearing from each of you.
20 I'd now like to introduce The Attorney General
21 of The United States and ask him for his opening
22 remarks.

1 ATTORNEY GENERAL SESSIONS: Thank you,
2 Secretary Azar, for your leadership. And particularly
3 I want to thank Secretary DeVos for Chairing this
4 School Safety Commission. It’s an important subject.
5 We need to make progress. I think we can do so.
6 When you meet with law enforcement, as I do,
7 on a regular basis and post-violence in our schools,
8 we’ve had a number of meetings, there is a common
9 theme, much of which I think will be discussed today,
10 about how we can do better in working with law
11 enforcement, schools and mental health and health
12 departments, to be more effective.
13 We know that mental health is a big problem in
14 our criminal justice system. The average study shows
15 that fourteen percent of state and federal prisoners,
16 these are people in the prison system, have experienced
17 serious psychological distress. Whereas 26 percent of
18 jail inmates have reported serious psychological
19 distress.
20 So, the jails are the local places, where
21 often it used to be the town drunks, they would say,
22 would - would be there, but really a lot more than

1 that, people with different, serious problems.
2 Whereas, among the American public, about five percent
3 suffer from psychological distress.
4 I believe this is important. In the meetings
5 we've had, in the meetings with law enforcement, we
6 recognize that there are a number of potential
7 (silencers). Maybe this is not legally a problem, but
8 we think it's a problem.
9 You have Juvenile Courts. They maintain
10 records quite confidentially and secret. You have
11 school systems that maintain records and information
12 and they keep it private.
13 Police are taught to maintain privacy in what
14 they do. Psychological treatment is maintained quite
15 privately, as well as medical treatments that are - is
16 that on? Thank you.
17 So, in a way, you would think, wouldn't it be
18 good if all the people that were involved in this, the
19 school resource officers, our counselors, our
20 principals, teachers, could discuss a child pretty
21 openly, about what kind of difficulties this child may
22 be having, what kind of risks are there.

1 And it may be that the laws are not as
2 restrictive as we think they are. And it may be that
3 in some instances we need to change the rules.
4 But certainly, there's a perception out there,
5 that we need to be – by many, that you can't share
6 information of this kind, because it would violate some
7 law, you could be sued. And this, I believe, is a
8 detriment to actually helping children avoid a problem.
9 Thank you, Mr. Chairman. It's great to be
10 with you.
11 SECRETARY AZAR: Well, thank you very much,
12 Attorney General Sessions.
13 And I'd like to now turn the floor over to
14 Secretary Nielsen, for her opening remarks. Secretary.
15 SECRETARY NIELSEN: Thank you. And good
16 morning to everyone. It's a pleasure to join you here
17 today for this very important topic.
18 I'd like to start off by thanking Secretary
19 DeVos and Secretary Azar, for hosting the Commission
20 Meeting today.
21 And in particular, I'd like to thank HHS for
22 bringing together such an expert panel, that I really

1 look forward to listening to your remarks.

2 As this Commission has discussed before,

3 enhancing school safety involves not only physical

4 security, which is what we do at The Department of

5 Homeland Security, but also mental and behavioral

6 health.

7 I look forward to continuing to work with all

8 of you, in the coming months, to determine ways that

9 DHS can support our mutual efforts.

10 I'd also like to thank those that are here

11 today, to provide their prospectives. I am very

12 interested in learning more about how we can better

13 integrate mental health into schools and to ensure that

14 while we are striving to provide our students with a

15 safe and secure place, we are also respecting their

16 privacy and civil rights, as the Attorney General

17 mentioned.

18 By sharing your knowledge and experiences with

19 the Commission, we will be better able to identify and

20 implement a plan in enhancing the safety and security

21 of our nation's schools.

22 As we discuss ways to better integrate

1 behavioral and mental health services, I just want to
2 highlight a few of the things we're doing at DHS.
3 In previous meetings, we've discussed
4 information sharing, alert and warning, capacity
5 building with state and local law enforcement, incident
6 response, emergency planning.
7 And we certainly continue to identify lessons
8 learned from school emergencies, which highlight the
9 importance of preparing school officials and first
10 responders to implement emergency operations plans.
11 Today, I want to mention that in collaboration
12 with our local government and community partners,
13 schools can take steps to plan for these potential
14 emergencies through the creation of an Emergency
15 Operations Plan.
16 By having plans in place to keep students and
17 staff safe, schools play a key role in taking
18 preventive and protective measures to stop the
19 emergency or to mitigate it, if one should occur,
20 incorporating FERPA and HIPPA, as Secretary Azar
21 mentioned, into this planning process, we'll talk a bit
22 about that today.

1 While in the process of developing or revising
2 these plans, schools must take steps to consider
3 student privacy and civil rights and other laws, as we
4 work towards their safety.
5 To assist schools in this process, we here at
6 the table, have issued a guide for developing high-
7 quality School Emergency Operations Plans.
8 I'd like to direct schools, administrators,
9 state and local officials, to our guide and to work
10 with us to better understand how we can incorporate
11 this information into school planning throughout the
12 school systems.
13 Included in this guide is a discussion on how
14 Emergency Operation Planning within schools should
15 consider these very important privacy aspects.
16 We recommend that planning teams, responsible
17 for developing and revising them, understand the laws,
18 as the Attorney General said, there is much discussion
19 to be had on how we can use the laws to ensure that we
20 are also protecting those most vulnerable among us.
21 I'd like to thank, again, Secretary Azar and
22 DeVos for organizing today's meeting. And I look

1 forward to hearing from the panelists. Thank you.

2 SECRETARY AZAR: Excellent. Thank you very

3 much, Secretary Nielsen.

4 As we get going, with our testimony, I would

5 just like to remind you that each our panelists that

6 we'll have through the three panels today, that your

7 full testimony will be in the record, as we try to

8 manage to our times. So, please do know that we'll

9 have your full remarks in the record.

10 So, first I'd like to welcome Dr. Sheryl

11 Kataoka. Did I pronounce that correctly?

12 DR. KATAOKA: Yes.

13 SECRETARY AZAR: Thank you. Doctor Kataoka is

14 Professor-in-Residence in the UCLA Division of Child

15 and Adolescent Psychiatry.

16 She will be speaking today about integrating

17 Behavioral Health Services into schools. And we look

18 forward to your comments.

19 Dr. Kataoka. Thank you.

20 DR. KATAOKA: Great. Thank you so much for

21 inviting me here today. I really appreciate it. And I

22 look forward to talking to you more about how we can

1 better improve access to mental health services for our
2 children.
3 As a child psychiatrist, not only do I see
4 patients in the University Hospital, but I also see
5 them in school-based health centers, a place where I
6 see many children and families who would not have
7 otherwise gotten mental health treatment, had it not
8 been available in their schools.
9 As you know, schools are often the center of a
10 community and for many families a familiar place that
11 they trust.
12 For almost 20 years I have been consulting to
13 the Los Angeles Unified School District, a district
14 that serves 600,000 students, K through 12.
15 Through my work in schools, I have - oh, sorry
16 - through my work in schools, I have come to appreciate
17 the importance of promoting the mental health and well-
18 being of students, through the school system, which can
19 decrease the stigma associated with mental health care
20 and decrease many of the barriers to care associated
21 with children getting services.
22 Child mental health problems not only result

1 in emotional distress, but can also lead to significant
2 educational problems.
3 Students with mental health problems are more
4 likely to have lower grades, higher rates of
5 absenteeism and also are at a greater risk for drop-out
6 from high school.
7 Mental health problems in childhood can also
8 lead to worse adult outcomes, such as higher rates of
9 unemployment and relationship problems.
10 Despite the fact that more than one in every
11 five youth in The United States has a mental health
12 disorder, less than half receive the treatment they
13 need.
14 Of those youth who receive care, they are more
15 likely to get that care in schools, more likely than in
16 specialty mental health care or primary care.
17 In fact, when my colleague, Dr. Lisa Jacox did
18 a randomized trial, looking at two effective
19 treatments, but one provided in schools, the other in
20 community mental health clinics, the results were
21 striking.
22 It turned out that in the school setting, over

1 90 percent of the students finished the treatment,
2 versus in the community mental health clinics, there
3 was only 23 percent even started care and 15 percent
4 completed treatment.
5 In other words, only nine of the sixty youth,
6 who were getting treatment in the community mental
7 health clinic completed treatment versus 53 of 58
8 completed treatment in schools.
9 Providing on-site mental health services in
10 schools can greatly increase access to mental health
11 care, especially in low-resource communities, where
12 multiple barriers to care exist.
13 I would like to now turn our attention to ways
14 in which mental health services can be integrated into
15 schools.
16 One school-wide approach to mental health is
17 the multi-tiered systems of support, otherwise known as
18 MTSS.
19 With this model there is an effort to align
20 schools' resources in order to promote students
21 academic, behavioral and emotional development across
22 three tiers of services.

1 So, if you picture a triangle, the bottom part
2 of the triangle is what we call Tier One, for Universal
3 Prevention Services.
4 So, one example of these universal approaches
5 is the PBIS, or Positive Behavioral Intervention and
6 Supports approach that you all have been introduced, by
7 your site visit at Randall Schools, in Maryland.
8 A second example is a Universal Prevention
9 Program called Life Skills Training, which is delivered
10 in middle schools and teaches self-management, social
11 skills, drug awareness, and also teaches students how
12 to resist using drugs.
13 This program has been shown to be effective in
14 decreasing alcohol and drug use, but also decreases
15 aggression as well as delinquency.
16 If we go back to our triangle, so the middle
17 part of the triangle is the Tier Two Services or
18 Services for At-Risk Youth.
19 So, in my district, in Los Angeles, they did a
20 survey of all the 6th Graders in our district. And
21 they found that 40 percent of students reported knife
22 or gun violence exposure in the last year.

1 So, they really - and we - when we looked at
2 our research, we found that more exposure to violence,
3 led to greater likelihood of school suspensions and was
4 also related to absenteeism in school.
5 In response to this pervasive problem, our
6 district has implemented a Tier Two Group Intervention,
7 called CBITS, the Cognitive Behavioral Intervention for
8 Trauma in Schools.
9 This program has been shown to decrease Post
10 Traumatic Stress as well as depressive symptoms and has
11 also improved school grades.
12 Now, let's consider the tip of our triangle,
13 or Tier Three. Treatments that are necessary, for
14 about the top one to five percent of students, that
15 really need individual diagnosis, treatment, family
16 therapy, even psychiatric care, treatment services can
17 be provided through a variety of school-based health
18 models.
19 For example, through school-based health
20 centers that integrate mental health treatment with
21 general health services and are often located right on
22 the school campus.

1 Another model is the Mental Health
2 Consultation Model, where clinicians can consult to
3 individual students or to teachers for their whole
4 classroom, or even to schools and districts.
5 Finally, there are University District
6 Partnerships, such as the one that we have between UCLA
7 and Los Angeles Unified.
8 These models also use a multi-disciplinary
9 team with clinicians, such as psychiatrists,
10 psychologists, clinical social workers and counselors.
11 Additionally, others have shown that tele-
12 medicine can be very effective in reaching especially
13 the most under-served areas, such as rural schools.
14 In summary, mental health problems are common
15 and can deeply affect school performance in a number of
16 key areas. Mental health is a critical ingredient for
17 overall child development and educational success and
18 is an essential component to the educational mission.
19 As The National Academy of Science has
20 documented in their report, entitled Preventing Mental,
21 Emotional and Behavioral Disorders Among Young People,
22 a number of evidence-based universal and indicated

1 prevention programs already exist, unfortunately few
2 schools deliver them.
3 In order for every child to have access to a
4 multi-tiered system of support in their school, ranging
5 from Universal Interventions for all students,
6 Indicated Prevention Programs for kids at risk, as well
7 as treatments for those few that need intensive
8 treatments, I recommend the Commission consider the
9 following three points:
10 Number One, we need to expand the mental
11 health workforce in schools. This can be accomplished
12 in a number of ways.
13 We can better link community behavioral health
14 agencies with neighboring school campus. We can
15 increase the number of onsite clinicians, especially in
16 low-resource communities, where unmet need is greatest.
17 We can create more school-based health
18 centers, like the one I work at, where students can
19 just walk straight from class to their appointment with
20 me. And then they can see the pediatrician next door
21 for their well-child check.
22 By expanding the Mental Health Workforce in

1 schools, clinical social workers, counselors,
2 psychologists and child psychiatrists can all intervene
3 in schools much earlier in the course of a mental
4 illness, instead of waiting for them to show up at our
5 offices, often too little, too late.
6 Number Two, we need to provide training and
7 technical assistance for school-based clinicians. So,
8 this expanded Mental Health Workforce will need to be
9 trained in the prevention and treatment interventions
10 that have been studied and found to be effective.
11 Registries of evidence-based prevention
12 programs, such as Blueprints for Healthy Youth
13 Development, can point schools to the types of
14 interventions proven to promote healthy development in
15 children and decrease their risk for mental illness.
16 Finally, Number Three, we need to ensure that
17 all stake-holders in the school environment are
18 equipped to understand and support the social emotional
19 development of children.
20 This includes not only educating our students,
21 their parents and families, our teachers and
22 principals, but also the bus drivers, cafeteria workers

1 and school resource officers.
2 School community has a critical role to play
3 in ensuring that our young people thrive and that we
4 all work toward preventing mental disorders and
5 suicides that are impacting our children.
6 Thank you for this opportunity to speak today
7 about ways to improve access to mental health services
8 in schools as one part of your larger plan to address
9 school safety.
10 SECRETARY AZAR: Wonderful. Thank you very
11 much, Dr. Kataoka. And thank you especially for the
12 evidence you presented, as well as the recommendations,
13 the concrete recommendations.
14 We'll now turn to hearing from our other
15 panelists on the topic of psychotropic medications for
16 children.
17 This is a very important topic. And we're
18 going to hear two viewpoints on this matter. Our first
19 speaker is Dr. Gabrielle Carlson, Professor of
20 Psychiatry and Pediatrics and Director of the Division
21 of Child and Adolescent Psychiatry at the State
22 University of New York. She is going to be speaking on

1 the importance of medication use for children.

2 Dr. Carlson, if I could turn to you.

3 DR. CARLSON: Good morning. Thank you for

4 inviting me to speak to you today about the importance

5 of psychiatric medication treatment for complex

6 behavioral health needs in children.

7 Knowing the high morbidity of children with

8 emotional disturbance, I developed a consultation

9 program between Stoney Brook's Division of Child and

10 Adolescent Psychiatry and the school districts in

11 Suffolk County, New York, in 1990.

12 We've seen over 3,000 cases since then. Some

13 of them are managed in the community and some in

14 regular education schools, some have needed psychiatric

15 hospitalizations, and some need combined schools and

16 mental health programs, like what you've just heard

17 about.

18 I'd like to introduce you to six students who

19 were referred to our program, for making violent

20 threats. And someone in school was so worried about

21 then, that they wanted a psychiatric evaluation. I've

22 eliminated the identifying information, for privacy

1 protection.
2 Adam was in Second Grade. He was being
3 bullied, so he kept a Boy scout knife in his pocket, to
4 protect himself. When he impulsively brandished it, he
5 was suspended and ultimately referred to us, to
6 ascertain if he was truly a danger.
7 Brian was a High School Junior. His life was
8 a series of mishaps and bad decisions, including
9 smoking marijuana in school.
10 His most recent infraction was a phone call
11 threatening to blow up the school. Parents thought he
12 was just expressing boyish hygienics.
13 Colin is 11 and has long, severe tantrums and
14 becomes physically aggressive when he doesn't get his
15 way, feels overwhelmed by a task, has to switch tasks
16 or things get too noisy and confusing.
17 Tantrums last for up to an hour. His
18 communication skills are poor. He takes everything
19 literally. And when he's enraged, there is no talking
20 to him. He is unmanageable in school.
21 Emily was in 9th Grade and has always been
22 shy. She had been frequently absent from school since

1 Kindergarten.

2 She learned early that if she got

3 uncomfortable in a situation and avoided it, she felt

4 better.

5 In (9th Grade she stopped going to school and

6 withdrew herself from everyone else), if her Mother

7 sent her to school.

8 Janelle was also in 9th Grade. She described

9 herself as mean and angry, hated everything fun and

10 just wanted to be left alone. She'd even been

11 suspended for fighting. Previously a good student.

12 Her grades had slipped, because she was unmotivated and

13 cut class.

14 Finally, Raphael was 17. He'd become

15 increasingly withdrawn and seemed paranoid. That is,

16 he misinterpreted events around him, personalizing

17 them, when there was no evidence that anyone or any

18 thing was against him.

19 He too had been a reasonable student in the

20 past, but appeared to lose the ability to be logical,

21 when he spoke or wrote. His notebook was found to have

22 weird drawings in it of dismembered bodies of people

1 and animals.
2 So, Adam and Brian have ADHD, Attention
3 Deficit Hyperactivity Disorder. (The symbol is)
4 "HIDE," which is what you want to do these kids
5 sometimes. The "H" is for Hyperactive, the "I" is for
6 Impulsive, the "D" is for Distractible and Disorganized
7 and the "E" is for Emotional. The worldwide prevalence
8 of ADHD is about five percent.
9 Adam was uncomplicated. He wouldn't sit or be
10 quiet in class. He did impulsive things, like carrying
11 a knife, which he knew he shouldn't have.
12 He was disorganized and lost his homework,
13 assuming he even did it, and had temper-tantrums when
14 he was upset.
15 He responded to ADHD medication. Up to 80
16 percent of children will. The teachers and parents
17 worked together on a Behavior Plan and he improved
18 considerably.
19 There is evidence that supports the long-term
20 effectiveness of ongoing medication for ADHD. So,
21 there is good reason to believe that he will remain
22 functional.

1 Now, Brian is an example of what happens with
2 untreated ADHD. ADHD symptoms (often can lead to)
3 dropouts, arrests, drug abuse and car accidents, are
4 common consequences. Thank you.
5 His parents didn't believe in prescription
6 medication, so their son self-medicated with marijuana.
7 He slid under the radar screen until secondary school.
8 Parents minimized the problems until the
9 school arranged for our consultation. It probably
10 isn't too late to treat him. Teens do respond to ADHD
11 medications.
12 However, the possibility of diversion,
13 difficulty monitoring effectiveness and even getting
14 the teen to take medication, because of stigma, make
15 treatment much more complicated.
16 In fact, up to 40 percent of youth with ADHD
17 don't get treated at all. And the 60 percent who may
18 get medication don't necessarily have their treatment
19 optimized.
20 Brian may well end up in jail. The prevalence
21 of mental illness in the juvenile justice system, are
22 as high as 70 percent.

1 Colin is an example of diagnostic complexity.
2 It would be easy to mistake his problems for ADHD or
3 brattiness. In fact, he has Autism.
4 This is a disorder that probably starts in
5 childhood, and at birth and impacts social interaction,
6 language problems, the ability to switch gears quickly
7 or to tolerate excessive sensory input.
8 When those symptoms are overwhelming, the
9 child does what non-verbal animals do under stress.
10 They shut down, run away or become aggressive.
11 Like all medical conditions, autism comes in
12 mild, moderate and severe. Up to 2.4 percent of people
13 may have it, but some are much more impaired than
14 others.
15 (Sometimes medication may regulate the
16 emotion) - may regulate the emotional overload. The
17 medications that have been studied for this are drugs
18 that have been used to treat other serious disorders
19 and are called anti-psychotics, even though these
20 children are not psychotic.
21 Children who previously might have been
22 institutionalized can be maintained in the community,

1 sometimes even in regular education classrooms.
2 Colin needed to be hospitalized, where the
3 correct diagnosis was established, treatment was
4 initiated, and he was referred to a school program for
5 behaviorally dysregulated children with Autism.
6 The educational, psychological and psychiatric
7 supports would help his outburst behavior. But the
8 waiting list to get into this program was very long.
9 Emily and Janelle looked like they had
10 behavioral problems, but are suffering from anxiety and
11 depressive disorders.
12 Emily had been shy as a child. And the more
13 avoidant she became, the more avoidant she got. She
14 developed Social Anxiety Disorder, an extreme fear of
15 (inaudible - no sound) - only 30 percent of Social
16 Anxiety Disorder is treated in spite of the fact that
17 there have been robust (inaudible - no sound) 80
18 percent of the (inaudible - no sound) medication, but
19 these figures are often not available.
20 (Inaudible - no sound) that change is one of
21 the (inaudible - no sound) 60 percent of depression is
22 ever treated. That's a shame, because there are

1 treatments for depression.
2 It doesn't respond quite as quickly as
3 anxiety. Seventy percent of children responded to
4 combined behavioral and medication treatment in three
5 months and by six months 80 percent had responded.
6 Although we worried about whether these
7 medications caused suicide, more evidence is on the
8 side of their preventing suicide, with benefits clearly
9 outweighing risks.
10 It is extremely concerning that there has been
11 a common rise of both depression and suicide rates in
12 young people.
13 Raphael has the least common condition of
14 those I have discussed, because it's difficult to make
15 the diagnosis accurately.
16 He appears to be developing a psychosis, a
17 loss of ability to distinguish what is real from what
18 is his own thinking. It effects logic, concentration
19 and motivation.
20 Although up to 63 percent of patients can
21 reach a symptomatic remission with medication and other
22 treatments, the treatments are multi-factorial,

1 requires considerable skill. And so, Raphael needed a
2 psychiatric program embedded in the schools.
3 They've become increasingly necessary with the
4 decrease of hospital beds and the lengths of stay in
5 those hospitals.
6 These cases are intended to demonstrate three
7 points, mental illness is significant and impairing.
8 It's treatable, but requires accurate diagnosis and
9 attention to individual circumstances.
10 The child, the school and his family, we often
11 know what to do, but it's the lack of resources that
12 keep us from doing it.
13 It often works best with combined psycho-
14 social treatments and a good school program. And it's
15 a tragedy that misinformation and stigma and lack of
16 access keep people from effective treatments.
17 These children are not likely to be
18 contributing majorly to violence in schools, but they
19 require a lot of care.
20 And I want to thank this Commission for the
21 attention and examination of our situation of schools,
22 of children in those schools and allowing our children

1 the best opportunity for growing up and becoming great
2 adults. Thank you.
3 SECRETARY AZAR: Great. Thank you, Dr.
4 Carlson. And thank you for bringing a human face to
5 the issue of the challenges we're facing as well as to
6 the question of psychotropic medications for children
7 with serious mental disorders.
8 Our second speaker is Dr. Mark Olfson,
9 Professor of Psychiatry and Epidemiology, Mental Health
10 Services Researcher and Research Psychiatrist at
11 Columbia University and the New York State Psychiatric
12 Institute.
13 He is going to be speaking on the importance
14 of using caution when medicating children. Thank you
15 very much.
16 DR. OLFSON: Well, thank you. I am pleased to
17 have an opportunity to discuss improving the use of
18 psychotropic medication in children and adolescents in
19 The United States.
20 As someone who studies patterns and trends, in
21 psychotropic medications, I'm often asked whether young
22 people in The U.S., are undertreated or overtreated

1 with these drugs, to which I always answer, "Both,"
2 which generally provokes mild consternation. So, let
3 me explain.
4 First, I'd like to make a few points about
5 under-treatment. There is compelling evidence that
6 U.S. children and adolescents are under-treated with
7 psychotropic medications.
8 And adolescent depression provides a case in
9 point. As you've heard, depression is highly
10 distressing, puts young people at increased risk not
11 only for suicide, but also and much more commonly, it
12 increases their risk of educational failure, obesity,
13 smoking and other drug problems.
14 In recent years we have seen an increase in
15 depression among adolescents that's coincided with
16 rising national rates of youth suicide.
17 In any given year, around one in nine
18 adolescents has a major depressive episode. But only
19 around 40 percent of them receive any treatment and
20 only half of them, or 20 percent of the total, receive
21 an antidepressant, even though we know that
22 antidepressants are effective for adolescents with

1 moderate or severe depression.

2 And, as Dr. Carlson has mentioned, there are

3 even larger gaps in the treatment of anxiety and

4 substance use problems.

5 Now, there are many factors that contribute to

6 under-recognition and undertreatment of mental health

7 problems in young people. And this morning I'd like to

8 focus on just two of them.

9 First, on difficulties in recognizing a need

10 for mental healthcare and in seeking it out. And,

11 second, on critical shortages in the availability of

12 mental health professionals who treat young people.

13 Children generally don't have sophisticated

14 language for describing their feelings. And one way to

15 group the features of child mental illness is to

16 distinguish externalizing from internalizing features.

17 Examples of externalizing features, including

18 things like fighting and truancy, these behaviors

19 readily attract the attention of parents and teachers

20 and sometimes law enforcement.

21 Internalizing problems, on the other hand,

22 such as social withdrawal, loss of interest in

1 activities and difficulty concentrating, these are much
2 harder to detect and are commonly described by parents
3 and teachers to the young person simply going through a
4 phase.
5 However, even when these more difficult to
6 detect problems are recognized, the young person often
7 does not receive effective mental health treatment.
8 When a child or adolescent first begins to
9 experience mental health symptoms, there are many
10 potential barriers that can occur as he or she moves
11 towards receiving care. And these barriers delay the
12 delivery of treatment and they result in needless
13 suffering.
14 So, let's think about all the steps that need
15 to occur to get a child into special mental health
16 treatment.
17 First, parents or other concerned adults will
18 attempt to evaluate the significance and the likely
19 consequences of the problem.
20 And, second, they'll seek to determine whether
21 the problem requires treatment. Third, they'll assess
22 the benefits and costs of various treatment options.

1 And, finally, they'll search for an
2 appropriate, accessible and affordable healthcare
3 professional.
4 When viewed from this prospective, it's not at
5 all surprising that most children and adolescents, even
6 most with severe mental health impairment don't receive
7 treatment.
8 Beyond these barriers, there are also critical
9 shortages in healthcare professionals who are trained
10 to treat child and adolescent mental health problems.
11 National shortages are exacerbated by
12 geographic mail distribution. Mental health
13 professionals tend to aggregate in urban rather than
14 rural areas and in affluent rather than poor
15 communities.
16 On a per capita basis, there are roughly three
17 to five times as many psychiatrists and psychologists
18 in states that are primarily urban than in rural
19 states.
20 And as a result, rural families, who are
21 seeking mental healthcare for their children face
22 particularly difficult challenges, often involve long

1 travel distances and long wait lists that leave many of
2 their children's problems either untreated or
3 reluctantly treated by nurse practitioners or
4 pediatricians.
5 Even in urban areas, qualified child and
6 adolescent mental health professionals are often
7 unavailable for low income and middle-income families.
8 Now, let's think about overtreatment.
9 Alongside the widespread undertreatment and under-use
10 of effective psychotropic medications I have described,
11 we have also seen a recent increase in psychotropic
12 medications prescribed to children and adolescents.
13 Over a recent 15-year period, there was a six-
14 fold increase in child and adolescents treated with
15 anti-psychotic medications and a near doubling of those
16 treated with antidepressants or stimulants.
17 Although rising numbers of medicated treated
18 children and adolescents does not necessarily mean that
19 young people are being overtreated.
20 There are concerns that many young people are
21 being unnecessarily treated with these medications
22 because approximately two-thirds of the increase, the

1 overall increase in psychotropic medication use in
2 youth has occurred among those with less severe or no
3 impairment.
4 These concerns have focused most intensively
5 on anti-psychotic medications, particularly their use
6 in very young children and children in the foster care
7 system.
8 In addition to uncertainty over the long-term
9 effects on the developing brain, side effects of anti-
10 psychotic medications include weight gain, high
11 cholesterol levels and increased risk of diabetes.
12 As compared to a young person who is not
13 treated with an anti-psychotic medication, one who is
14 treated has more than a three-fold increased risk of
15 developing diabetes because of these side effects.
16 Simply put, these medications should be
17 prescribed only when the potential benefits clearly
18 outweigh the changes of bad or adverse effects.
19 Now these concerns over drug safety are
20 compounded by evidence that the medications are
21 sometimes prescribed in a less than judicious manner.
22 According to the FDA, anti-psychotic

1 medications are only indicated in young people for
2 schizophrenia, bipolar disorder, irritability
3 associated with Autism, as we've heard, and Tourette’s
4 Disorder, yet, most young people who are prescribed
5 anti-psychotic medications aren't diagnosed with any of
6 these conditions.
7 In one study of children, the top diagnosis
8 for anti-psychotic prescribing was Unspecified Mood
9 Disorder.
10 In another study most of the young people
11 starting anti-psychotic medications had not received
12 any counseling or psychotherapy services in the
13 preceding three months.
14 These patterns suggest that some healthcare
15 professionals jump to anti-psychotic medications before
16 trying safer alternatives.
17 So, to summarize, while many young people in
18 our country, with serious mental health problems who
19 would benefit from psychotropic medications do not
20 receive them, others are prescribed these medications
21 that they may not need.
22 Now, unfortunately, there are no simple

1 solutions to this complicated miss-match. But, to help
2 address the problem, I have three recommendations.
3 First, increase screening for mental health
4 conditions in public schools. Because youth often do
5 not spontaneously disclose emotional distress and
6 parents are often unaware of their child's mental
7 health problems, voluntary mental health screening,
8 either in public schools or primary care offices,
9 offers a feasible means for identifying and connection
10 high-risk young people to school and community mental
11 health services.
12 I urge the Commission to recommend extending
13 the availability of voluntary mental health screening
14 for young people.
15 Second, expand opportunities to support
16 professionals to work in public schools in under-served
17 areas.
18 To help address critical regional shortages of
19 child and adolescent mental health professionals, I
20 urge that the Commission recommend broadening the
21 eligibility for The National Health Service Course
22 Training Sites.

1 This is a Federal Loan Payment Program that
2 offers financial incentives to attract healthcare
3 professionals to practice in under-served areas.
4 And over the last several years, this program
5 has included several mental health professionals. But
6 increasing the range of facilities that are eligible to
7 become these NHSC sites and placing greater emphasis on
8 recruiting Child and Adolescent Mental Health
9 Professionals to them, will help to alleviate shortages
10 of these professionals in some areas.
11 Third, and finally, strengthen the standards
12 and quality metrics so that more children have access
13 to high-quality treatment that matches their needs.
14 Because of the uneven quality, of psychotropic
15 medication, there is a need to coordinate Federal,
16 State and Local approaches to measuring the quality of
17 mental healthcare for children and adolescents,
18 including the use of psychotropic medications.
19 Private insurance plans, Medicaid Programs and
20 Child Welfare Agencies all need to attend to these
21 quality of care concerns.
22 The recent development of psychotropic

1 medication quality measures for children, by The
2 National Committee on Quality Assurance, provides a
3 foundation, a strong foundation for a concerted effort
4 to improve the quality of care in this area.
5 So, in closing, I urge the Commission to
6 recommend broad adoption of evidence-supported quality
7 measures of psychotropic medication for use in children
8 and adolescents, and I think you.
9 SECRETARY AZAR: Excellent. Thank you, Dr.
10 Olfson. Very important cautions as well as important
11 recommendations for the Commission to consider, so,
12 thank you.
13 At this point we've got about nine minutes for
14 questions. Let me turn it over to Secretary DeVos, if
15 you've got a question to kick us off?
16 SECRETARY DEVOS: Thank you, Secretary Azar.
17 And thank you to the panelists. I really very much
18 appreciate what you had to say this morning.
19 I have a question for either Dr. Olfson or Dr.
20 Carlson, or maybe both of you. And you referenced it,
21 Dr. Olson.
22 But, what do we know about how the use of

1 medication alters the brains of adolescent or young
2 children? And is it a positive or a negative
3 alteration?
4 DR. OLFSON: Well, I'll defer to Dr. Carlson,
5 but just make a brief comment. My - my short response
6 is that we don't know enough.
7 We've got some evidence, from animal-modeled
8 studies. But we really haven't had the sort of long-
9 term perspective carefully conducted studies in
10 children as they become adolescents and young adults.
11 And I think it's a critical area for research,
12 to better understand that issue.
13 DR. CARLSON: And I also think we don't have
14 enough information about how the brain changes with the
15 illnesses that we're treating.
16 So that, what you'd really need to be able to
17 do, in order to do that, is a lot of research, in a
18 randomized trial and a longitudinal trial, to be able
19 to say what this group of people on medication, what
20 happens to them over time and which - you know, here's
21 this population, unmedicated over here, what happens to
22 them over time?

1 And we have to say, "You can't get treated,"
2 or "You must stay treated." And I can't imagine how we
3 would be able to do that.
4 So that we end up, I think, with the clinical
5 dilemma of treating the impairment or trying to figure
6 out what do with the impairment of the serious problems
7 that the children have and then the best way of doing
8 it, to minimize any of the costs of treatment and not
9 just financial costs. I think you know what I mean.
10 SECRETARY AZAR: Excellent. Thank you.
11 Secretary Nielsen, do you have a question for
12 one of our panelists?
13 SECRETARY NIELSEN: Sure. For Dr. Kataoka -
14 hopefully I said that correctly - so, I greatly
15 appreciate your listing of gaps in areas where we can
16 improve as a community.
17 I wondered if any of your research, if you
18 found any of those same recommendations applied to
19 schools that have been attacked?
20 So, have you seen any studies or have you
21 yourself been able to review the mental health programs
22 that they offered, prior to the attack?

1 DR. KATAOKA: Yeah, certainly. So, our group
2 from California has consulted with Newtown and other
3 school districts across the country that have had
4 similar attacks.
5 And what they have set up is that multi-tiered
6 systems of support. So, they have really recognized
7 that starting early and doing early prevention is
8 important.
9 But also, being mindful of understanding and
10 identifying students that have post-traumatic stress as
11 a result of those attacks. And then providing them
12 evidence-based treatments like the CBITS Program that I
13 mentioned.
14 We have programs for Elementary School
15 students, like Bounce-Back, to help even teach those
16 little ones' skills to cope with post-traumatic stress
17 and depressive symptoms that result from attacks like
18 what we've seen in our nations' schools.
19 So, there's a number, an array of programs.
20 And what they're really focusing on is kind of early
21 prevention and actually universal prevention as well.
22 SECRETARY AZAR: Attorney General Sessions, do

1 you have a question you would like to address to the
2 panel?
3 ATTORNEY GENERAL SESSIONS: Two things. One,
4 is there any evidence or do you have any opinions about
5 why we're seeing more depression and suicide?
6 And, secondly, do you find as a practical
7 matter a lack of ability in the schools, as a result of
8 fear of rules and regulations, to confront a child's
9 difficulties and get to the heart of it in an effective
10 way?
11 DR. KATAOKA: Well, I think that's a multi-
12 component question. But we are - you know, we are
13 seeing a rise in suicide and depression, as you know.
14 And there could be a lot of factors, from
15 societal pressures to changes in our healthcare system,
16 that actually have limited mental health services and
17 access to care.
18 And so, you know, what we really need to do is
19 to be able to detect those kids early, like Dr. Olfson
20 was presenting, in terms of screening and identifying
21 students early, providing them with an even
22 understanding of mental illness.

1 So, there's programs like The Mental Health
2 First Aid Program that educates students and teachers
3 about even what mental illness is.
4 The more we can erase the stigma of mental
5 illness, similar to what we have done with cancer. So,
6 if you look back like two decades ago, Cancer was a bad
7 word.
8 You know, people walked around with these
9 burdens of having a Cancer diagnosis, you know, "Don't
10 tell Grandma."
11 And now we're very open. We're screening for
12 Breast Cancer, we're catching it early. We have a lot
13 of things that we can do. Similar with mental illness,
14 we need to really educate our public about mental
15 illness broadly.
16 So, in schools, places of worship, everywhere,
17 we need to really get the word out, do a public health
18 campaign, to really help people understand that it's
19 not a death sentence, it's not something to be afraid
20 of and that there's a lot of things that we can do
21 about it.
22 DR. CARLSON: If I could answer your question,

1 it's not like to say I wouldn't be sitting here, I
2 would be, you know, famous and doing things in a broad
3 scale.
4 It is a multi-determined question. And I've
5 been interested in the question of suicide and the fact
6 that there are barriers to getting treatment.
7 But there are also things that are
8 exacerbating it. It has nothing to do with schools,
9 per se. But your bullying - uh, the focus you had on
10 bullying, I think is an important one.
11 I think the increase in bullying, or the
12 increase of cyber bullying, the availability of
13 information for young people, that used to protect
14 people from committing suicide, they didn't know how to
15 do it. Now they know how to do it. And so, I think
16 that there are some things like that, that have
17 changed.
18 I also think that there have been limitations
19 in the kinds of treatment that we need to be able to
20 give kids.
21 So, this is - every simple - what is it, every
22 complex problem has a simple solution that's wrong? I

1 don't think we have a good answer to the question.

2 DR. OLFSON: Well, I would agree with my

3 colleagues, who have pointed to some factors.

4 I think it's important to recognize that the

5 increase in suicide that's occurred has not been

6 confined to young people. Although it's apparent in

7 young people, it's been observed in all ages except

8 among the elderly.

9 And that doesn't mean that all of - that the

10 same factors are driving the increases, across the age

11 spectrum.

12 You know, we've certainly seen among young

13 adults, a rise in the opioid epidemic and the risks

14 posed there. And they may be entwined with increases

15 in suicide, as opioid poses - opioid addiction, Opioid

16 Use Disorder, poses increased risk there.

17 In younger people, our focus this morning, you

18 know, there is some strong evidence, but there's sort

19 of a clinical presumption that - that electronic means

20 of communication opens children up to this cyber

21 bullying, which can be more intense and reach a longer

22 - a broader range of people, in a more enduring way

1 than an insult on the playground did in the old days.
2 And also, and I know it's not a function of
3 this Commission, we need to look at access to means.
4 And guns are - have now become available broadly to
5 wide segments of the population and nearly half of all
6 suicides are related to guns and about a third in young
7 people, so that's a part of this as well.
8 SECRETARY AZAR: Thank you. I think we have
9 time for one last question that Secretary Nielsen
10 wanted to raise.
11 SECRETARY NIELSEN: Sure. Yeah. So, as we
12 look at the emergency planning, that I mentioned
13 earlier, we have some school systems have suggested
14 back to us that they would like to have something
15 they've been calling Threat Assessment Teams.
16 So, that as parents or teachers raise
17 concerns, they have a full panoply of experts who can
18 help them look at the situation.
19 As part of that analysis, I'm curious as to
20 your recommendations as to how much that team should
21 consider or not consider whether the child is actively
22 taking drugs?

1 Because, as I think we've discussed, it could
2 cut both ways. So, I'm interested in any initial
3 thoughts. But it's an area we'd love to work with you,
4 to just help advise these Threat Assessment Teams, you
5 know, what information is appropriate and useful to
6 consider as they assess whether a given child could be
7 a violent threat?
8 DR. KATAOKA: Mm-hm. Well, I think on any
9 team like that, it would be so important to have a
10 mental health professional, whether it's a clinical
11 social worker or a psychiatrist to really help in the
12 assessment.
13 As Dr. Carlson's patients illustrate, students
14 who we may be afraid of - or, you know, we think need a
15 threat assessment, may actually have a mental health
16 disorder. And so really having someone that can
17 evaluate the student on that threat assessment is - is
18 critical.
19 In terms of drugs, certainly drugs of sub -
20 you know, substance abuse, are important to rule out as
21 well. But the medications that we provide have not
22 been related to violent threats.

1 And, in fact, when students are not treated
2 with medications appropriately, they are more likely to
3 be aggressive and assaultive, due to their mental
4 illness.
5 SECRETARY NIELSEN: Yeah. So, if I can just
6 say quickly, so it sounds like the key there is the
7 gap? In other words, the threat would be if the child
8 stops taking the medication that's helping them, right?
9 And what are the warning signs of them, perhaps,
10 choosing to stop taking it?
11 DR. KATAOKA: Right, or not treated at all -
12 SECRETARY NIELSEN: Or not treated at all.
13 DR. KATAOKA: - as Dr. Olfson was pointing
14 out.
15 DR. CARLSON: We're actually in the process,
16 at Stony Brook, of looking at all the children that
17 have made threats, that have been referred to us for
18 the past 30 years. So, maybe we can send you a report
19 on what we have found, in terms of those kinds of
20 things.
21 Honestly, we've had as much damage done to
22 children like little Adam, who was a 2nd Grader, with

1 Boy scout knife who has been suspended from school for
2 six months for doing something dumb, okay, but
3 certainly not harmful.
4 And so, in terms of the threat assessments, we
5 need to understand who we're harming by being draconian
6 in our response and who we really need to pick up on.
7 And I think the biggest concern that we have
8 is even if you had a way of saying, yes, this child is
9 a serious risk, then what do you do? How long do you
10 follow that person?
11 How - you know, do you force him into
12 treatment? Who monitors that? There are a lot of
13 ethical questions there, that I don't think we've come
14 to grips with.
15 SECRETARY NIELSEN: Thank you.
16 SECRETARY AZAR: Great. And thank you very
17 much to the expert panelists. We really appreciate
18 your testimony and your answers to our questions.
19 And we are scheduled for a break now. We're
20 running slightly behind schedule, only because we got
21 started late.
22 So, if we could reconvene at approximately

1 10:05, please, and we'll resume with our third panel
2 for the day.
3 Thank you very much. Thank you.
4 (Whereupon a recess was taken from 9:58 a.m.,
5 to 10:06 a.m.)
6 SECRETARY AZAR: All right. Well,
7 welcome back, everybody. Thank you for returning for
8 our third panel.
9 We have changed the microphone situation.
10 I would just remind our panelists and our
11 commissioners, that with the new microphones they are
12 on at all times. There is no button to push. So,
13 please be mindful of that.
14 Our third and final panel is on
15 addressing confidentiality issues related to HIPPA and
16 FERPA.
17 Our first two speakers are going to share
18 information about HIPPA and our final two speakers will
19 address FERPA.
20 Our first HIPPA speaker is Ms. Jennifer
21 Mathis, Director of Policy and Legal Advocacy at the
22 Bazelon Law Center for - The Bazelon Center for Mental

1 Health Law.

2 Ms. Mathis will be talking with us about

3 the importance of HIPPA's privacy protections. Thank

4 you. Ms. Mathis.

5 MS. MATHIS: Thank you for the opportunity to

6 speak to the Commission today, concerning the privacy

7 rights of students with mental health disabilities.

8 The privacy protections of HIPPA, or the

9 Health Information Portability and Accountability Act,

10 are extraordinarily important for individuals with

11 mental health disabilities, including students, to have

12 effective access to services.

13 Without the assurance of privacy protections,

14 students are both less likely to seek out help when

15 they need it and less likely to engage openly with

16 mental health counselors or other service providers.

17 Ensuring that services are available for

18 students with mental health disabilities should be one

19 of our highest priorities.

20 Among adolescents and young adults, the

21 prevalence of major depressive episodes has increased

22 in recent years, as other speakers have noted.

1 Similarly, the prevalence of suicidal thoughts and
2 suicide attempts has increased among young adults.
3 So, it's important to point out that having a
4 mental health disability does not make a student any
5 more likely to engage in violence towards others. But,
6 implementing measures to create a positive school
7 climate, including through strategies such as Positive
8 Behavioral Interventions and Supports improves academic
9 and behavioral outcomes for all students, including
10 students with disabilities.
11 In colleges and universities, it is critical
12 to implement measures to support students with mental
13 health disabilities, particularly in times of crisis,
14 rather than stigmatizing and penalizing them.
15 For example, encouraging students to seek help
16 or treatment that they may need, making reasonable
17 accommodations to enable students to continue their
18 education as normally as possible, and ensuring the
19 confidentiality of mental health information are all
20 important strategies.
21 Our schools must have the capacity to offer
22 students with mental health disabilities the services

1 they need to succeed, both at the elementary and
2 secondary school level, as well as for college and
3 university students.
4 A number of Federal Laws do afford these
5 students' rights, including, for example, the right to
6 reasonable modifications, to rules and policies to
7 ensure equal opportunity, guaranteed by the ADA, the
8 Americans with Disabilities Act, and Section 504 of the
9 Rehabilitation Act.
10 And for elementary and secondary public-school
11 students, the IDEA, Individuals with Disabilities
12 Education Act, also guarantees a free and appropriate
13 public education, including an educational program that
14 is appropriately ambitious and reasonably calculated to
15 enable a child to make progress, appropriate, in light
16 of the child's circumstances.
17 Despite these protections, many students
18 continue to face challenges in getting the help they
19 need. In too many situations, students with mental
20 health disabilities are made to feel unwelcome and
21 seeking help may result in negative consequences.
22 In one example, the Bazelon Center represented

1 a college student who voluntarily admitted himself to a
2 campus hospital, after his close friend committed
3 suicide, because the student had begun to think
4 generally about suicide himself.
5 The hospital shared his health information
6 with University Administrators. And the next day,
7 while still in the hospital, the student was handed a
8 letter from the university, charging him with violation
9 of the disciplinary code, allegedly for endangering
10 himself.
11 He was promptly suspended from school, barred
12 from entering the campus, including to see his
13 psychiatrist, threatened with arrest if he returned to
14 his dorm.
15 The student had to sit in the car, with a
16 university official, while his father and friends
17 removed his belongings from his dorm room.
18 Students learn from these experiences and are
19 far less likely to seek help or disclose important
20 information in the future.
21 In light of the negative consequences, that
22 may flow from disclosure of protected health

1 information shared in confidence with a treatment
2 provider, it is critical that students be afforded
3 basic privacy protections if we expect them to seek
4 help.
5 As the Department of Health and Human Services
6 observed last year, ensuring strong privacy protections
7 is critical to maintaining individuals' trust in their
8 healthcare providers and willingness to obtain needed
9 healthcare services.
10 And these protections are especially important
11 where very sensitive information is concerned, such as
12 mental health information.
13 It is precisely for these reasons that HIPPA
14 imposes restrictions on when healthcare providers can
15 disclose information related to healthcare services
16 that a person receives.
17 At the same time, HIPPA's Privacy Rule is
18 carefully balanced to allow disclosure of information
19 where it's necessary to ensure that an individual
20 receives the best treatment and for other purposes,
21 such as for the health and safety of the individual or
22 for others.

1 While some people have blamed HIPPA for
2 prohibiting disclosure of health information to family
3 members, in situations where their involvement would
4 make an important difference, that blame is misplaced.
5 The problems described typically result from
6 the misapplication and misunderstanding of HIPPA.
7 Exceptions to HIPPA's Privacy Protections, allow
8 disclosures to family members in a wide array of
9 circumstances.
10 For example, HIPPA allows disclosure in
11 situations where an individual does not object to the
12 disclosure of information to a family member or a
13 personal representative, including where the health
14 provider reasonably infers, based on the circumstances,
15 that the person does not object.
16 HIPPA allows disclosure where a health
17 provider believes in good faith that disclosure is
18 necessary to prevent or lessen a serious threat to the
19 health or safety of the person or others.
20 HHS has provided examples of when that may
21 occur, including when a doctor knows, from past
22 experience, that a person is at high-risk of committing

1 suicide when the person is not taking medication at a
2 certain level.
3 In that instance the doctor may tell the
4 person's family that the person has stopped taking
5 medication if the doctor believes the family member is
6 reasonably able to prevent or lessen the threat of
7 harm.
8 HIPPA also allows disclosure in emergency
9 circumstances, where the individual lacks the capacity
10 to consent or object and the provider believes that
11 disclosure is in the person's best interest.
12 HHS provides, there, the example of a person
13 who cannot meaningfully agree or object to sharing
14 information, due to temporary psychosis or the
15 influence of drugs or alcohol.
16 And there are other exceptions as well,
17 including exceptions for care coordination purposes,
18 sharing with other healthcare providers and others.
19 These exceptions to HIPPA's Privacy
20 Protections, allow disclosure of protected mental
21 health information where it is necessary, including to
22 overt a danger, to deal with an emergency or to protect

1 the interest of a person who is incapacitated.
2 Given the focus of this Commission, it's also
3 important to understand that HIPPA's application to
4 children and adolescents in schools is limited,
5 particularly with respect to elementary and secondary
6 school students, moreover for all students who are
7 under the age of majority, which in most states is 18,
8 HIPPA has been interpreted as generally allowing
9 disclosures of their health information to their
10 parents.
11 For elementary and secondary schools, as well
12 as for colleges and universities, FERPA, the Family
13 Educational Rights and Privacy Act, may have much more
14 relevance than HIPPA.
15 In addition, in both school and other
16 contexts, there are State Laws protecting the
17 confidentiality of health and mental health treatment
18 information.
19 Like Federal Law, they recognize the
20 importance of affording privacy, to encourage
21 treatment, and include common sense exceptions, as a
22 balance.

1 Congress recently considered whether HIPPA
2 interfered with effective treatment for people with
3 serious mental illnesses.
4 After extensive deliberation, Congress
5 ultimately concluded in the 21st Century Cures Act,
6 that there is confusion in the healthcare community
7 regarding permissible practices under HIPPA, and that
8 this confusion may hinder appropriate communication of
9 healthcare information or treatment preferences with
10 appropriate care givers.
11 To promote clarity, Congress directed HHS to
12 create adequate, accessible and easily comprehensible
13 resources, relating to appropriate uses and disclosures
14 of protected information, under HIPPA, and to issue
15 guidance clarifying permissible disclosures, and
16 addressing a set of specific situations involving
17 families of people with serious mental illnesses.
18 In December of 2017, HHS issued this guidance,
19 along with a new set of frequently asked questions and
20 other materials, specifically addressing HIPPA's
21 application to mental health treatment information.
22 These resources from HHS would go a long way

1 to clarifying, for providers as well as for individuals
2 and their families and schools, what HIPPA actually
3 does and does not permit.
4 They are available online, but they have not
5 received much attention or promotion. Much more could
6 be done to ensure that these resources are widely
7 distributed and are used in connections with trainings
8 and other education.
9 We would all benefit from measures to ensure
10 that people understand their rights and providers
11 understand their obligations, so that HIPPA can be
12 implemented in a way that both protects safety and the
13 important privacy interests that are pivotal to good
14 and effective mental health care. Thank you.
15 SECRETARY AZAR: Great. Thank you very much,
16 Ms. Mathis. The Commission clearly is going to have to
17 consider the interplay of your testimony with the
18 recommendations of Dr. Kataoka, around school-based
19 mental health services and how that - the unique
20 circumstances that are permitted there.
21 Our second HIPPA speaker is Ms. Doris Fuller.
22 Ms. Fuller is a Mental Illness Researcher, Advocate and

1 Family Member, who is going to share her experiences
2 regarding confidentiality in the mental health context.
3 Thank you. Ms. Fuller.
4 MS. FULLER: Thank you, members of the
5 Commission. It is a privilege to be here today, as a
6 mental health advocate and family member who has
7 observed HIPPA's role in mental healthcare delivery, in
8 a number of settings, including on campuses.
9 A few years ago, I was asked to talk about
10 mental illness and violence to the leading organization
11 for student affair officers on colleges and
12 universities.
13 Mental illness nearly always emerges by the
14 age of 24, in late adolescents or young adulthood. So,
15 these school officers are working on the frontlines of
16 mental health.
17 In fact, because of the age that serious
18 psychiatric disease typically starts, it is likely that
19 no single other institutional setting in America serves
20 so many individuals with mental health conditions as
21 our high schools and colleges.
22 During my talk, I extolled the phenomenal

1 communication support and encouragement my daughter
2 Natalie and I received from State University Officials
3 and healthcare providers when she had her first
4 psychotic break, as a College Senior.
5 Her symptoms led to a number of extreme
6 behaviors, including painting her naked body blue and
7 pressing her body print on the walls of the campus Art
8 Building.
9 She was not a typical or easy student to
10 serve. Yet, in significant part, because of the
11 university and its health centers, active collaboration
12 with me, in getting Natalie safely through these
13 episodes, she ultimately returned to campus and
14 graduated, unlike the unfortunate story that you told.
15 At the end of my talk to the group, I asked if
16 anyone from the university was in the room. Two hands
17 rose, timidly, in the back. And I said, "Thank you.
18 My daughter would not have succeeded without you."
19 After I finished, they came upfront to talk to
20 me. By this time, I was working at The Treatment
21 Advocacy Center, and regularly hearing from families in
22 crisis because of mental illness in their young adult

1 children.

2 I had learned that few students and families

3 experienced the open collaborative approach that

4 Natalie and I did. "Why was that," I asked the

5 officers, "How could you talk to me and work with me as

6 a family member when other schools around the country

7 won't even return parents' calls?"

8 They told me it was a matter of Institutional

9 Policy and Practice. The University was guided by the

10 conviction that it had the authority under HIPPA, FERPA

11 and applicable State Laws, to act in the best interest

12 of its students, even if their actions required

13 disclosing personal health information or other

14 confidential matters to families. It was their belief

15 that acting in the best interest of their students was

16 their business.

17 I heard a similar description of privacy

18 considerations when I attended a 2013 Hearing of the

19 House Subcommittee on Oversight and Investigation.

20 The committee was taking testimony into

21 whether HIPPA helps or hinders patient care and public

22 safety.

1 In his written and oral testimony, the
2 Director of the Office of Civil Rights for HHS,
3 emphasized that the HIPPA Privacy Rule allows
4 communications between healthcare providers and
5 patients family and friends.
6 Even so, he acknowledged, historically,
7 providers have been reluctant to share information with
8 patients' family - friends and family members.
9 Family members would tell you provider
10 reluctance is a gross understatement. Stonewalling
11 comes closer to what many experience.
12 I, myself, have stood in the emergency room of
13 a hospital, not 15 minutes from this room, with my
14 daughter bleeding and hallucinating on a gurney beside
15 me and been told that Federal Law prohibited hospital
16 personnel from informing or involving me in her care.
17 This was false.
18 As my colleague has already described, HIPPA
19 is, itself, flexible and accommodating. And the
20 Federal Government has made a significant effort to get
21 that message across to medical providers.
22 Since that 2013 House Subcommittee Hearing,

1 multiple Government Offices have issued unambiguous
2 guidance that should by now have ended the
3 stonewalling.
4 HHS distributes extremely user-friendly Fact
5 Sheets for providers and caregivers through its
6 website. Words like, "The health provider can share
7 information in the patient's best interest," are
8 repeated over and again.
9 The 21st Century Cures Act took these efforts
10 a step further, by establishing Statutory Requirements
11 for model training for healthcare providers, to assure
12 they know what is permissible under existing rules. To
13 date, however, these requirements have not been funded
14 and they have not been implemented.
15 It bears repeating that while medical
16 providers, schools and a host of others, routinely
17 claim they withhold information or bar family members
18 from treatment deliberations to avoid legal liability,
19 to my knowledge there has been no case ever of an
20 individual provider being sued for a HIPPA violation.
21 And, in fact, there is no statutory provision in HIPPA
22 for such legal action.

1 It also bears repeating that the mental health
2 treatment narrative, for young children in general, has
3 moved emphatically to the position that family members
4 play a critical role in recovery.
5 Family engagement is a cornerstone of the
6 Coordinated Care Model, developed by The National
7 Institute of Mental Health, for responding to First
8 Episode Psychosis, child and adolescent mental
9 healthcare has become firmly anchored in a model of
10 leaving children with serious emotional disorders or
11 mental illness in their natural settings, home and
12 school, whenever possible, and engaging all the players
13 around them, including family, in their mental health
14 development.
15 We are here today because of concerns about
16 school safety and the impact of mental health on it.
17 It cannot be repeated often enough that most violent
18 acts are not committed by people with mental illness.
19 And most people with mental illness are not violent.
20 We could eliminate all the murders associated
21 with mental illness, in this country, and 96 percent of
22 the nation's murders would still occur.

1 But, statistically, the risk of violence is
2 higher in people with psychiatric disorders, that
3 distort reality and impair daily function.
4 That risk is highest, early after mental
5 illness symptoms begin. Precisely, when individuals
6 are most likely to be in high school or on college
7 campuses. It is in the best interest of all to
8 intervene early and effectively, in these diseases.
9 To this end, nobody knows more about the
10 health histories, risk factors, triggers and other
11 characteristics of teenagers and young adults, than
12 their family members and caregivers, who have lived
13 with them and have known them all their lives.
14 Family members possess unique insights into
15 their loved ones facing mental health challenges. And
16 they are uniquely positioned and supremely motivated to
17 overcome those challenges.
18 When we talk about mental health and safety of
19 our school children, we should be mindful that the most
20 likely victim of mental health tragedy is the child,
21 him or herself.
22 In 2016 and '17, combined, five children died

1 in seven mass assaults in America's schools and 17 more
2 were wounded. It has been worse this year.
3 In the same year, we lost 2,117 teenagers
4 between 15 and 19 to suicide and 3,606 young adults,
5 age 20 to 24, 5,723 high school and college-aged young
6 people, combined.
7 Despite the productive collaboration I
8 experienced with my daughter's school and the vast
9 majority of her healthcare providers, I ultimately lost
10 my Natalie to suicide.
11 One of the things I did, to cope with my
12 grief, was to participate in a family support group of
13 The National Foundation for Suicide Prevention.
14 As heartbroken as I was, and remain, over my
15 daughter's death, I could not imagine the grief of
16 several parents I met there, whose first knowledge that
17 their child had mental health issues came in the call
18 notifying them that their son or daughter had died.
19 Almost without exception, the child's
20 struggles were known to the school, but had been
21 withheld from the family to protect the child's
22 privacy.

1 For the child, privacy all the way to the
2 grave. For the family, agony that they had never been
3 given a chance to help their child.
4 As Americans, we all cherish our personal
5 freedoms. We must also be cognizant that family
6 members may not recognize mental health symptoms.
7 And some may even be contributing factors in a
8 child's mental health disfunction. Families are not a
9 replacement for a functional mental health system.
10 But we should be beyond debating the principle
11 of whether it is in the best of interest of young
12 people, or their communities, or their schools, to
13 exclude family members from the Mental Healthcare Team.
14 We don't leave family members out of decisions
15 about the care of their aging parents with compromised
16 thinking. We don't shut family out of the ER when
17 their loved ones have a medical crisis or are injured
18 in car accidents.
19 Federal Law and clinical practice recognize
20 the family's vital role in mental health care.
21 Anything less than universal embrace should be
22 unacceptable.

1 Our school children are our future. For their
2 sake and ours, the HIPPA Training Mandates of the 21st
3 Century Cures Act, need to be funded and fulfilled, so
4 that inclusion not exclusion of families is to be
5 followed.
6 SECRETARY AZAR: Well, thank you very much,
7 Ms. Fuller. And thank you for sharing your personal
8 story as well as, I think the - the important cautions
9 you raised, not just about the importance of our right
10 to policy but our right to information, as family
11 members, very important.
12 Our final two speakers are going to be
13 discussing FERPA. Our first speaker is Ms. Sonja
14 Trainor, the Managing Director for Legal Advocacy at
15 the National School Boards Association.
16 So, Ms. Trainor, thank you very much.
17 MS. TRAINOR: Good morning, Commissioners.
18 Thank you for inviting the National School Boards
19 Association to offer comments on public schools'
20 interaction with the Family Educational Rights and
21 Privacy Act, FERPA, in the important context of school
22 safety.

1 NSBA, through its members, State School Boards
2 Association, represents the Nation's 95,000 board
3 members and 50 million public school students.
4 NSBA is fortunate to count, among its
5 programs, the NSBA Council of School Attorneys, which
6 is the professional network of three thousand plus
7 attorneys who represent public school boards.
8 The Council informs the work of local school
9 board attorneys, as they come together with their
10 school boards and district staff, to maintain safe and
11 supportive environments where students can learn and
12 thrive.
13 In pursuing this goal, schools call on their
14 attorneys to help them comply with legal requirements
15 on nearly every aspect of their mission, bidding,
16 employment and labor, special education, equity, equal
17 access, the list goes on.
18 But, perhaps more than any other Federal Law,
19 FERPA pervades nearly every step school staff take in
20 their daily interactions with students, families and
21 the community.
22 NSBA is pleased to appear before you today to

1 share our insight on how this law can inform matters of
2 school safety, as school boards work towards preventing
3 tragic acts of mass violence, such as school shootings.
4 For over 40 years, FERPA has provided a
5 federal framework for schools to safeguard student
6 education records and personally identifiable
7 information contained in them.
8 The law requires schools to give parents and
9 students access to their records and prohibits the
10 release of records without parental consent, with
11 various enumerated exceptions.
12 Since FERPA's passage in 1974, the statute and
13 implementing regulations have changed to address the
14 concerns of the times.
15 In 2008, Amendments allowed contractors access
16 to records, when they are acting as school officials.
17 After the devasting Virginia Tech shootings, schools
18 were given clear deference under a rational basis
19 standard, when applying the health and safety
20 exception, allowing release without consent.
21 The Department of Education, through its
22 Family Policy Compliance Office and Privacy Technical

1 Assistance Center, has provided timely and helpful
2 guidance for schools, as technology and safety needs
3 have evolved.
4 The Amendments and resulting guidance aim to
5 allow schools to fulfill their mission to keep students
6 and staff safe and to facilitate learning, while still
7 safeguarding student privacy.
8 Currently, schools work with law enforcement
9 and state - at the state and local level, and social
10 service organizations, to the extent permitted by law,
11 often through memoranda of understanding, outlining
12 guidelines for sharing information about students who
13 cross agencies.
14 As schools address increasingly heightened
15 awareness of risks and threats to school safety, there
16 have been some situations that show the limitations of
17 the current FERPA framework.
18 We will present two examples today, which are
19 explained in more detail in our submitted statement.
20 First, the brewing incident scenario.
21 School staff are alerted to activity on social
22 media, about two students taunting each other over the

1 course of the school year.

2 No time, place or manner of violence is

3 specifically threatened. And there is no threat of

4 imminent physical harm yet.

5 But the banter is escalating to the point

6 where school staff believe the students are a post or

7 two away from things boiling over into violence at

8 school.

9 School personnel have information, in some

10 education records, for example an on-campus fight that

11 occurred recently between the two students, that

12 resulted in discipline, or an exchange of words in the

13 hallway, that was noted as an infraction, that might

14 help local law enforcement intercede and head off the

15 violence directed at the school.

16 Under FERPA, school personnel would need

17 parent or student consent if the parent - if the

18 student is 18, to release education records or

19 personally identifiable information, or the situation

20 would have to fall under an exception.

21 Although many schools will and should seek

22 parent involvement and consent in this scenario, that

1 participation is not always forthcoming or possible,
2 especially if time is of the essence.
3 Each FERPA Exception that might apply has a
4 limitation, including the Health and Safety Exception,
5 which requires an articulable and significant threat to
6 the health or safety of a student or other individual.
7 When the perceived threat of violence is
8 arguably imminent, many attorneys will advise their
9 school clients that the risk of a FERPA violation is
10 low and recommend that they report information
11 necessary to keep the school community safe.
12 But, a rational and cautious approach would be
13 not to report information in education records, so as
14 not to violate FERPA.
15 A second real-world example shows a FERPA
16 barrier in reverse. A high school student, with
17 significant special needs and school-based services,
18 makes the statement, quote, "It would be easy to bring
19 a gun to the school."
20 This student is well known by the
21 administration, staff and students, as a person who
22 presents no danger, even considering the statement.

1 The administration does not, therefore, report the
2 statement to law enforcement.
3 A fellow student goes home and tells his
4 parents what the student said. Social media explodes,
5 and law enforcement shows up at school the next day,
6 with no subpoena or court order, but seeking
7 information from the school.
8 In this scenario, school personnel are unsure
9 what information they may share with the police
10 officer, as they do not believe there is any danger,
11 therefore the Health and Safety Emergency Exception, by
12 its own terms, does not apply.
13 Information in the student's education record,
14 would provide insight about the student's needs and
15 typical behaviors, including perhaps databased
16 assessments indicating the student's propensity for
17 inappropriate outbursts, but no propensity for
18 violence.
19 A cautious school attorney will advise against
20 disclosure, in this example, without parental consent,
21 to avoid a FERPA violation.
22 But, if parental consent is not obtainable, a

1 narrow exception allowing school personnel to share
2 information necessary for local officials to assess a
3 threat accurately, could defuse unnecessary panic in a
4 very limited set of circumstances, and prevent needless
5 law enforcement action against a student.
6 School officials should be granted limited and
7 narrow discretion to disclose information contained in
8 a student's education record when, in the exercise of
9 their professional discretion, the school personnel
10 find disclosure is necessary to protect students or
11 staff from reasonably foreseeable risk of physical
12 harm, such as a mass shooting, or when there is a
13 concern that the student may be considered a threat,
14 absent knowledge of his background that would indicate
15 otherwise.
16 A FERPA change could also expressly allow
17 states, local governments and community service
18 agencies to enter a memoranda of understanding,
19 permitting certain narrowly defined standards for
20 sharing information.
21 In addition to or in lieu of such a regulatory
22 change, technical assistance in the form of guidance,

1 with specific examples from The Department of
2 Education, would assist schools.
3 Such changes to FERPA would require policy-
4 makers to consider long standing juris prudence
5 establishing limits on 1st Amendment Free Speech
6 Rights.
7 Similarly, because confidentiality is a
8 cornerstone of mental health treatment in this country,
9 care should be taken to avoid broad, new rules that
10 discourage access to treatment for mental, behavioral
11 or emotional issues.
12 Rather, the goal should be to craft narrowly
13 defined exceptions that permit referral to mental
14 health services and to law enforcement when physical
15 harm or violence, such as a school shooting, is
16 reasonably foreseeable.
17 Any change to FERPA and its regulation,
18 allowing additional discretion to school officials,
19 should come with clear safeguards for family and
20 student privacy and clear limits on school authority.
21 The goal behind any change would be to remove
22 a barrier to collaboration between schools and

1 community services, including law enforcement, that
2 would prevent a particular act of violence, such as a
3 shooting at school.
4 Parental participation in the process and
5 consent for disclosure of education records should
6 remain the first and preferred approach when a student
7 is perceived to present a threat.
8 NSBA asks the Commission to consider narrow
9 and carefully crafted amendments to the FERPA Statute
10 and Regulations, that give school officials the
11 discretion, not the command, to share relevant
12 information when needed, to keep schools safe, as we
13 have outlined today.
14 Such discretion could lead to greater
15 coordination of services for students before a tragedy
16 occurs. Many of these services already exist.
17 What is needed is a Federal System that
18 supports limited information sharing without unfunded
19 mandates and provides much needed funding and technical
20 assistance to encourage coordination of services.
21 NSBA also urges federal policy makers to
22 confer with school boards, as the local policy makers,

1 to ensure the Final Guidance Rule or Statute can be
2 implemented and supported by Federal Funding.
3 We urge the Commission and The Department of
4 Education to consult meaningfully with school boards
5 and their representatives, including State School
6 Boards Associations, to address implementation
7 specifics.
8 NSBA appreciates the Commission's attention to
9 this integral component of the school safety effort.
10 We look forward to assisting the Commission in its
11 future work.
12 SECRETARY AZAR: Great. Ms. Trainor, thank
13 you for laying out some of the complexities of FERPA,
14 as well as some thoughtful recommendations for sensible
15 reforms to it.
16 Our final FERPA speaker of the day is John
17 Verdi, Vice-President of Policy at the Future of
18 Privacy Forum, in Washington, D.C. Thank you.
19 MR. VERDI: Thank you for the opportunity to
20 testify, for convening today's meeting and for your
21 work to help make schools and students safer. This is
22 a vital mission.

1 The Future of Privacy Forum is a non-profit
2 organization that serves as a catalyst for privacy
3 leadership and scholarship, advancing principle data
4 practices in support of emerging technologies.
5 We are optimists about data. We believe that
6 the power of information technology is a net benefit to
7 society and that it can be well managed to control risk
8 to individuals.
9 Data-driven efforts have the potential to
10 improve educational outcomes. And privacy requirements
11 should enhance, rather than undermine student safety.
12 Today my testimony focuses on defining privacy
13 risks, discussing how the use of children's data can
14 present unique or heightened risks, identifying
15 existing legal authorities that permit appropriate data
16 sharing in response to health and safety risks, while
17 maintaining meaningful privacy safeguards and
18 recommending that the Commission explore opportunities
19 to better educate stakeholders and engage in additional
20 fact-finding, concerning the risks at issue in this
21 important discussion.
22 Schools have long used students' personal

1 information to improve learning outcomes and protect
2 the health and safety of teachers and children.
3 As digital technologies have become more
4 integral to daily life, schools have implemented data-
5 driven programs that can make these efforts more
6 personalized, more effective and more efficient.
7 Parents recognize the potential benefits of
8 technology and information sharing. At the same time
9 parents and children rightly worry that personal
10 information can be collected, used and shared in
11 inappropriate ways that cause real concrete harms to
12 students and families.
13 Strong privacy protections are necessary to
14 sustain the trust that supports data-driven
15 initiatives. Without that trust individuals will rush
16 to freeze data use and sharing, even when that use
17 facilitates crucial services.
18 Several frameworks can be helpful to identify
19 and mitigate privacy harms. I find it helpful to
20 organize privacy risks into four general categories,
21 including risks of physical harm, risk of financial
22 harm, loss of liberty, loss of opportunity and social

1 detriment.

2 These privacy harms can result from a range of

3 factors, including inappropriate collection use or

4 sharing of personal information, failure to ensure

5 accuracy, provide appropriate redress or unreasonable

6 security measures.

7 They can occur even when data is used with the

8 best of intentions, to support the most laudable

9 purposes.

10 When person information is shared, it can

11 amplify the risk of data breach. And incorrect

12 information in government databases can lead to

13 wrongful detention, search, arrest or even

14 incarceration.

15 Privacy risks pose particular challenges when

16 they arise in the context of children's or students'

17 personal information.

Physical harm and loss of

18 liberty are particularly egregious when the victim is a

19 child.

20 Financial fraud and identify theft

21 increasingly target young Americans, who are often

22 unable to discover or combat the crimes until years

1 later.

2 Worse, children are susceptible to specialized

3 schemes, including medical identity theft that can

4 create substantial health risks when multiple

5 individuals' medical records are merged as a result of

6 the crime.

7 In recognition of these heightened risks to

8 children, FERPA grants enhanced protections to students

9 and their parents. These protections promote

10 accountability, accuracy and transparency.

11 Congress created these safeguards in the wake

12 of citizen complaints, complaints that schools were

13 depriving parents of access to basic education records,

14 while at the same time filling those records with

15 inappropriate, inaccurate data and disclosing students'

16 personal information to unauthorized parties who are

17 unaffiliated with the school, the student or their

18 parents.

19 Congress enacted these provisions and has

20 amended them over the years in an effort to strike the

21 right balance, supporting the benefits of student data,

22 for children in schools, while mitigating privacy risks

1 to vulnerable students.

2 FERPA is designed to protect student privacy

3 and student safety, not to foil appropriate law

4 enforcement investigations or endanger schools.

5 The law includes provisions that permit

6 disclosure of student records in response to legal

7 processes, as well as in circumstances involving health

8 and safety emergencies.

9 It's been amended several times, to ensure

10 that the law is sufficiently flexible in cases

11 involving physical threats.

12 FERPA contains a specific exception that

13 permits information to be shared to protect the health

14 and safety of students, whether the child in question

15 is a threat to themselves or to others.

16 In 2008 The Department of Education amended

17 FERPA Regulations to remove the language requiring

18 strict construction of this exception, and instead to

19 permit disclosure of when an articulable and

20 significant safety threat exists.

21 The Department went on to ensure school

22 officials that they would support the disclosure if

1 there was a rational basis for the school's
2 determination at the time that determination was made.
3 The key legal aspects of the 2008 Amendments
4 are the adoption of the Totality of the Circumstances
5 Test and the Rational Basis Approach to Department
6 Review of School Decisions.
7 These Amendments substantially broaden
8 schools' legal and practical ability to share student
9 information in response to emerging health and safety
10 threats.
11 At the same time, they retain some protections
12 for students. The amendments prohibit disclosure of
13 personal information in the absence of an articulable
14 threat or based on determinations that lack any
15 rational basis.
16 Some have urged further expansion of the
17 Disclosure Exemption, which could grant schools
18 authority that is unconstrained by the requirement that
19 officials identify an articulable threat or found their
20 determinations on a rational basis.
21 However, such expansions would likely have
22 negative consequences for both privacy and for safety.

1 Untethering disclosure authority from the totality of
2 the circumstances and rational basis standards, would
3 necessarily increase privacy risks to students.
4 And a dramatic broadening of authority could
5 increase sharing of student information in a way that
6 overwhelms the administrators with data, casts
7 suspicion on the students who show no signs of violent
8 behavior and fails to promptly identify individuals who
9 pose genuine threats to school safety.
10 For example, mentally ill students can be
11 disincentivized from seeking help if they fear that
12 their privacy will not be protected. Their worries
13 include stigma and reduced access to academic
14 opportunities.
15 In some cases, inappropriate disclosures to
16 parents can put students at risk for abuse within their
17 homes.
18 And the National Association of School
19 Psychologists found that trust between students and
20 adults is crucial to ensure that children reach out for
21 help when they need it and report concerns about other
22 students when they have them. Maintaining appropriate

1 safeguards for students' privacy helps create and
2 maintain that trust.
3 Rather than expand legal basis for disclosure
4 of student data, I urge the Commission to recommend
5 additional initiatives to educate school officers and
6 other stakeholders, regarding the existing legal
7 authorities for sharing data to support school safety.
8 The Department of Education's Privacy
9 Technical Assistance Center has been a vital resource
10 for schools seeking practical guidance regarding FERPA.
11 PTAC could publish guidance, hold training
12 sessions and provide additional technical assistance on
13 this issue.
14 I also urge the Commission to recommend
15 further fact-finding and research, regarding the
16 intersection of privacy and school safety.
17 In September 2017, the Bipartisan Commission
18 on Evidence-Based Policy Making released its final
19 report, noting that policy makers must have good
20 information on which to base their decisions about
21 improving the viability and effectiveness of Government
22 Programs and Policies.

1 The issues at stake regarding school safety
2 are of the utmost importance. They involve complex
3 risk assessments concerning potential threats to
4 students' safety as well as potential privacy harms
5 that implicate the interest of individuals, communities
6 and society more broadly.
7 This analysis could be better informed by
8 empirical data regarding the nature, extent and leading
9 causes of the privacy risks and safety risks facing
10 students in schools.
11 I thank you for your attention and for your
12 commitment to safe schools and meaningful privacy
13 protections for students.
14 SECRETARY AZAR: Well, excellent, Mr. Verdi,
15 thank you very much. And I think a good caution, or a
16 good - good way of phrasing the balance between privacy
17 and access to data, and some of the things the
18 Commission needs to focus on in terms of better
19 educating stakeholders here, some of the myth-busting
20 we've heard about today also, on this panel.
21 We have about 12 minutes for questions. I'd
22 also like to introduce Beth Williams, who is the

1 Assistant Attorney General for the Office of Legal
2 Policy, standing in for the Attorney General.
3 And, Ms. Williams, how about if I turn it to
4 you, if you have any questions for our panelists,
5 first?
6 ASSISTANT ATTORNEY GENERAL WILLIAMS: Sure.
7 Sure. Thank you, Secretary.
8 One question I had, for Ms. Trainor, is
9 drawing on what Mr. Verdi said, why - why is FERPA -
10 why doesn't FERPA's Rational Basis Standard provide
11 sufficient reflexibility for schools, as is?
12 What more needs to be done or what's
13 preventing school officials, under the current
14 standard?
15 MS. TRAINOR: I think that the articulable and
16 substantial threat language is - is a barrier, in some
17 situations.
18 And, again, I'd like to stress, we're talking
19 about a very narrow set of situations, when this
20 happens.
21 I think, for the most part, local schools work
22 very closely with their local law enforcement and have

1 established guidelines, either through a memoranda of
2 understanding or other means, where they agree how
3 they're gonna share information in certain
4 circumstances.
5 So, again, this is a very limited set of
6 situations. But, when - when they are faced with the
7 thought of, "Do I have an articulable and substantial
8 threat here," and it's more like the factual scenario I
9 presented, which is we have some kids exchanging words
10 on social media, we know these kids, this could turn
11 into something, but it's not quite something yet,
12 that's - that's the moment when schools are hesitating.
13 And that's why we're asking for a bit of an
14 expansion on the discretion, and again, discretion, not
15 - not requirement.
16 ASSISTANT ATTORNEY GENERAL WILLIAMS: Thank
17 you.
18 SECRETARY AZAR: Ms. Fuller, I was - I was
19 struck by your own personal story in the hospital, in
20 the ER, close to here, and obviously concerned since my
21 department has HIPPA within it.
22 And you said that HHS has been very good about

1 trying to educate providers about their lawyer’s over-
2 caution or overstatement about what the rules are.
3 I wonder if you have any particular ideas on
4 what we can do, in addition to just continuing to
5 educate?
6 For instance, people, when we all go to see a
7 doctor or go to the hospital, we get a Notice of
8 Privacy Practices, that we have the right to.
9 I don't know if that actually tells us not
10 just about our Right to Privacy but about our Right to
11 Information?
12 And it might be - I wonder if it might be
13 useful if one could point to a document saying, "No,
14 no, I have this right," when someone doesn't want to
15 provide you information?
16 If you have any ideas or thoughts on that or
17 other things we could be doing?
18 MS. FULLER: Yeah. I think we've all kind of
19 touched on education in our comments. There's a huge
20 educational knowledge deficit in the public, medical
21 providers, school officials, across the board.
22 When Natalie was in - when we were on, what I

1 used to call the mental illness roller coaster, and I
2 was in and out of ER's and other treatment settings, I
3 kept a notebook.
4 And it had printouts of what the law said.
5 Now, I - you know, and I carried them in. And when I
6 hit the stone wall, I would whip them out.
7 That doesn't work as well in emergency as it
8 does when you're building a relationship with a school
9 or a medical provider.
10 You know, there are good tools on the HHS
11 website. We just - how we get those out to providers,
12 to family members - uh, could probably be a whole other
13 commission meeting.
14 I mean, we really - we need better-equipped
15 people. We need better educated advocates for
16 themselves and their loves ones and their students and
17 all of the rest.
18 I'm not sure how we get there.
19 SECRETARY AZAR: Thank you. Thank you.
20 MS. FULLER: Jennifer?
21 SECRETARY AZAR: Ms. Mathis, do you have -
22 MS. MATHIS: Yes. I just wanted to agree with

1 Ms. Fuller on that. And I think those resources, we
2 appreciate them, they are terrific, that HHS did.
3 My impression has been that they are not
4 really getting out in the world. And I think there is
5 a lot more that could be done, you know, other than
6 having them on the website.
7 I mean, getting, you know, breaking things
8 down into videos and things that get wider
9 distribution, that take pieces of those guidance
10 documents that, you know, get them into other fora,
11 that get them into provider conferences and advocates
12 conferences and getting other people to amplify those
13 resources.
14 I mean, I think there is really a lot that can
15 be done, even, you know, without a big budget, to get
16 those things out into the world.
17 The other thing I would just say is, I think
18 to the extent that many of the circumstances, including
19 Ms. Fuller's story, you know, show you that it's not
20 about what the law says, in - in most of these cases.
21 And, so I'm not sure how much changing the law
22 changes behavior. There are other ways to change

1 behavior. And I think there is a lot that can be done
2 in terms of incentivizing providers and encouraging and
3 sort of ensuring that reimbursement mechanisms build
4 in, you know, a value of engaging families, where
5 appropriate, and, you know, being appropriate, doing -
6 sharing, where appropriate.
7 SECRETARY AZAR: Yeah, good caution and with
8 apologies to my former profession, lawyers are - uh,
9 always going to over-caution and over-warn.
10 And that, I think, no matter what one says,
11 that we'll - we will see that behavioral aspect. So,
12 we have to think about other counter-building
13 incentives that one can put in place and programs
14 beyond just informing.
15 So, Secretary DeVos, do you have a question
16 for the panel?
17 SECRETARY DEVOS: Yes. Thank you, Secretary
18 Azar.
19 Thank you, Ms. Trainor and Mr. Verdi, for your
20 comments and helping educate us more about the FERPA
21 Statute and Regulations.
22 And a question, with regard to FERPA, do you

1 know what the minimum and maximum penalties are for
2 violation of FERPA?
3 MS. TRAINOR: I do, in theory, it is a removal
4 of Federal Funds. And of course, there's a process
5 that takes place before that.
6 If your next question is, "Has it ever been
7 invoked?" The answer is, no. But that doesn't mean
8 that it's - uh, mere words in the wind, as - as we say,
9 because schools are very - uh, aware that they've
10 promised to uphold it in exchange for Federal Funds.
11 MR. VERDI: Yeah. And I would note, that this
12 is not a statute that contemplates robust private
13 rights of action and lawsuits from individuals, as an
14 enforcement mechanism.
15 SECRETARY DEVOS: So, could I just ask you,
16 Mr. Verdi -
17 MR. VERDI: Sure.
18 SECRETARY DEVOS: - just a little further?
19 You alluded to the opportunity to have further
20 education and training around the extent to which you
21 can share information under the FERPA Law.
22 Could you expand on that a little further?

1 You know, providing information on a website, we've
2 just talked about the limitations of that.
3 There are, you know, tens of hundreds of
4 thousands of schoolchildren, across the country, who
5 are all impacted by this.
6 And I think knowing and understanding, from a
7 parental perspective as well, what those boundaries and
8 rights are, is really important for all of us.
9 MR. VERDI: Yeah. Thank you. I agree. There
10 are a variety of ways that we have seen this done in
11 other domains and in the education domain.
12 You know, at FPF, we run boot camps with
13 school administrators, with educational technology
14 providers with vendors who sell into the schools, with
15 other stakeholders in this eco system, to provide face-
16 to-face, one-on-one training about these sorts of
17 issues. I think that that sort of one-on-one training
18 can be very effective.
19 We also provide written materials, and I know
20 PTAC and other folks at The Department of Education
21 have provided written materials, that can be visually
22 compelling, that can be relatively concise, things like

1 checklists and FAQ's have been very helpful.
2 The other thing that has been very helpful, I
3 think, over the years, has been the kind of more
4 official guidance, the "Dear Colleague" letters and the
5 other sorts of official guidance that lawyers, like
6 Sonja's constituency can rely on, in these
7 circumstances and point teachers and administrators and
8 other stakeholders to, to say, "We have concrete formal
9 guidance from The Department of Education," who
10 ultimately are the arbitrators of the Federal Funding
11 question, the enforcement question, that you raised.
12 And that we, on the basis, of this guidance,
13 therefore feel very comfortable that even if particular
14 language is not in the statute or the regulation, it's
15 in the formal guidance of the department.
16 So, I think there's a range, from the very
17 formal, like formal guidance, to the less formal, like
18 checklists and FAQ's and one-pager's and down to one-
19 on-one or one-to-many face-to-face education.
20 SECRETARY AZAR: Okay. Thank you. Thank you.
21 Secretary Nielsen?
22 SECRETARY NIELSEN: Sure. So, I just wanted

1 to start - uh, I take your comments, Mr. Verdi, to
2 heart on the data protection.
3 So, I would like to just encourage us, as the
4 Commission, to make sure that we do have
5 recommendations. There certainly are Best Practices,
6 that we can provide out to NSAB.
7 But, the retention, the use, the access, you
8 know, these are - these are all issues of data
9 management that we deal with on a day-to-day basis at
10 DHS and throughout the - so, I do - I do take that
11 point. I don't want to lose it, it is very important
12 to make sure we're protecting the data.
13 I did want to ask a bit more on the concept of
14 an MOU. So, short of revising FERPA or looking at
15 different potential restrictions from HIPPA, I did
16 wonder if there is a standardized MOU that we could
17 work with you to provide, that very high-level talks
18 about the need for point of contacts?
19 You know, in any emergency management
20 situation, we always say the worst time to exchange
21 business cards is during the emergency, right?
22 So, what would be a standardized way that we

1 could, within the community, law enforcement and
2 schools, have point of contacts identified, talk about
3 rules and responsibilities at least at a high level,
4 talk about perhaps thresholds or criteria?
5 It sounds like there are instances where we're
6 in a general agreement that sharing could occur, and
7 then there's a gray area. But at least we could
8 clarify, you know, through perhaps a standardized MOU
9 those areas where we are in agreement.
10 The standard that you described, the
11 "Articulable and substantial," I would love to work to
12 get some additional meat on what that means.
13 From an intel community perspective, we always
14 use "Credible and specific." And the key there is we
15 talk about credible. We don't try to necessarily
16 anticipate the length or the amount of harm.
17 But, if there is a specific and credible
18 threat, we usually take action. So, there might be
19 some interesting ways to think about what it is that
20 we're really trying to set forth, in terms of that
21 standard.
22 But on the MOU, in particular, I just wonder

1 if that would be additional guidance, I guess, a - a
2 question for the panel, would that be useful for
3 schools to lay some of this out in advance, so that at
4 least they're not, you know, real trying - real-time
5 trying to untangle all these very complex questions and
6 laws and regs?
7 MS. TRAINOR: Uh - yes. Thank you for the
8 question. I think so. I think there is always room
9 for coordinated and stakeholder information provided
10 guidance and models. And schools are thirsty for that,
11 and communities are thirsty for that.
12 So, I think there is an opportunity to do a
13 model MOU. The caution there is that there's a web of
14 State Law that overlays Federal Law, when it comes to
15 privacy, student records, student data. As John's
16 testimony pointed out, there are all these new State
17 Laws addressing student data privacy.
18 So, it would have to be, as I'm picturing it,
19 very 30,000 feet, and it would probably have to involve
20 State Law Enforcement Representatives, so that the
21 State Level legal web is imposed.
22 But I think there is some interest in that.

1 And, as I mentioned, there are many local agreements
2 already in existence, that I'm sure could be good
3 models as well.
4 SECRETARY NIELSEN: Maybe it could be more of
5 a - just to follow-up, more of a framework, so in other
6 words it could list the questions that a local school
7 should ask to make sure they're complying with state
8 laws, to make sure they understand the capacity and
9 capability of local law enforcement.
10 In other words, it could be some best
11 practices, such as you need the POC's created.
12 ASSISTANT ATTORNEY GENERAL WILLIAMS: Mm-hm.
13 SECRETARY NIELSEN: But then perhaps the rest
14 could be a guide to, these are the questions and
15 considerations you need to think about to come up with
16 a model MOU for your state or locality?
17 ASSISTANT ATTORNEY GENERAL WILLIAMS: Mm-hm.
18 Always helpful, yep.
19 SECRETARY AZAR: All right. Well, thank you,
20 panelists. And I'd like to thank each of our speakers
21 today, from all three of our panels, for your remarks
22 today.

1 You have given us a great deal of critical
2 information, in a short period of time. And it's
3 assisted us in understanding these very important
4 matters. Thank you for sharing your expertise with us
5 today.
6 I'd also like to thank the Commission's
7 leadership, as well as our staff, for ensuring the
8 Commission has heard both sides of the very complex
9 issues that we are facing today around mental health.
10 We have found the information from today's and
11 previous commission meetings to be very enlightening,
12 in considering how we can foster positive school
13 environments and improve the behavioral health of our
14 children and our adolescents.
15 I am pleased to announce today that HHS is
16 already taking action on the challenge that we face. I
17 have asked the Assistant Secretary for Mental Health
18 and Substance Use, Dr. Elinore McCance-Katz, to
19 establish technical assistance and training within
20 every mental health technology transfer center funded
21 by SAMHSA, the Substance Abuse Mental Health Services
22 Administration.

1 This national network of technical assistance
2 programs has been placed in each of the ten HHS Regions
3 of The United States. And there is a Technical
4 Assistance and Training Center, with a focus on
5 American Indians, Alaska Natives and Hispanic Latino
6 Communities.
7 This assistance is going to help training
8 clinicians, teachers and other school-based personnel
9 in evidence-based practices that can help establish
10 positive and nurturing environments in schools and
11 address the behavioral health needs of our children.
12 This is a significant step forward for the
13 assistance SAMHSA provides to local communities. And
14 we believe this will be an important tangible step in
15 addressing the behavioral health needs of our young
16 people.
17 I would now like to give my fellow
18 Commissioners the opportunity to make any closing
19 remarks.
20 Secretary DeVos, do you have any remarks to
21 close with?
22 SECRETARY DEVOS: Well, thank you, Secretary

1 Azar. And I'd like to thank you for your leadership
2 here today and the work that your team has done for our
3 session here today.
4 Thank you very much to all the panelists,
5 really appreciate your insight and expertise as we
6 consider these issues of students' mental health,
7 behavioral health and student privacy.
8 So, we very much appreciate the work that you
9 have brought forward today. Thank you.
10 SECRETARY AZAR: Thank you. Secretary
11 Nielsen, do you have any closing remarks?
12 SECRETARY NIELSEN: Yes. Just to, of course,
13 thank the Secretaries for their leadership. And I
14 really appreciate all of the panelists for taking the
15 time to come today, sharing your clear wealth of
16 experience and expertise, personal experiences, in some
17 cases. It's extraordinarily helpful to us, as we try
18 to come up with recommendations that can move this
19 conversation forward.
20 I think what's clear is we all need to do
21 more. So, we just need to find out the most productive
22 ways and things that can both scale and accommodate

1 scopes of different school systems, different
2 localities, different cultures within our system, to
3 make sure that we are in fact looking at the best
4 interests of giving individual children.
5 So, thank you very much.
6 SECRETARY AZAR: All right. Assistant
7 Attorney General Williams, do you have any closing?
8 ASSISTANT ATTORNEY GENERAL WILLIAMS: Sure.
9 Thank you, Secretary Azar.
10 I'm pleased to be here on behalf of the
11 Attorney General. And on behalf of the Attorney
12 General and The Department of Justice, I want to thank
13 The Department of Health and Human Services for
14 coordinating this meeting of The Federal Commission.
15 And I want to extend special thanks to our
16 panelists today, who have provided a wealth of
17 information to consider and for sharing your personal
18 stories.
19 It's our hope that, through the work of the
20 Commission, we can identify additional steps that we
21 can take to prevent school violence.
22 The Department of Justice is fully committed

1 to listening and learning, throughout this process, and
2 collaborating with our partners on the Commission, to
3 ensure the safety of our schools.
4 So, thank you very much for being here today.
5 SECRETARY AZAR: Excellent. Thank you very
6 much. And this concludes the third Federal Commission
7 on School Safety Meeting. Good Day!
8 (Whereupon the meeting was concluded at 11:05 a.m.)
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1 2:2
10 2:7,11
108 2:20
109 2:21
10:05 55:1
10:06 55:5
11 1:4 2:13 25:13
110 2:22
111 2:22
11:05 1:5 112:8
12 2:14 15:14 94:21
13 2:15
14 2:8,16 6:5
15 2:17 6:9 17:3 38:13 69:13 73:4
16 2:18
1650 1:9
17 2:19 26:14 72:22 73:1
18 2:20 63:7 79:18
19 2:21 73:4
1974 77:12
1990 24:11
1st 83:5

2

2 2:1,3
2,117 73:3
2.4 29:12
20 2:22 15:12 34:20 73:5
2008 77:15 90:16 91:3
2013 68:18 69:22
2016 72:22
2017 64:18 93:17
2018 1:4 114:11
21 2:22
21st 64:5 70:9 75:2
23 2:9 17:3 114:11
24 6:6,9 66:14 73:5
26 8:17
2nd 53:22

3

3 2:4,4
3,000 24:12
3,606 73:4
30 30:15 53:18
30,000 106:19
33 2:10

4

4 2:5,5
40 18:21 28:16 34:19 77:4
43 2:12

5

5 2:6
5,723 73:5
50 76:3
504 58:8
53 17:7
56 2:13
58 17:7

6

6 2:7
60 28:17 30:21
600,000 15:14
63 31:20
66 2:14
6th 18:20

7

7 2:6,8
70 28:22
75 2:15

8

8 2:9
80 27:15 30:17 31:5
85 2:16

9

9 2:10
90 17:1
95 2:17
95,000 76:2
96 71:21
9:00 1:5
9:58 55:4
9th 25:21 26:5,8

a

a.m. 1:5,5 55:4,5 112:8
ability 26:20 29:6 31:17 47:7 91:8 113:7 114:4
able 11:19 44:16 44:18 45:3,21 47:19 49:19 62:6
absence 91:13
absent 25:22 82:14
absenteeism 16:5 19:4
abuse 28:3 52:20 92:16 108:21
academic 17:21 57:8 92:13
academy 20:19
access 6:1 15:1 17:10 21:3 23:7 32:16 42:12 47:17 51:3 56:12 76:17 77:9,15 83:10 89:13 92:13 94:17 104:7
accessible 37:2 64:12
accidents 28:3 74:18
accommodate 110:22
accommodating 69:19
accommodations 57:17
accomplished 21:11
accountability 56:9 89:10
accuracy 88:5 89:10
accurate 32:8 113:6
accurately 31:15 82:3
acknowledge 7:8
acknowledged 69:6
act 56:9 58:8,9,12 63:13 64:5 68:11 70:9 75:3,21 84:2
acting 68:15 77:16
action 70:22 82:5 101:13 105:18 108:16 113:9,13 114:6,8
actions 68:12
active 67:11
actively 51:21
activities 36:1
activity 78:21
acts 71:18 77:3
ada 58:7
adam 25:2 27:2,9 53:22
addiction 50:15
addition 6:7 39:8 63:15 82:21 97:4
additional 83:18 86:19 93:5,12 105:12 106:1 111:20
additionally 20:11
address 4:4,13 23:8 41:2,18 47:1 55:19 77:13 78:14 85:6 109:11

addressing 5:21 55:15 64:16,20 106:17 109:15
adequate 5:20 64:12
adhd 27:2,8,15,20 28:2,2,10,16 29:2
administration 80:21 81:1 108:22
administrators 13:8 59:6 92:6 102:13 103:7
admitted 59:1
adolescent 14:15 23:21 24:10 34:8 36:8 37:10 38:6 41:19 42:8 44:1 71:8
adolescents 33:18 34:6,15,18,22 37:5 38:12,14,18 42:17 43:8 44:10 56:20 63:4 66:14 108:14
adoption 43:6 91:4
adult 6:5 16:8 67:22
adulthood 66:14
adults 6:8 33:2 36:17 44:10 50:13 56:20 57:2 72:11 73:4 92:20
advance 106:3
advancing 86:3
adverse 39:18
advise 52:4 80:8 81:19
advocacy 55:21 67:21 75:14
advocate 65:22 66:6
advocates 98:15 99:11
affair 66:11
affect 20:15
affluent 37:14
afford 58:4
affordable 37:2
afforded 60:2
affording 63:20
afraid 48:19 52:14
age 6:5,6,9,12,16 50:10 63:7 66:14 66:17 73:5
aged 73:5
agencies 21:14 42:20 78:13 82:18
ages 50:7
aggregate 37:13
aggression 18:15
aggressive 25:14 29:10 53:3
aging 74:15
ago 48:6 66:9
agony 74:2
agree 50:2 62:13 96:2 98:22 102:9
agreement 105:6 105:9
agreements 107:1
ahead 3:19
aid 48:2
aim 78:4
alaska 109:5
alcohol 18:14 62:15
alert 12:4
alerted 78:21
alex 2:5
align 17:19
allegedly 59:9
alleviate 42:9
allow 60:18 61:7 62:20 78:5 82:16
allowed 77:15
allowing 32:22 63:8 77:20 82:1 83:18
allows 61:10,16 62:8 69:3
alluded 101:19
alongside 38:9
alteration 44:3
alternatives 40:16
alters 44:1
ambitious 58:14
amended 89:20 90:9,16
amendment 83:5
amendments 77:15 78:4 84:9 91:3,7,12
america 66:19
america's 73:1
american 9:2 109:5
americans 58:8 74:4 88:21
amount 105:16
amplify 88:11 99:12
analysis 51:19 94:7
anchored 71:9
angeles 15:13 18:19 20:7
angry 26:9
animal 44:7
animals 27:1 29:9
announce 108:15
answer 2:11,17 34:1 48:22 50:1 101:7
answers 54:18
anti 29:19 38:15 39:5,9,13,22 40:5 40:8,11,15
anticipate 105:16
antidepressant 34:21
antidepressants 34:22 38:16
anxiety 30:10,14 30:16 31:3 35:3
apologies 100:8
apparent 50:6
appear 76:22
appeared 26:20
appears 31:16
applicable 68:11
application 63:3 64:21
applied 45:18
apply 80:3 81:12
applying 77:19
appointment 21:19
appreciate 14:21 15:16 43:18 45:15 54:17 99:2 110:5 110:8,14
appreciates 85:8
approach 4:8 5:22 6:20 17:16 18:6 68:3 80:12 84:6 91:5
approaches 18:4 42:16
appropriate 37:2 52:5 58:12,15 64:8,10,13 86:15 88:5 90:3 92:22 100:5,5,6
appropriately 53:2 58:14
approximately 38:22 54:22
arbitrators 103:10
area 43:4 44:11 52:3 105:7
areas 20:13,16 37:14 38:5 41:17 42:3,10 45:15

105:9
arguably 80:8
arranged 28:9
array 46:19 61:8
arrest 59:13 88:13
arrested 6:13
arrests 28:3
art 67:7
articulable 80:5 90:19 91:13,19 95:15 96:7 105:11
ascertain 25:6
asked 33:21 64:19 66:9 67:15 68:4 108:17
asking 96:13
asks 84:8
aspect 76:15 100:11
aspects 13:15 91:3
assaultive 53:3
assaults 73:1
assess 36:21 52:6 82:2
assessment 51:15 52:4,12,15,17
assessments 54:4 81:16 94:3
assist 13:5 83:2
assistance 22:7 78:1 82:22 84:20 93:9,12 108:19 109:1,4,7,13
assistant 2:22 95:1 95:6 96:16 107:12 107:17 108:17 111:6,8
assisted 108:3
assisting 85:10
associated 15:19 15:20 40:3 71:20
association 75:15 75:19 76:2 92:18
associations 85:6
assuming 27:13
assurance 43:2 56:13
assure 70:11
attack 45:22
attacked 45:19
attacks 46:4,11,17
attempt 36:18
attempts 57:2
attend 42:20
attended 68:18
attention 17:13 27:2 32:9,21 35:19 65:5 85:8 94:11
attorney 2:6,22 7:20 8:1 10:12 11:16 13:18 46:22 47:3 81:19 95:1,2 95:6 96:16 107:12 107:17 111:7,8,11 111:11 113:11
attorneys 76:5,7,9 76:14 80:8
attract 35:19 42:2
audience 5:6
audio 114:3
authorities 86:15 93:7
authority 68:10 83:20 91:18 92:1 92:4
autism 29:3,11 30:5 40:3
availability 35:11 41:13 49:12
available 15:8 30:19 51:4 56:17 65:4
avenue 1:9
average 8:14
avoid 10:8 70:18 81:21 83:9
avoidant 30:13,13
avoided 26:3
aware 3:17 101:9
awareness 18:11 78:15
azar 2:5,20 5:2 8:2 10:11,19 12:20 13:21 14:2,13 23:10 33:3 43:9 43:16 45:10 46:22 51:8 54:16 55:6 65:15 75:6 85:12 94:14 96:18 98:19 98:21 100:7,18 103:20 107:19 110:1,10 111:6,9 112:5

b

b 114:2,12
back 18:16 46:15 48:6 51:14 55:7 67:17
background 82:14
bad 25:8 39:18 48:6
balance 63:22 89:21 94:16
balanced 60:18
banter 79:5
bar 70:17
barred 59:11
barrier 80:16 83:22 95:16
barriers 15:20 17:12 36:10,11 37:8 49:6
base 93:20
based 15:5 19:17 19:19 20:22 21:17 22:7,11 46:12 61:14 65:18 80:17 91:14 93:18 109:8 109:9
basic 60:3 89:13
basis 8:7 37:16 77:18 91:1,5,15 91:20 92:2 93:3 95:10 103:12 104:9
bazelon 55:22,22 58:22
bears 70:15 71:1
becoming 33:1
beds 32:4
begins 6:5,6 36:8
begun 59:3
behalf 111:10,11
behavior 6:2 27:17 30:7 92:8 99:22 100:1
behavioral 6:17 7:2 11:5 12:1 14:17 17:21 18:5 19:7 20:21 21:13 24:6 30:10 31:4 57:8,9 83:10 100:11 108:13 109:11,15 110:7
behaviorally 30:5
behaviors 35:18 67:6 81:15
belief 68:14
believe 9:4 10:7 27:21 28:5 79:6 81:10 86:5 109:14
believes 61:17 62:5,10
belongings 59:17
benefit 40:19 65:9 86:6
benefits 31:8 36:22 39:17 87:7 89:21
best 3:11 4:15 32:13 33:1 45:7 60:20 62:11 68:11 68:15 70:7 72:7

74:11 88:8 104:5 107:10 111:3 113:6 114:3
beth 94:22
betsy 2:4,21
better 8:10 11:12 11:19,22 13:10 15:1 21:13 26:4 44:12 86:19 94:7 94:18 98:14,15
beyond 37:8 74:10 100:14
bidding 76:15
big 8:13 99:15
biggest 54:7
bipartisan 93:17
bipolar 40:2
birth 29:5
bit 12:21 96:13 104:13
blame 61:4
blamed 61:1
bleeding 69:14
blow 25:11
blue 67:6
blueprints 22:12
board 76:2,9 97:21
boards 75:15,18 76:1,7,10 77:2 84:22 85:4,6
bodies 26:22
body 67:6,7
boiling 79:7
boot 102:12
bottom 18:1
bounce 46:15
boundaries 102:7
boy 25:3 54:1
boyish 25:12
brain 39:9 44:14
brains 44:1
brandished 25:4
brattiness 29:3
breach 88:11
break 54:19 67:4
breaking 99:7
breast 48:12
brewing 78:20
brian 25:7 27:2 28:1,20
brief 44:5
bring 80:18
bringing 10:22 33:4
broad 43:6 49:2 83:9
broaden 91:7
broadening 41:20 92:4
broader 50:22
broadly 48:15 51:4 94:6
brook 53:16
brook's 24:9
brought 110:9
budget 99:15
build 100:3
building 1:8 4:15 12:5 67:8 98:8 100:12
bullied 25:3
bullying 3:7 49:9 49:10,11,12 50:21
burdens 48:9
bus 22:22
business 68:16 104:21
busting 94:19
button 55:12

c

c 3:1
cafeteria 22:22
calculated 58:14
california 46:2
call 18:2 25:10 73:17 76:13 98:1
called 18:9 19:7 29:19
calling 51:15
calls 68:7
campaign 48:18
camps 102:12
campus 4:16 19:22 21:14 59:2 59:12 67:7,13 79:10
campuses 66:8 72:7
cancer 48:5,6,9,12
can't 10:5
capability 107:9
capacity 12:4 57:21 62:9 107:8
capita 37:16
car 28:3 59:15 74:18
cards 104:21
care 5:20 15:19,20 16:14,15,16,16 17:3,11,12 19:16 32:19 36:11 39:6 41:8 42:21 43:4 47:17 62:17 64:10 65:14 68:21 69:16 71:6 74:15,20 83:9
carefully 44:9 60:18 84:9
caregivers 70:5 72:12
carlson 2:9 23:19 24:2,3 33:4 35:2 43:20 44:4,13 48:22 53:15
carlson's 52:13
carried 98:5
carrying 27:10
case 34:8 70:19
cases 24:12 32:6 90:10 92:15 99:20
110:17
casts 92:6
catalyst 86:2
catching 48:12
categories 87:20
cause 6:9 87:11
caused 31:7
causes 94:9
caution 33:14 94:15 97:2 100:7 100:9 106:13
cautions 43:10 75:8
cautious 80:12 81:19
cbits 19:7 46:12
center 15:9 55:22 55:22 58:22 67:21 78:1 93:9 108:20 109:4
centers 15:5 19:20 21:18 67:11
century 64:5 70:9 75:3
certain 62:2 82:19 96:3
certainly 10:4 12:7 46:1 50:12 52:19 54:3 104:5
certificate 113:1 114:1
certify 113:3 114:2
chairing 8:3
chairman 10:9
challenge 108:16
challenges 5:18 33:5 37:22 58:18 72:15,17 88:15
chance 74:3
change 10:3 30:20 82:16,22 83:17,21 99:22

changed 49:17 55:9 77:13
changes 39:18 44:14 47:15 83:3 99:22
changing 99:21
character 4:14
characteristics 72:11
charging 59:8
check 21:21
checklists 103:1 103:18
cherish 74:4
child 9:20,21 14:14 15:3,22 20:17 21:3,21 22:2 23:21 24:9 29:9 30:12 32:10 35:15 36:8,15 37:10 38:5,14 41:19 42:8,20 51:21 52:6 53:7 54:8 58:15 71:8 72:20 73:17 74:1 74:3 88:19 90:14
child's 41:6 47:8 58:16 73:19,21 74:8
childhood 16:7 29:5
children 5:16 6:3 7:4 10:8 15:2,6,21 22:15,19 23:5,16 24:1,6,7 27:16 29:20,21 30:5 31:3 32:17,22,22 33:6,14,18 34:6 35:13 37:5,21 38:12,18 39:6,6 40:7 42:12,17 43:1,7 44:2,10 45:7 50:20 53:16 53:22 63:4 68:1 71:2,10 72:19,22 75:1 87:2,9 89:2,8 89:22 92:20 108:14 109:11 111:4
children's 38:2 86:13 88:16
children’s 5:15
cholesterol 39:11
choosing 53:10
chronic 6:16
circumstances 32:9 58:16 61:9 61:14 62:9 65:20 82:4 90:7 91:4 92:2 96:4 99:18 103:7
citizen 89:12
civil 11:16 13:3 69:2
claim 70:17
clarify 105:8
clarifying 64:15 65:1
clarity 64:11
class 21:19 26:13 27:10
classroom 20:4
classrooms 30:1
clear 77:18 83:19 83:20 110:15,20
clearly 31:8 39:17 65:16
clients 80:9
climate 57:7
clinic 17:7
clinical 20:10 22:1 45:4 50:19 52:10 74:19
clinicians 20:2,9 21:15 22:7 109:8
clinics 16:20 17:2
close 59:2 96:20 109:21
closely 95:22
closer 69:11
closing 2:19 43:5 109:18 110:11 111:7
coaster 98:1
code 59:9
cognitive 19:7
cognizant 74:5
coincided 34:15
colin 25:13 29:1 30:2
collaborating 112:2
collaboration 12:11 67:11 73:7 83:22
collaborative 68:3
colleague 16:17 69:18 103:4
colleagues 50:3
collected 87:10
collection 88:3
college 58:2 59:1 67:4 72:6 73:5
colleges 57:11 63:12 66:11,21
columbia 33:11 113:18
combat 88:22
combined 24:15 31:4 32:13 72:22 73:6
come 7:17 15:16 54:13 76:9 83:19 107:15 110:15,18
comes 4:8 29:11 69:11 106:14
comfortable 103:13
coming 11:8
command 84:11
comment 44:5
comments 14:18 75:19 97:19 100:20 104:1
commission 1:1 3:3,5,13,21 4:2,11 5:8 6:19 8:4 10:19 11:2,19 21:8 32:20 41:12,20 43:5,11 51:3 56:6 63:2 65:16 66:5 84:8 85:3,10 86:18 93:4,14,17 94:18 98:13 104:4 108:8,11 111:14 111:20 112:2,6
commission's 85:8 108:6
commissioners 4:22 5:5 7:11 55:11 75:17 109:18
commissioners’ 7:8
commission’s 7:7
commitment 7:8 94:12
committed 59:2 71:18 111:22
committee 43:2 68:20
committing 49:14 61:22
common 6:7 8:8 20:14 28:4 31:11 31:13 63:21
commonly 34:11 36:2
communication 25:18 50:20 64:8 67:1
communications 69:4
communities 3:19 17:11 21:16 37:15

74:12 94:5 106:11 109:6,13
community 4:10 12:12 15:10 16:20 17:2,6 21:13 23:2 24:13 29:22 41:10 45:16 64:6 76:21 80:11 82:17 84:1 105:1,13
compared 6:11 39:12
compelling 34:5 102:22
complaints 89:12 89:12
completed 17:4,7 17:8
complex 24:5 49:22 94:2 106:5 108:8
complexities 85:13
complexity 29:1
compliance 77:22
complicated 28:15 41:1
comply 76:14
complying 107:7
component 20:18 47:12 85:9
compounded 39:20
comprehensible 64:12
compromised 74:15
concentrating 36:1
concentration 31:18
concept 104:13
concern 54:7 82:13
concerned 36:17 60:11 96:20
concerning 31:10 56:6 86:20 94:3
concerns 38:20 39:4,19 42:21 51:17 71:15 77:14 92:21
concerted 5:22 43:3
concise 102:22
concluded 64:5 112:8
concludes 112:6
concrete 23:13 87:11 103:8
condition 6:17 31:13
conditions 29:11 40:6 41:4 66:20
conducted 44:9
confer 84:22
conferences 99:11 99:12
confidence 60:1
confidential 68:14
confidentiality 7:4 55:15 57:19 63:17 66:2 83:7
confidentially 9:10
confined 50:6
confront 47:8
confusing 25:16
confusion 64:6,8
congress 64:1,4,11 89:11,19
connection 41:9
connections 65:7
consent 62:10 77:10,20 79:17,22 81:20,22 84:5
consequences 28:4 36:19 58:21 59:21 91:22
consider 13:2,15 19:12 21:8 43:11 51:21,21 52:6 65:17 83:4 84:8 110:6 111:17
considerable 32:1
considerably 27:18
considerations 68:18 107:15
considered 3:6 64:1 82:13
considering 80:22 108:12
consternation 34:2
constituency 103:6
construction 90:18
consult 20:2 85:4
consultation 20:2 24:8 28:9
consulted 46:2
consulting 15:12
consumption 3:7
contacts 104:18 105:2
contained 77:7 82:7
contains 90:12
contemplates 101:12
context 66:2 75:21 88:16
contexts 63:16
continue 3:18 4:5 12:7 57:17 58:18
continues 3:21 4:19
continuing 11:7 97:4
contractors 77:15
contribute 35:5
contributing 32:18 74:7
control 86:7
convening 85:20
conversation 110:19
conviction 68:10
coordinate 42:15
coordinated 71:6 106:9
coordinating 111:14
coordination 62:17 84:15,20
cope 46:16 73:11
core 6:4
cornerstone 71:5 83:8
correct 30:3
correctly 14:11 45:14
costs 36:22 45:8,9
council 76:5,8
counsel 113:8,11 114:5
counseling 6:21 40:12
counselors 4:1 9:19 20:10 22:1 56:16
count 76:4
counter 100:12
country 4:7 40:18 46:3 68:6 71:21 83:8 102:4
county 24:11
course 22:3 41:21 79:1 101:4 110:12
court 81:6
courts 9:9
cover 5:11

coverage 3:8
craft 83:12
crafted 84:9
create 21:17 57:6 64:12 89:4 93:1
created 89:11 107:11
creation 12:14
credible 105:14,15 105:17
crime 89:6
crimes 88:22
criminal 8:14
crisis 4:15 5:21 57:13 67:22 74:17
criteria 105:4
critical 5:11 7:15 7:18 20:16 23:2 35:11 37:8 41:18 44:11 52:18 57:11 60:2,7 71:4 108:1
cross 78:13
crucial 87:17 92:20
cultures 111:2
curating 6:20
cures 64:5 70:9 75:3
curious 51:19
current 78:17 95:13
currently 78:8
cut 26:13 52:2
cyber 3:6 49:12 50:20

d

d 2:2 3:1 27:6
d.c. 1:11 85:18
daily 5:18 72:3 76:20 87:4
damage 53:21
danger 25:6 62:22 80:22 81:10
data 86:3,5,9,13 86:15 87:4,14,16 88:7,11 89:15,21 92:6 93:4,7 94:8 94:17 104:2,8,12 106:15,17
databased 81:15
databases 88:12
date 70:13 114:12
daughter 67:1,18 69:14 73:18
daughter's 73:8 73:15
day 55:2 59:6 81:5 85:16 104:9,9 112:7
days 51:1
deal 62:22 104:9 108:1
dear 103:4
death 6:9 48:19 73:15
debating 74:10
decades 48:6
december 64:18
decisions 25:8 74:14 91:6 93:20
decrease 15:19,20 19:9 22:15 32:4
decreases 18:14
decreasing 18:14
deeply 20:15
defer 44:4
deference 77:18
deficit 27:3 97:20
defined 82:19 83:13
defining 86:12
defuse 82:3
delay 36:11
deliberation 64:4
deliberations 70:18
delinquency 18:15
deliver 21:2
delivered 18:9
delivery 36:12 66:7
demonstrate 32:6
department 5:9 11:4 60:5 77:21 83:1 85:3 90:16 90:21 91:5 93:8 96:21 102:20 103:9,15 111:12 111:13,22
departments 8:12
depression 30:21 31:1,11 34:8,9,15 35:1 47:5,13
depressive 19:10 30:11 34:18 46:17 56:21
depriving 89:13
described 26:8 36:2 38:10 61:5 69:18 105:10
describing 35:14
description 68:17
designed 90:2
designs 4:16
despite 5:19 16:10 58:17 73:7
detail 78:19
detect 36:2,6 47:19
detention 88:13
determination 91:2,2
determinations 91:14,20
determine 11:8 36:20
determined 49:4
detriment 10:8 88:1
devasting 77:17
developed 24:8 30:14 71:6
developing 13:1,6 13:17 31:16 39:9 39:15
development 17:21 20:17 22:13 22:14,19 42:22 71:14
developments 4:14
devos 2:4,21 3:2 5:3 7:9 8:3 10:19 13:22 43:14,16 100:15,17 101:15 101:18 109:20,22
dhs 11:9 12:2 104:10
diabetes 39:11,15
diagnosable 5:19
diagnosed 40:5
diagnosis 19:15 30:3 31:15 32:8 40:7 48:9
diagnostic 29:1
died 72:22 73:18
difference 61:4
different 4:10 6:22 9:1 104:15 111:1,1,2
difficult 31:14 36:5 37:22
difficulties 9:21 35:9 47:9
difficulty 28:13 36:1
digital 87:3
dilemma 45:5
dimensional 5:22
direct 13:8
directed 64:11 79:15

direction 113:5
director 23:20 55:21 69:2 75:14
disabilities 56:7 56:11,18 57:10,13 57:22 58:8,11,20
disability 6:16 57:4
disciplinary 20:8 59:9
discipline 79:12
disclose 41:5 59:19 60:15 82:7
disclosing 68:13 89:15
disclosure 59:22 60:18 61:2,10,12 61:16,17 62:8,11 62:20 81:20 82:10 84:5 90:6,19,22 91:12,17 92:1 93:3
disclosures 61:8 63:9 64:13,15 92:15
discourage 83:10
discover 88:22
discretion 82:7,9 83:18 84:11,14 96:14,14
discuss 9:20 11:22 33:17
discussed 8:9 11:2 12:3 31:14 52:1
discussing 75:13 86:13
discussion 13:13 13:18 86:21
disease 66:18
diseases 72:8
disfunction 74:8
disincentivized 92:11
dismembered 26:22
disorder 16:12 27:3 29:4 30:14 30:16 40:2,4,9 50:16 52:16
disorders 5:19 6:12,15 20:21 23:4 29:18 30:11 33:7 71:10 72:2
disorganized 27:6 27:12
distances 38:1
distinguish 31:17 35:16
distort 72:3
distractible 27:6
distress 8:17,19 9:3 16:1 41:5
distressing 34:10
distributed 65:7
distributes 70:4
distribution 37:12 99:9
district 15:13,13 18:19,20 19:6 20:5 76:10 113:18
districts 20:4 24:10 46:3
disturbance 24:8
disturbances 5:17
diversion 28:12
division 14:14 23:20 24:9
doctor 14:13 61:21 62:3,5 97:7
document 97:13
documented 20:20
documents 99:10
doing 12:2 32:12 45:7 46:7 49:2 54:2 97:17 100:5
domain 102:11
domains 102:11
door 21:20
doris 2:14 65:21
dorm 59:14,17
doubling 38:15
douglas 3:15
dr 14:10,12,19,20 16:17 23:11,19 24:2,3 33:3,8,16 35:2 43:9,19,19 43:21 44:4,4,13 45:13 46:1 47:11 47:19 48:22 50:2 52:8,13 53:11,13 53:13,15 65:18 108:18
draconian 54:5
dramatic 92:4
drawing 95:9
drawings 26:22
driven 86:9 87:5 87:14
drivers 22:22
driving 50:10
drop 6:13 16:5
dropouts 28:3
drug 18:11,14 28:3 34:13 39:19
drugs 18:12 29:17 34:1 51:22 52:19 52:19 62:15
drunks 8:21
due 53:3 62:14
dumb 54:2
dysregulated 30:5

e

e 2:2 3:1,1 27:7
earlier 22:3 51:13
early 6:2 26:2 46:7,7,20 47:19 47:21 48:12 72:4 72:8
easily 64:12
easy 29:2 67:9 80:18
eco 102:15
educate 48:14 86:19 93:5 97:1,5 100:20
educated 98:15
educates 48:2
educating 22:20 94:19
education 24:14 30:1 57:18 58:12 58:13 65:8 76:16 77:6,21 79:10,18 80:13 81:13 82:8 83:2 84:5 85:4 89:13 90:16 97:19 101:20 102:11,20 103:9,19
education's 93:8
educational 16:2 20:17,18 30:6 34:12 58:13 63:13 75:20 86:10 97:20 102:13
effect 4:16
effective 8:12 16:18 18:13 20:12 22:10 32:16 34:22 36:7 38:10 47:9 56:12 64:2 65:14 87:6 102:18
effectively 72:8
effectiveness 27:20 28:13 93:21
effects 31:18 39:9 39:9,15,18
efficient 87:6
effort 17:19 43:3 69:20 85:9 89:20
efforts 11:9 70:9 86:9 87:5
egregious 88:18

eisenhower 1:8
either 38:2 41:8 43:19 96:1
elderly 50:8
electronic 50:19
elementary 46:14 58:1,10 63:5,11
eligibility 41:21
eligible 42:6
eliminate 71:20
eliminated 24:22
elinore 108:18
email 4:4
embedded 32:2
embrace 74:21
emergencies 12:8 12:14 90:8
emergency 4:14 12:6,10,14,19 13:7,14 51:12 62:8,22 69:12 81:11 98:7 104:19 104:21
emerges 66:13
emerging 86:4 91:9
emily 25:21 30:9 30:12
emotion 29:16
emotional 5:17 16:1 17:21 20:21 22:18 24:8 27:7 29:16 41:5 71:10 83:11
emphasis 42:7
emphasized 69:3
emphatically 71:3
empirical 94:8
employed 113:8 113:11 114:6
employee 113:10
employment 76:16
enable 57:17 58:15
enacted 89:19
encourage 63:20 84:20 104:3
encouragement 67:1
encouraging 57:15 100:2
endanger 90:4
endangering 59:9
ended 70:2
enduring 50:22
enforcement 8:6 8:11 9:5 12:5 35:20 78:8 79:14 81:2,5 82:5 83:14 84:1 90:4 95:22 101:14 103:11 105:1 106:20 107:9
engage 56:15 57:5 86:19
engagement 71:5
engaging 71:12 100:4
enhance 86:11
enhanced 89:8
enhancing 11:3,20
enlightening 108:11
enraged 25:19
ensure 11:13 13:19 22:16 58:7 60:19 65:6,9 85:1 88:4 90:9,21 92:20 112:3
ensuring 7:13 23:3 56:17 57:18 60:6 100:3 108:7
enter 82:18
entering 59:12
entertainment 3:7 4:17
entitled 20:20
entwined 50:14
enumerated 77:11
environment 7:14 22:17
environments 76:11 108:13 109:10
epidemic 50:13
epidemiology 33:9
episode 34:18 71:8
episodes 56:21 67:13
equal 58:7 76:16
equipped 22:18 98:14
equity 76:16
er 74:16 96:20
er's 98:2
erase 48:4
escalating 79:5
especially 17:11 20:12 21:15 23:11 60:10 80:2
essence 80:2
essential 6:18 20:18
establish 108:19 109:9
established 3:14 30:3 96:1
establishing 70:10 83:5
ethical 54:13
evaluate 36:18 52:17
evaluation 24:21
events 26:16
everybody 55:7
evidence 20:22 22:11 23:12 26:17 27:19 31:7 34:5 39:20 43:6 44:7 46:12 47:4 50:18 93:18 109:9
evolved 78:3
exacerbated 37:11
exacerbating 49:8
examination 32:21
example 18:4,8 19:19 28:1 29:1 57:15 58:5,22 61:10 62:12 79:10 80:15 81:20 92:10
examples 35:17 61:20 78:18 83:1
excellent 14:2 43:9 45:10 94:14 112:5
exception 73:19 77:20 79:20 80:3 80:4 81:11 82:1 90:12,18
exceptions 61:7 62:16,17,19 63:21 77:11 83:13
excessive 29:7
exchange 79:12 101:10 104:20
exchanging 96:9
exclude 74:13
exclusion 75:4
executive 1:8
exemption 91:17
exercise 82:8
exist 17:12 21:1 84:16
existence 107:2
existing 70:12 86:15 93:6
exists 90:20
expand 21:10 41:15 93:3 101:22
expanded 22:8
expanding 21:22
expansion 91:16 96:14

expansions 91:21
expect 60:3
experience 6:13 36:9 61:22 69:11 110:16
experienced 8:16 68:3 73:8
experiences 11:18 59:18 66:1 110:16
expert 4:20 10:22 54:17
expertise 7:1,17 108:4 110:5,16
experts 3:11 51:17
explain 34:3
explained 78:19
explodes 81:4
explore 86:18
exposure 18:22 19:2
expressing 25:12
expressly 82:16
extend 111:15
extending 41:12
extensive 64:4
extent 78:10 94:8 99:18 101:20
externalizing 35:16,17
extolled 66:22
extraordinarily 56:10 110:17
extreme 30:14 67:5
extremely 7:11 31:10 70:4

f

face 33:4 37:21 58:18 102:15,16 103:19,19 108:16
faced 96:6
facilitate 78:6
facilitates 87:17
facilities 42:6
facing 33:5 72:15 94:9 108:9
fact 16:10,17 28:16 29:3 30:16 49:5 53:1 66:17 70:4,21 86:20 93:15 111:3
factorial 31:22
factors 35:5 47:14 50:3,10 72:10 74:7 88:3
factual 96:8
fails 92:8
failure 34:12 88:4
faith 61:17
fall 79:20
false 69:17
familiar 15:10
families 6:4 15:6 15:10 22:21 37:20 38:7 64:17 65:2 67:21 68:2,14 74:8 75:4 76:20 87:12 100:4
family 19:15 32:10 61:2,8,12 62:4,5 63:12 66:1 66:6 68:6 69:5,8,8 69:9 70:17 71:3,5 71:13 72:12,14 73:12,21 74:2,5 74:13,14,16 75:10 75:20 77:22 83:19 98:12
family's 74:20
famous 49:2
faq's 103:1,18
far 59:19
farkas 1:21 113:2 113:16
father 59:16
fda 39:22
fear 30:14 47:8 92:11
feasible 41:9
features 35:15,16 35:17
federal 1:1 3:3 8:15 42:1,15 58:4 63:19 69:15,20 74:19 76:18 77:5 84:17,21 85:2 101:4,10 103:10 106:14 111:14 112:6
feedback 4:3
feel 58:20 103:13
feelings 35:14
feels 25:15
feet 106:19
fellow 4:22 5:4 7:8 81:3 109:17
felt 26:3
ferpa 7:5 12:20 55:16,19 63:12 68:10 75:13,21 76:19 77:4 78:17 79:16 80:3,9,14 80:15 81:21 82:16 83:3,17 84:9 85:13,16 89:8 90:2,12,17 93:10 95:9 100:20,22 101:2,21 104:14
ferpa's 77:12 95:10
field 4:3
fight 79:10
fighting 26:11 35:18
figure 45:5
figures 30:19
filling 89:14
final 7:7 55:14,18 75:12 85:1,16 93:18
finally 20:5 22:16 26:14 37:1 42:11
financial 42:2 45:9 87:21 88:20
financially 113:12 114:7
find 47:6 82:10 87:19 110:21
finding 86:20 93:15
finished 17:1 67:19
firmly 71:9
first 5:8 12:9 14:10 23:18 34:4 35:9 36:8,17 41:3 48:2 55:17,20 67:3 71:7 73:16 75:13 78:20 84:6 95:5
fits 4:7
five 9:2 16:11 19:14 27:8 37:17 72:22
flexible 69:19 90:10
floor 10:13
florida 3:16
flow 59:22
focus 5:14 35:8 49:9 50:17 63:2 94:18 109:4
focused 39:4
focuses 86:12
focusing 46:20
foil 90:3
fold 38:14 39:14
folks 102:20
follow 54:10 107:5
followed 75:5
following 21:9
fora 99:10
force 54:11

foregoing 113:3
foreseeable 82:11 83:16
form 82:22
formal 103:8,15 103:17,17,17
former 100:8
forms 4:17
forth 105:20
forthcoming 80:1
fortunate 76:4
forum 85:18 86:1
forward 4:20 7:19 11:1,7 14:1,18,22 85:10 109:12 110:9,19
foster 39:6 108:12
found 18:21 19:2 22:10 26:21 45:18 53:19 91:19 92:19 108:10
foundation 43:3,3 73:13
four 87:20
fourteen 8:15
fourths 6:6
fpf 102:12
framework 77:5 78:17 107:5
frameworks 87:18
fraud 88:20
free 58:12 83:5
freedoms 74:5
freeze 87:16
frequently 25:22 64:19
friend 59:2
friendly 70:4
friends 59:16 69:5 69:8
frontlines 66:15
fulfill 78:5
fulfilled 75:3
full 3:5 14:7,9 51:17
fuller 2:14 65:21 65:22 66:3,4 75:7 96:18 97:18 98:20 99:1
fuller's 99:19
fully 111:22
fun 26:9
function 51:2 72:3
functional 27:22 74:9
funded 70:13 75:3 108:20
funding 84:19 85:2 103:10
funds 101:4,10
further 70:10 91:16 93:15 101:18,19,22 113:10
future 59:20 75:1 85:11,17 86:1

g

g 3:1
gabrielle 2:9 23:19
gain 39:10
gap 53:7
gaps 35:3 45:15
gather 4:5
gathering 3:21
gears 29:6
general 2:6,22 7:20 8:1 10:12 11:16 13:18 19:21 46:22 47:3 71:2 87:20 95:1,2,6 96:16 105:6 107:12,17 111:7,8 111:11,12
generally 34:2 35:13 59:4 63:8
genuine 92:9
geographic 37:12
getting 15:21 17:6 28:13 49:6 58:18 67:12 99:4,7,12
give 49:20 77:8 84:10 109:17
given 34:17 52:6 63:2 74:3 77:18 108:1
givers 64:10
giving 111:4
go 18:16 64:22 97:6,7
goal 76:13 83:12 83:21
goes 76:17 81:3
going 14:4 23:18 23:22 26:5 33:13 36:3 55:17 65:16 66:1 75:12 100:9 109:7
gonna 96:3
good 3:2 5:4,5 9:18 10:15 24:3 26:11 27:21 32:14 50:1 61:17 65:13 75:17 93:19 94:15 94:16,16 96:22 98:10 100:7 107:2 112:7
gotten 15:7
government 12:12 69:20 70:1 88:12 93:21
governments 82:17
grade 25:2,21 26:5,8
grader 53:22
graders 18:20
grades 16:4 19:11 26:12
graduated 67:14
grandma 48:10
grant 91:17
granted 82:6
grants 89:8
grave 74:2
gray 105:7
great 5:2 10:9 14:20 33:1,3 54:16 65:15 85:12 108:1
greater 16:5 19:3 42:7 84:14
greatest 21:16
greatly 17:10 45:14
grief 73:12,15
grips 54:14
gross 69:10
group 6:12,16 19:6 35:15 44:19 46:1 67:15 73:12
growing 33:1
guaranteed 58:7
guarantees 58:12
guess 106:1
guidance 64:15,18 70:2 78:2,4 82:22 85:1 93:10,11 99:9 103:4,5,9,12 103:15,17 106:1 106:10
guide 13:6,9,13 107:14
guided 68:9
guidelines 78:12 96:1
gun 18:22 80:19
guns 51:4,6
gurney 69:14

h

h 27:5
half 6:4 16:12 34:20 51:5

hallucinating 69:14
hallway 79:13
hand 35:21
handed 59:7
hands 67:16
happens 28:1 44:20,21 95:20
harder 36:2
harm 62:7 79:4 82:12 83:15 87:21 87:22 88:17 105:16
harmful 54:3
harming 54:5
harms 87:11,19 88:2 94:4
hated 26:9
head 79:14
health 5:9,12,15 5:17,21 6:2,15,17 6:18,21 7:2 8:11 8:11,13 11:6,13 12:1 14:17 15:1,5 15:7,17,19,22 16:3,7,11,16,20 17:2,7,9,10,14,16 19:17,19,20,21 20:1,14,16 21:11 21:13,17,22 22:8 23:7 24:6,16 33:9 35:6,12 36:7,9,15 37:6,10,12 38:6 40:18 41:3,7,7,11 41:13,19,21 42:5 42:8 45:21 47:16 48:1,17 52:10,15 56:1,7,9,11,16,18 57:4,13,19,22 58:20 59:5,22 60:5,12,21 61:2 61:13,16,19 62:21 63:9,17,17 64:21 65:14,19 66:2,6 66:16,20 67:11 68:13 70:6 71:1,7 71:13,16 72:10,15 72:18,20 73:17 74:6,8,9,20 77:19 80:4,6 81:11 83:8 83:14 86:16 87:2 89:4 90:7,13 91:9 108:9,13,17,20,21 109:11,15 110:6,7 111:13
healthcare 35:10 37:2,9,21 40:14 42:2,17 47:15 60:8,9,14,15 62:18 64:6,9 66:7 67:3 69:4 70:11 71:9 73:9 74:13
healthier 6:20 7:13
healthy 22:12,14
hear 3:10 23:18
heard 24:16 34:9 40:3 68:17 94:20 108:8
hearing 4:20 6:22 7:19 14:1 23:14 67:21 68:18 69:22
heart 47:9 104:2
heartbroken 73:14
heightened 78:14 86:14 89:7
help 7:6 30:7 41:1 41:18 42:9 46:15 48:18 51:18 52:4 52:11 56:14 57:15 58:18,21 59:19 60:4 74:3 76:14 79:14 85:21 92:11 92:21 109:7,9
helpful 78:1 87:18 87:19 103:1,2 107:18 110:17
helping 10:8 53:8 100:20
helps 68:21 93:1
hereto 113:11
hesitating 96:12
hhs 6:19 10:21 61:20 62:12 64:11 64:18,22 69:2 70:4 96:22 98:10 99:2 108:15 109:2
hhs’s 6:4
hide 27:4
high 3:16 6:1 13:6 16:6 24:7 25:7 28:22 39:10 41:10 42:13 61:22 66:21 72:6 73:5 80:16 104:17 105:3
higher 16:4,8 72:2
highest 56:19 72:4
highlight 12:2,8
highly 34:9
hinder 64:8
hinders 68:21
hippa 7:4 12:20 55:15,18,20 56:8 60:13 61:1,6,10 61:16 62:8 63:8 63:14 64:1,7,14 65:2,11,21 68:10 68:21 69:3,18 70:20,21 75:2 96:21 104:15
hippa's 56:3 60:17 61:7 62:19 63:3 64:20 66:7
hispanic 109:5
historically 69:6
histories 72:10
hit 98:6
hm 52:8 107:12,17
hold 93:11
holders 22:17
home 71:11 81:3
homeland 11:5
homelessness 6:13
homes 92:17
homework 27:12
honestly 53:21
hope 111:19
hopefully 45:14
hospital 15:4 32:4 59:2,5,7 69:13,15 96:19 97:7
hospitalizations 24:15
hospitalized 30:2
hospitals 32:5
host 70:16
hosted 5:9
hosting 5:7 10:19
hour 25:17
house 68:19 69:22
huge 97:19
human 5:9 33:4 60:5 111:13
hundreds 102:3
hygienics 25:12
hyperactive 27:5
hyperactivity 27:3

i

idea 58:11
ideas 97:3,16
identifiable 77:6 79:19
identification 6:3
identified 105:2
identify 11:19 12:7 87:18 88:20 91:19 92:8 111:20
identifying 24:22 41:9 46:10 47:20 86:14
identity 89:3
illness 6:5 22:4,15 28:21 32:7 35:15 47:22 48:3,5,13

48:15 53:4 65:22 66:10,13 67:22 71:11,18,19,21 72:5 98:1
illnesses 44:15 64:3,17
illustrate 52:13
imagine 45:2 73:15
imminent 79:4 80:8
impact 3:6 71:16
impacted 102:5
impacting 23:5
impacts 29:5
impair 72:3
impaired 29:13
impairing 32:7
impairment 37:6 39:3 45:5,6
implement 11:20 12:10 57:12
implementation 85:6
implemented 19:6 65:12 70:14 85:2 87:4
implementing 57:6 77:13
implicate 94:5
importance 7:14 12:9 15:17 24:1,4 33:13 56:3 63:20 75:9 94:2
important 4:19 7:12,18 8:4 9:4 10:17 13:15 23:17 43:10,10 46:8 49:10 50:4 52:9 52:20 56:10 57:3 57:20 59:19 60:10 61:4 63:3 65:13 75:8,11,21 86:21 102:8 104:11
108:3 109:14
imposed 106:21
imposes 60:14
impression 99:3
improve 15:1 23:7 43:4 45:16 86:10 87:1 108:13
improved 19:11 27:17
improves 57:8
improving 6:1 33:17 93:21
impulsive 27:6,10
impulsively 25:4
inaccurate 89:15
inappropriate 81:17 87:11 88:3 89:15 92:15
inaudible 30:15 30:17,18,20,21
incapacitated 63:1
incarceration 88:14
incentives 42:2 100:13
incentivizing 100:2
incident 3:18 12:5 78:20
include 39:10 63:21 92:13
included 13:13 42:5
includes 22:20 90:5
including 4:14 6:2 25:8 35:17 42:18 56:11 57:7,9 58:5 58:13 59:12 61:13 61:21 62:17,21 66:8 67:6 71:13 80:4 81:15 84:1 85:5 87:21 88:3
89:3 99:18
inclusion 75:4
income 38:7,7
incorporate 13:10
incorporating 12:20
incorrect 88:11
increase 17:10 21:15 34:14 38:11 38:14,22 39:1 41:3 49:11,12 50:5 92:3,5
increased 34:10 39:11,14 50:16 56:21 57:2
increases 34:12 50:10,14
increasing 42:6
increasingly 26:15 32:3 78:14 88:21
indiana 1:10
indians 109:5
indicate 82:14
indicated 20:22 21:6 40:1
indicating 81:16
individual 19:15 20:3 32:9 60:19 60:21 61:11 62:9 70:20 80:6 111:4
individuals 56:10 58:11 60:7 65:1 66:20 72:5 86:8 87:15 89:5 92:8 94:5 101:13
infers 61:14
influence 62:15
inform 77:1
information 3:22 4:6 9:11 10:6 12:4 13:11 24:22 44:14 49:13 52:5 55:18 56:9 57:19 59:5 59:20 60:1,11,12
60:15,18 61:2,12 62:14,21 63:9,18 64:9,14,21 68:13 69:7 70:7,17 75:10 77:7 78:12 79:9,19 80:10,13 81:7,9,13 82:2,7 82:20 84:12,18 86:6 87:1,8,10 88:4,10,12,17 89:16 90:13 91:9 91:13 92:5 93:20 96:3 97:11,15 101:21 102:1 106:9 108:2,10 111:17
informed 94:7
informing 69:16 100:14
informs 76:8
infraction 25:10 79:13
ingredient 20:16
initial 52:2
initiated 30:4
initiative 7:9
initiatives 87:15 93:5
injured 74:17
injury 6:10
inmates 8:18
input 29:7
insight 77:1 81:14 110:5
insights 72:14
instance 62:3 97:6
instances 10:3 105:5
institute 33:12 71:7
institutional 66:19 68:8
institutionalized 29:22

insult 51:1
insurance 42:19
integral 85:9 87:4
integrate 11:13,22 19:20
integrated 17:14
integrating 7:2 14:16
intel 105:13
intended 32:6
intense 50:21
intensive 21:7
intensively 39:4
intentions 88:8
interaction 29:5 75:20
interactions 76:20
intercede 79:14
interest 35:22 62:11 63:1 68:11 68:15 70:7 72:7 74:11 94:5 106:22
interested 11:12 49:5 52:2 113:12 114:7
interesting 105:19
interests 65:13 111:4
interfere 5:18
interfered 64:2
internalizing 35:16,21
interplay 65:17
interpreted 63:8
intersection 93:16
intervene 22:2 72:8
intervention 6:3 18:5 19:6,7
interventions 21:5 22:9,14 57:8
introduce 7:20 24:18 94:22
introduced 18:6
investigation 68:19
investigations 90:4
inviting 14:21 24:4 75:18
invoked 101:7
involve 37:22 94:2 106:19
involved 9:18
involvement 61:3 79:22
involves 11:3
involving 64:16 69:16 90:7,11
irritability 40:2
isolated 3:18
issue 33:5 44:12 64:14 86:20 93:13
issued 13:6 64:18 70:1
issues 4:14 5:11 6:20 7:4 55:15 73:17 83:11 94:1 102:17 104:8 108:9 110:6
issuing 4:12
it’s 8:4 9:8 10:9,16
i’d 3:2 7:20 10:13 10:18,21 11:10 13:8,21 14:10
i’ve 3:13

j

jacox 16:17
jail 8:18 28:20
jails 8:20
janelle 26:8 30:9
jeff 2:6
jennifer 2:13 55:20 98:20
job 7:12
john 2:16 85:16
john's 106:15
join 10:16
judicious 39:21
july 1:4 114:11
jump 40:15
june 3:6
junior 25:7
juris 83:4
justice 8:14 28:21 111:12,22
juvenile 9:9 28:21

k

k 15:14
kataoka 2:8 14:11 14:12,13,19,20 23:11 45:13 46:1 47:11 52:8 53:11 53:13 65:18
katz 108:18
keep 9:12 12:16 32:12,16 78:5 80:11 84:12
keeping 3:12
kept 25:3 98:3
key 12:17 20:16 53:6 91:3 105:14
kick 43:15
kids 21:6 27:4 47:19 49:20 96:9 96:10
kim 114:2,12
kind 9:21,22 10:6 46:20 97:18 103:3
kindergarten 26:1
kinds 49:19 53:19
kirstjen 2:7
knew 27:11
knife 18:21 25:3 27:11 54:1
know 4:7 8:13 14:8 15:9 32:11 34:21 43:22 44:6 44:20 45:9 47:12 47:13,18 48:8,9 49:2,14,15 50:12 50:18 51:2 52:5 52:14,20 54:11 70:12 96:10 97:9 98:5,10 99:5,7,10 99:15,19 100:4,5 101:1 102:1,3,12 102:19 104:8,19 105:8 106:4
knowing 24:7 102:6
knowledge 4:21 7:1,17 11:18 70:19 73:16 82:14 97:20 113:7
known 5:16 17:17 72:13 73:20 80:20
knows 61:21 72:9

l

labor 76:16
lack 32:11,15 47:7 91:14
lacks 62:9
language 29:6 35:14 90:17 95:16 103:14
larger 23:8 35:3
late 3:6 22:5 28:10 54:21 66:14
latino 109:5
laudable 88:8
law 8:6,10 9:5 10:7 12:5 35:20 55:22 56:1 63:19 69:15 74:19 76:18 77:1,8 78:8,10 79:14 81:2,5 82:5 83:14 84:1 90:3,5 90:10 95:22 98:4 99:20,21 101:21 105:1 106:14,14 106:20 107:9
laws 10:1 13:3,17 13:19 58:4 63:16

68:11 106:6,17 107:8
lawsuits 101:13
lawyers 100:8 103:5
lawyer's 97:1
lay 106:3
laying 85:13
lead 16:1,8 28:2 84:14 88:12
leadership 7:10 8:2 86:3 108:7 110:1,13
leading 6:8 66:10 94:8
learn 59:18 76:11
learned 12:8 26:2 68:2
learning 11:12 78:6 87:1 112:1
leave 38:1 74:14
leaving 71:10
led 19:3 67:5
left 26:10
legal 55:21 70:18 70:22 75:14 76:14 86:15 90:6 91:3,8 93:3,6 95:1 106:21
legally 9:7
length 105:16
lengths 32:4
lessen 61:18 62:6
lessons 12:7
letter 59:8
letters 103:4
level 58:2 62:2 78:9 104:17 105:3 106:21
levels 39:11
liability 70:18
liberty 87:22 88:18
lieu 82:21
life 18:9 25:7 87:4
light 58:15 59:21
likelihood 19:3
limitation 80:4
limitations 49:18 78:16 102:2
limited 47:16 63:4 82:4,6 84:18 96:5
limits 83:5,20
link 21:13
lisa 16:17
list 30:8 76:17 107:6
listening 4:3 11:1 112:1
listing 45:15
lists 38:1
literally 25:19
little 22:5 46:16 53:22 101:18,22
lived 72:12
lives 5:18 72:13
loan 42:1
local 3:19 8:20 12:5,12 13:9 42:16 76:8 78:9 79:14 82:2,17 84:22 95:21,22 107:1,6,9 109:13
localities 111:2
locality 107:16
located 19:21
logic 31:18
logical 26:20
long 25:13 27:19 30:8 37:22 38:1 39:8 44:8 54:9 64:22 83:4 86:22
longer 50:21
longitudinal 44:18
look 4:20 7:19 11:1,7 13:22 14:17,22 48:6 51:3,12,18 85:10
looked 19:1 30:9
looking 16:18 53:16 104:14 111:3
los 15:13 18:19 20:7
lose 26:20 104:11
loss 31:17 35:22 87:22,22 88:17
lost 27:12 73:3,9
lot 8:22 32:19 44:17 47:14 48:12 48:20 54:12 99:5 99:14 100:1
love 52:3 105:11
loved 72:15 74:17
loves 98:16
low 17:11 21:16 38:7 80:10
lower 16:4

m

m.d. 2:8,9,10
mail 37:12
maintain 9:9,11 9:13 76:10 93:2
maintained 9:14 29:22
maintaining 60:7 86:17 92:22
major 34:18 56:21
majority 63:7 73:9
majorly 32:18
makers 83:4 84:21 84:22 93:19
making 24:19 57:16 93:18
manage 14:8
managed 24:13 86:7
management 18:10 104:9,19
managing 75:14
mandates 4:12 75:2 84:19
manner 39:21 79:2
march 3:14
margery 3:15
marijuana 25:9 28:6
mark 2:10 33:8
maryland 18:7
mass 3:9 73:1 77:3 82:12
match 41:1
matches 42:13
materials 64:20 102:19,21
mathis 2:13 55:21 56:2,4,5 65:16 98:21,22
matter 23:18 47:7 68:8 100:10
matters 7:19 68:14 77:1 108:4
maximum 101:1
mccance 108:18
mean 26:9 38:18 45:9 50:9 98:14 99:7,14 101:7
meaningful 86:17 94:12
meaningfully 62:13 85:4
means 41:9 50:19 51:3 96:2 105:12
measures 12:18 43:1,7 57:6,12 65:9 88:6
measuring 42:16
meat 105:12
mechanism 101:14
mechanisms 100:3

media 3:8 78:22 81:4 96:10
medicaid 42:19
medical 9:15 29:11 69:21 70:15 74:17 89:3,5 97:20 98:9
medicated 28:6 38:17
medicating 33:14
medication 24:1,5 27:15,20 28:6,14 28:18 29:15 30:18 31:4,21 33:18 39:1,13 42:15 43:1,7 44:1,19 53:8 62:1,5
medications 7:3 23:15 28:11 29:17 31:7 33:6,21 34:7 38:10,12,15,21 39:5,10,16,20 40:1,5,11,15,19 40:20 42:18 52:21 53:2
medicine 20:12
meet 8:6
meeting 3:4,5 5:7 5:8 6:17,19 10:20 13:22 85:20 98:13 111:14 112:7,8
meetings 3:10 4:2 8:8 9:4,5 12:3 108:11
member 61:12 62:5 66:1,6 68:6
members 61:3,8 66:4 69:8,9 70:17 71:3 72:12,14 74:6,13,14 75:11 76:1,3 98:12
memoranda 78:11 82:18 96:1
mental 5:15,17 6:5 6:12,15,21 8:11 8:13 11:5,13 12:1 15:1,7,17,19,22 16:3,7,11,16,20 17:2,6,9,10,14,16 19:20 20:1,14,16 20:20 21:10,22 22:3,8,15 23:4,7 24:16 28:21 32:7 33:7,9 35:6,10,12 35:15 36:7,9,15 37:6,10,12,21 38:6 40:18 41:3,6 41:7,10,13,19 42:5,8,17 45:21 47:16,22 48:1,3,4 48:13,14 52:10,15 53:3 55:22 56:7 56:11,16,18 57:4 57:12,19,22 58:19 60:12 62:20 63:17 64:3,17,21 65:14 65:19,22 66:2,6,7 66:10,13,16,20 67:22 71:1,7,8,11 71:13,16,18,19,21 72:4,15,18,20 73:17 74:6,8,9,13 74:20 83:8,10,13 98:1 108:9,17,20 108:21 110:6
mentally 92:10
mention 12:11
mentioned 11:17 12:21 35:2 46:13 51:12 107:1
mere 101:8
merged 89:5
message 69:21
met 3:6 73:16
metrics 42:12
michael 1:21 113:2,16
microphone 55:9
microphones 55:11
middle 18:10,16 38:7
mild 29:12 34:2
million 76:3
mindful 46:9 55:13 72:19
minimize 45:8
minimized 28:8
minimum 101:1
minutes 43:13 69:13 94:21
misapplication 61:6
mishaps 25:8
misinformation 32:15
misinterpreted 26:16
misplaced 61:4
mission 20:18 76:15 78:5 85:22
missions 6:4
mistake 29:2
misunderstanding 61:6
mitigate 12:19 87:19
mitigating 89:22
mm 52:8 107:12 107:17
model 17:19 20:1 20:2 70:11 71:6,9 106:13 107:16
modeled 44:7
models 19:18 20:8 106:10 107:3
moderate 29:12 35:1
modifications 58:6
moler 114:2,12
moment 96:12
monitoring 28:13
monitors 54:12
months 11:8 31:5 31:5 40:13 54:2
mood 40:8
morbidity 24:7
morning 3:2 5:4,5 10:16 24:3 35:7 43:18 50:17 75:17
mother 26:6
motivated 72:16
motivation 31:19
mou 104:14,16 105:8,22 106:13 107:16
move 110:18
moved 71:3
moves 36:10
mtss 17:18
multi 5:22 17:17 20:8 21:4 31:22 46:5 47:11 49:4
multiple 17:12 70:1 89:4
murders 71:20,22
mutual 11:9
myth 94:19

n

n 2:2 3:1
naked 67:6
narrative 71:2
narrow 82:1,7 84:8 95:19
narrowly 82:19 83:12
natalie 67:2,12 68:4 73:10 97:22
nation 3:20
nation's 71:22 76:2
national 20:19 34:16 37:11 41:21

43:2 71:6 73:13 75:15,18 92:18 109:1
nations 46:18
nation's 11:21
natives 109:5
natural 71:11
nature 94:8
near 38:15
nearly 51:5 66:13 76:15,19
necessarily 28:18 38:18 92:3 105:15
necessary 19:13 32:3 60:19 61:18 62:21 80:11 82:2 82:10 87:13
need 8:5 10:3,5 16:13 19:15 21:7 21:10,16 22:6,8 22:16 24:15 35:9 36:14 40:21 42:15 42:20 44:16 47:18 48:14,17 49:19 51:3 52:14 54:5,6 56:15 57:16 58:1 58:19 75:3 79:16 92:21 98:14,15 104:18 107:11,15 110:20,21
needed 24:14 30:2 32:1 60:8 84:12 84:17,19
needless 36:12 82:4
needs 6:18 24:6 42:13 78:2 80:17 81:14 94:18 95:12 109:11,15
negative 44:2 58:21 59:21 91:22
neighboring 21:14
neither 113:7 114:5
net 86:6
network 76:6 109:1
never 74:2
new 23:22 24:11 33:11 55:11 64:19 83:9 106:16
newtown 46:2
nhsc 42:7
nielsen 2:7,22 10:14,15 14:3 45:11,13 51:9,11 53:5,12 54:15 103:21,22 107:4 107:13 110:11,12
nine 17:5 34:17 43:13
noisy 25:16
non 29:9 86:1
normally 57:18
notary 113:1,17
note 101:11
notebook 26:21 98:3
noted 3:13 56:22 79:13
notice 97:7
notifying 73:18
noting 93:19
nsab 104:6
nsba 76:1,4,5,22 84:8,21 85:8
number 8:8 9:6 20:15,22 21:10,12 21:15 22:6,16 46:19 58:4 66:8 67:5
numbers 38:17
nurse 38:3
nurturing 109:10
nw 1:9

o

o 3:1
obesity 34:12
object 61:11,15 62:10,13
obligations 65:11
observed 50:7 60:6 66:7
obtain 60:8
obtainable 81:22
obviously 96:20
occur 12:19 36:10 36:15 61:21 71:22 88:7 105:6
occurred 39:2 50:5 79:11
occurs 84:16
offer 57:21 75:19
offered 45:22
offers 41:9 42:2
office 1:8 69:2 77:22 95:1
officer 81:10 113:2
officers 9:19 23:1 66:11,15 68:5 93:5
offices 22:5 41:8 70:1
official 59:16 103:4,5
officials 12:9 13:9 67:2 77:16 82:2,6 83:18 84:10 90:22 91:19 95:13 97:21
oh 15:15
okay 54:2 103:20
old 51:1
older 6:8
olfson 2:10 33:8 33:16 43:10,19 44:4 47:19 50:2 53:13
olson 43:21
ones 72:15 74:17 98:16
ones' 46:16
ongoing 27:20
online 65:4
onsite 21:15
open 48:11 68:3
opening 7:21 10:14
openly 9:21 56:15
opens 50:20
operation 13:14
operations 12:10 12:15 13:7
opinions 47:4
opioid 50:13,15,15 50:15
opportunities 41:15 86:18 92:14
opportunity 23:6 33:1,17 56:5 58:7 85:19 87:22 101:19 106:12 109:18
optimists 86:5
optimized 28:19
options 36:22
oral 69:1
order 17:20 21:3 44:17 81:6
organization 66:10 86:2
organizations 78:10
organize 87:20
organizing 13:22
outburst 30:7
outbursts 81:17
outcome 113:12 114:7
outcomes 16:8 57:9 86:10 87:1

outlined 84:13
outlining 78:11
outweigh 39:18
outweighing 31:9
overall 20:17 39:1
overcome 72:17
overlays 106:14
overload 29:16
oversight 68:19
overstatement 97:2
overt 62:22
overtreated 33:22 38:19
overtreatment 38:8
overwhelmed 25:15
overwhelming 29:8
overwhelms 92:6

p

p 3:1
page 2:1,3
pager's 103:18
painting 67:6
panel 10:22 47:2 55:1,8,14 94:20 100:16 106:2
panelists 14:1,5 23:15 43:17 45:12 54:17 55:10 95:4 107:20 110:4,14 111:16
panels 4:20 14:6 107:21
panic 82:3
panoply 51:17
paranoid 26:15
parent 79:17,17 79:22
parental 77:10 81:20,22 84:4 102:7
parents 3:22 22:21 25:11 27:16 28:5,8 35:19 36:2 36:17 41:6 51:16 63:10 68:7 73:16 74:15 77:8 81:4 87:7,9 89:9,13,18 92:16
parkland 3:16
part 18:1,17 23:8 51:7,19 67:10 95:21
participate 73:12
participation 80:1 84:4
particular 5:14 6:1 10:21 84:2 88:15 97:3 103:13 105:22
particularly 8:2 37:22 39:5 57:13 63:5 88:18
parties 89:16 113:9,11 114:6
partners 12:12 112:2
partnerships 20:6
passage 77:12
patient 68:21
patient's 70:7
patients 15:4 31:20 52:13 69:5 69:8
patterns 33:20 40:14
payment 42:1
pbis 18:5
pediatrician 21:20
pediatricians 38:4
pediatrics 23:20
peers 6:11
penalizing 57:14
penalties 101:1
pennsylvania 1:9
people 6:11,18,21 8:16 9:1,18 20:21 23:3 26:22 29:12 31:12 32:16 33:22 34:10 35:7,12 38:19,20 40:1,4 40:10,17 41:10,14 44:19 48:8,18 49:13,14 50:6,7 50:17,22 51:7 61:1 64:2,17 65:10 71:18,19 72:2 73:6 74:12 97:6 98:15 99:12 109:16
perceived 80:7 84:7
percent 8:15,17 9:2 17:1,3,3 18:21 19:14 27:8,16 28:16,17,22 29:12 30:15,18,21 31:3 31:5,20 34:19,20 71:21
perception 10:4
performance 20:15
period 38:13 108:2
permissible 64:7 64:15 70:12
permit 65:3 83:13 86:15 90:5,19
permits 90:13
permitted 65:20 78:10
permitting 82:19
person 36:3,6 39:12 54:10 60:16 61:15,19,22 62:1 62:4,12 63:1 80:21 88:10
person's 62:4,11
personal 61:13 68:13 74:4 75:7 86:22 87:9 88:4 88:17 89:16 91:13 96:19 110:16 111:17
personalized 87:6
personalizing 26:16
personally 77:6 79:19
personnel 69:16 79:9,16 81:8 82:1 82:9 109:8
perspective 44:9 102:7 105:13
pervades 76:19
pervasive 19:5
phase 36:4
phenomenal 66:22
phone 25:10
phrasing 94:16
physical 11:3 79:4 82:11 83:14 87:21 88:17 90:11
physically 25:14
pick 54:6
picture 18:1
picturing 106:18
pieces 99:9
pivotal 65:13
place 11:15 12:16 15:5,10 79:2 100:13 101:5
placed 109:2
places 8:20 48:16
placing 42:7
plan 4:8 11:20 12:13,15 23:8 27:17
planning 12:6,21 13:11,14,16 51:12

plans 12:10,16 13:2,7 42:19
play 7:14 12:17 23:2 71:4
players 71:12
playground 51:1
please 14:8 55:1 55:13
pleased 5:7 33:16 76:22 108:15 111:10
pleasure 10:16
plus 76:6
poc's 107:11
pocket 25:3
point 22:13 34:9 43:13 57:3 79:5 97:13 103:7 104:11,18 105:2
pointed 50:3 106:16
pointing 53:13
points 21:9 32:7 34:4
police 9:13 81:9
policies 58:6 93:22
policy 55:21 68:9 75:10 77:22 83:3 84:21,22 85:17 93:18,19 95:2
poor 25:18 37:14
population 44:21 51:5
portability 56:9
pose 88:15 92:9
posed 50:14
poses 50:15,16
position 71:3
positioned 72:16
positive 18:5 44:2 57:6,7 108:12 109:10
possess 72:14
possibility 28:12
possible 57:18 71:12 80:1
post 8:7 19:9 46:10,16 79:6
potential 9:6 12:13 36:10 39:17 86:9 87:7 94:3,4 104:15
power 86:6
practical 47:6 91:8 93:10
practice 42:3 68:9 74:19
practices 3:11 4:15 64:7 86:4 97:8 104:5 107:11 109:9
practitioners 38:3
preceding 40:13
precisely 60:13 72:5
preferences 64:9
preferred 84:6
prepared 114:3
preparing 12:9
prescribed 38:12 39:17,21 40:4,20
prescribing 40:8
prescription 28:5
present 78:18 84:7 86:14
presented 23:12 96:9
presenting 47:20
presents 80:22
president 3:14 85:17
press 3:19
pressing 67:7
pressures 47:15
presumption 50:19
pretty 9:20
prevalence 27:7 28:20 56:21 57:1
prevent 61:18 62:6 82:4 84:2 111:21
preventing 20:20 23:4 31:8 77:2 95:13
prevention 18:3,8 21:1,6 22:9,11 46:7,21,21 73:13
preventive 12:18
previous 12:3 108:11
previously 26:11 29:21
primarily 37:18
primary 16:16 41:8
principals 9:20 22:22
principle 74:10 86:3
print 67:7
printouts 98:4
prior 45:22
priorities 56:19
prison 8:16
prisoners 8:15
privacy 9:13 11:16 13:3,15 24:22 56:3,6,8,13 60:3,6,17 61:7 62:19 63:13,20 65:13 68:17 69:3 73:22 74:1 75:21 77:22 78:7 83:20 85:18 86:1,2,10 86:12,17 87:13,19 87:20 88:2,15 89:22 90:2 91:22 92:3,12 93:1,8,16 94:4,9,12,16 97:8 97:10 106:15,17 110:7
private 9:12 42:19 101:12
privately 9:15
privilege 66:5
probably 28:9 29:4 98:12 106:19
problem 8:13 9:7 9:8 10:8 19:5 36:19,21 41:2 49:22
problems 9:1 15:22 16:2,3,7,9 20:14 28:8 29:2,6 30:10 34:13 35:4 35:7,21 36:6 37:10 38:2 40:18 41:7 45:6 61:5
proceeding 113:3
proceedings 113:4 113:6
process 7:15 12:21 13:1,5 53:15 84:4 101:4 112:1
processes 90:7
produce 6:15
productive 73:7 110:21
profession 100:8
professional 37:3 52:10 76:6 82:9
professionals 4:1 4:6 35:12 37:9,13 38:6 40:15 41:16 41:19 42:3,5,9,10
professor 14:14 23:19 33:9
profit 86:1
program 18:9,13 19:9 24:9,19 30:4 30:8 32:2,14 42:1 42:4 46:12 48:2 58:13

programs 21:1,6 22:12 24:16 42:19 45:21 46:14,19 48:1 76:5 87:5 93:22 100:13 109:2
progress 8:5 58:15
prohibit 91:12
prohibited 69:15
prohibiting 61:2
prohibits 77:9
promised 101:10
promote 17:20 22:14 64:11 89:9
promoting 15:17
promotion 65:5
promptly 59:11 92:8
pronounce 14:11
propensity 81:16 81:17
prospective 37:4
prospectives 11:11
protect 25:4 49:13 62:22 73:21 82:10 87:1 90:2,13
protected 59:22 62:20 64:14 92:12
protecting 13:20 63:16 104:12
protection 25:1 104:2
protections 56:3,8 56:13 58:17 60:3 60:6,10 61:7 62:20 87:13 89:8 89:9 91:11 94:13
protective 12:18
protects 65:12
proven 22:14
provide 11:11,14 22:6 52:21 81:14 88:5 93:12 95:10 97:15 102:15,19 104:6,17
provided 16:19 19:17 61:20 77:4 78:1 102:21 106:9 111:16
provider 60:2 61:14,17 62:10 69:9 70:6,20 98:9 99:11
providers 56:16 60:8,14 62:18 65:1,10 67:3 69:4 69:7,21 70:5,11 70:16 73:9 97:1 97:21 98:11 100:2 102:14
provides 34:8 43:2 62:12 84:19 109:13
providing 17:9 46:11 47:21 102:1
provision 70:21
provisions 89:19 90:5
provokes 34:2
prudence 83:4
psychiatric 19:16 24:5,14,21 30:6 32:2 33:11 66:18 72:2
psychiatrist 15:3 33:10 52:11 59:13
psychiatrists 20:9 22:2 37:17
psychiatry 14:15 23:20,21 24:10 33:9
psycho 32:13
psychological 8:17,18 9:3,14 30:6
psychologists 20:10 22:2 37:17 92:19
psychosis 31:16 62:14 71:8
psychotherapy 40:12
psychotic 29:20 38:15 39:5,10,13 39:22 40:5,8,11 40:15 67:4
psychotics 29:19
psychotropic 7:3 23:15 33:6,18,21 34:7 38:10,11 39:1 40:19 42:14 42:18,22 43:7
ptac 93:11 102:20
public 5:21 9:2 41:4,8,16 48:14 48:17 58:10,13 68:21 75:19 76:3 76:7 97:20 113:1 113:17
publish 93:11
purpose 3:10
purposes 60:20 62:17 88:9
pursuing 76:13
push 55:12
put 39:16 92:16 100:13
puts 34:10

q

qualified 38:5
quality 6:2 13:7 42:12,13,14,16,21 43:1,2,4,6
question 2:11,17 5:15 33:6 43:15 43:19 45:11 47:1 47:12 48:22 49:4 49:5 50:1 51:9 90:14 95:8 100:15 100:22 101:6 103:11,11 106:2,8
questions 43:14 54:13,18 64:19 94:21 95:4 106:5 107:6,14
quickly 29:6 31:2 53:6
quiet 27:10
quite 9:10,14 31:2 96:11
quote 80:18

r

r 3:1
radar 28:7
raise 51:10,16
raised 75:9 103:11
randall 18:7
randomized 16:18 44:18
range 4:13 42:6 50:22 88:2 103:16
ranging 21:4
raphael 26:14 31:13 32:1
rates 16:4,8 31:11 34:16
rational 77:18 80:12 91:1,5,15 91:20 92:2 95:10
reach 31:21 50:21 92:20
reaching 20:12
readily 35:19
real 31:17 80:15 87:11 106:4,4
reality 72:3
really 8:22 10:22 14:21 19:1,15 43:17 44:8,16 46:6,20 47:18 48:14,17,18 52:11 52:16 54:6,17 98:14 99:4,14 102:8 105:20 110:5,14

reason 27:21
reasonable 26:19 57:16 58:6
reasonably 58:14 61:14 62:6 82:11 83:16
reasons 60:13
receive 4:4 5:20 16:12,14 34:19,20 36:7 37:6 40:20
received 40:11 65:5 67:2
receives 60:16,20
receiving 36:11
recess 55:4
recognition 35:6 89:7
recognize 9:6 50:4 63:19 74:6,19 87:7
recognized 36:6 46:6
recognizing 35:9
recommend 13:16 21:8 41:12,20 43:6 80:10 93:4 93:14
recommendations 3:12 4:11,13 23:12,13 41:2 43:11 45:18 51:20 65:18 85:14 104:5 110:18
recommending 86:18
reconvene 54:22
record 14:7,9 81:13 82:8 113:6
recorded 113:4
records 9:10,11 77:6,9,10,16 79:10,18 80:13 84:5 89:5,13,14 90:6 106:15
recovery 71:4
recruiting 42:8
redress 88:5
reduced 92:13 113:5
referenced 43:20
referral 83:13
referred 24:19 25:5 30:4 53:17
reflexibility 95:11
reforms 85:15
regard 100:22
regarding 64:7 66:2 93:6,10,15 94:1,8
regional 41:18
regions 109:2
registries 22:11
regs 106:6
regular 8:7 24:14 30:1
regularly 67:21
regulate 29:15,16
regulation 83:17 103:14
regulations 47:8 77:13 84:10 90:17 100:21
regulatory 82:21
rehabilitation 58:9
reimbursement 100:3
related 5:12 7:4 19:4 51:6 52:22 55:15 60:15 113:8 114:5
relating 64:13
relationship 16:9 98:8
relative 113:10
relatively 102:22
release 77:10,20 79:18
released 93:18
relevance 63:14
relevant 84:11
reluctance 69:10
reluctant 69:7
reluctantly 38:3
rely 103:6
remain 27:21 73:14 84:6
remarks 7:6,22 10:14 11:1 14:9 107:21 109:19,20 110:11
remind 14:5 55:10
remission 31:21
removal 101:3
remove 83:21 90:17
removed 59:17
repeated 70:8 71:17
repeating 70:15 71:1
replacement 74:9
report 7:7 20:20 53:18 80:10,13 81:1 92:21 93:19
reported 8:18 18:21
reporter 1:21
represent 76:7
representative 61:13
representatives 85:5 106:20
represented 58:22
represents 76:2
require 32:19 83:3
required 68:12
requirement 91:18 96:15
requirements 70:10,13 76:14 86:10
requires 5:21 32:1 32:8 36:21 77:8 80:5
requiring 90:17
research 19:2 33:10 44:11,17 45:17 93:15
researcher 33:10 65:22
residence 14:14
resist 18:12
resource 9:19 17:11 21:16 23:1 93:9
resources 17:20 32:11 64:13,22 65:6 99:1,13
respect 63:5
respecting 11:15
respond 28:10 31:2
responded 27:15 31:3,5
responders 12:10
responding 71:7
response 3:15 12:6 19:5 44:5 54:6 86:16 90:6 91:9
responsibilities 105:3
responsible 13:16
rest 98:17 107:13
restrictions 60:14 104:15
restrictive 10:2
result 15:22 36:12 37:20 46:11,17 47:7 58:21 61:5 88:2 89:5
resulted 79:12
resulting 78:4
results 16:20

resume 55:1
retain 91:11
retention 104:7
return 68:7
returned 59:13 67:13
returning 55:7
reverse 80:16
review 45:21 91:6
revising 13:1,17 104:14
right 19:21 53:8 53:11 55:6 58:5 75:9,10 89:21 97:8,10,10,14 104:21 107:19 111:6
rightly 87:9
rights 11:16 13:3 56:7 58:5 63:13 65:10 69:2 75:20 83:6 101:13 102:8
rise 31:11 47:13 50:13
rising 34:16 38:17
risk 16:5 18:18 21:6 22:15 34:10 34:12 39:11,14 41:10 50:16 54:9 61:22 72:1,4,10 80:9 82:11 86:7 87:21 88:11 92:16 94:3
risks 9:22 31:9 50:13 78:15 86:13 86:14,16,20 87:20 87:21 88:15 89:4 89:7,22 92:3 94:9 94:9
robust 30:17 101:12
role 7:15 12:17 23:2 66:7 71:4 74:20
roles 7:12
roller 98:1
room 1:10 59:17 67:16 69:12,13 106:8
rose 67:17
roughly 37:16
routinely 70:16
rule 52:20 60:17 69:3 85:1
rules 10:3 47:8 58:6 70:12 83:9 97:2 105:3
run 29:10 102:12
running 54:20
rural 20:13 37:14 37:18,20
rush 87:15

s

safe 3:12 11:15 12:17 76:10 78:6 80:11 84:12 94:12
safeguard 77:5
safeguarding 78:7
safeguards 83:19 86:17 89:11 93:1
safely 67:12
safer 6:20 7:13 40:16 85:21
safety 1:1 3:4 4:9 5:12 8:4 11:3,20 13:4 23:9 39:19 60:21 61:19 65:12 68:22 71:16 72:18 75:22 77:2,19 78:2,15 80:4,6 81:11 85:9 86:11 86:16 87:2 90:3,8 90:14,20 91:9,22 92:9 93:7,16 94:1 94:4,9 112:3,7
safetynet.gov. 4:4
sake 75:2
samhsa 108:21 109:13
saying 54:8 97:13
says 99:20 100:10
scale 49:3 110:22
scenario 78:20 79:22 81:8 96:8
schedule 54:20
scheduled 54:19
schemes 89:3
schizophrenia 40:2
scholarship 86:3
school 1:1 3:4,12 3:16,22 4:8,10,15 6:14 7:13 8:4 9:11 9:19 11:3 12:8,9 13:7,11,12 15:5 15:13,18 16:6,22 17:16 19:3,4,11 19:17,19,22 20:15 21:4,14,17 22:7 22:17 23:1,2,9 24:10,20 25:7,9 25:11,20,22 26:5 26:7 28:7,9 30:4 32:10,14 41:10 46:3,14 51:13 54:1 57:6 58:2,10 59:11 63:6,15 65:18 66:15 71:12 71:16 72:6,19 73:5,8,20 75:1,15 75:18,21 76:1,3,5 76:7,8,10,19 77:2 77:2,3,16 78:15 78:21 79:1,6,8,9 79:15,16 80:9,11 80:16,17,19 81:5 81:7,8,19 82:1,6,9 83:15,18,20 84:3 84:10,22 85:4,5,9 89:17 90:21 91:6 92:9,18 93:5,7,16 94:1 95:13 97:21 98:8 102:13 107:6 108:12 109:8 111:1,21 112:7
school's 91:1
schoolchildren 102:4
schools 5:13 7:3 8:7,11 11:13,21 12:13,17 13:2,5,8 13:14 14:17 15:8 15:9,15,16 16:15 16:19 17:8,10,15 18:7,10 19:8 20:4 20:13 21:2,11 22:1,3,13 23:8 24:14,15 32:2,18 32:21,22 41:4,8 41:16 45:19 46:18 47:7 48:16 49:8 57:21 63:4,11 65:2 66:21 68:6 70:16 73:1 74:12 76:13 77:5,8,17 78:2,5,8,14 79:21 83:2,22 84:12 85:21 86:22 87:4 89:12,22 90:4 91:8,17 93:10 94:10,12 95:11,21 96:12 101:9 102:14 105:2 106:3,10 109:10 112:3
schools’ 17:20 75:19
science 20:19
scopes 111:1
scout 25:3 54:1
screen 28:7
screening 41:3,7 41:13 47:20 48:11
se 49:9

search 37:1 88:13
second 3:5 6:8 18:8 25:2 33:8 35:11 36:20 41:15 65:21 80:15
secondary 28:7 58:2,10 63:5,11
secondly 47:6
secret 9:10
secretaries 4:22 110:13
secretary 2:4,5,7 2:20,21,22 3:2 5:2 5:3 7:9 8:2,3 10:11,14,14,15,18 10:19 12:20 13:21 14:2,3,13 23:10 33:3 43:9,14,16 43:16 45:10,11,13 46:22 51:8,9,11 53:5,12 54:15,16 55:6 65:15 75:6 85:12 94:14 95:7 96:18 98:19,21 100:7,15,17,17 101:15,18 103:20 103:21,22 107:4 107:13,19 108:17 109:20,22,22 110:10,10,12 111:6,9 112:5
section 58:8
secure 11:15
security 4:16 11:4 11:5,20 88:6
see 3:19 15:3,4,6 21:20 59:12 97:6 100:11
seeing 47:5,13
seek 36:20 56:14 57:15 59:19 60:3 79:21
seeking 35:10 37:21 58:21 81:6
92:11 93:10
seen 24:12 34:14 38:11 45:20 46:18 50:12 102:10
segments 51:5
self 18:10 28:6
sell 102:14
send 53:18
senior 67:4
sense 63:21
sensible 85:14
sensitive 60:11
sensory 29:7
sent 26:7
sentence 48:19
september 93:17
series 25:8
serious 5:16 8:17 8:18 9:1 29:18 33:7 40:18 45:6 54:9 61:18 64:3 64:17 66:17 71:10
seriously 7:13
serve 67:10
served 20:13 41:16 42:3
serves 15:14 66:19 86:2
service 41:21 56:16 78:10 82:17
services 5:10 7:2 12:1 14:17 15:1 15:21 17:9,14,22 18:3,17,18 19:16 19:21 23:7 33:10 40:12 41:11 47:16 56:12,17 57:22 60:5,9,15 65:19 80:17 83:14 84:1 84:15,16,20 87:17 108:21 111:13
session 2:11,17 110:3
sessions 2:6 4:3 8:1 10:12 46:22 47:3 93:12
set 46:5 64:16,19 82:4 95:19 96:5 105:20
setting 16:22 66:19
settings 66:8 71:11 98:2
seven 6:22 73:1
seventy 31:3
severe 5:17 25:13 29:12 35:1 37:6 39:2
shame 30:22
shape 7:7
share 7:1,17 10:5 55:17 66:1 69:7 70:6 77:1 81:9 82:1 84:11 91:8 96:3 101:21
shared 59:5 60:1 87:10 88:10 90:13
sharing 11:18 12:4 62:13,18 75:7 78:12 82:20 84:18 86:16 87:8 87:16 88:4 92:5 93:7 100:6 105:6 108:4 110:15 111:17
she'd 26:10
sheets 70:5
sheryl 2:8 14:10
shooting 82:12 83:15 84:3
shootings 3:9 77:3 77:17
short 44:5 104:14 108:2
shortages 35:11 37:9,11 41:18 42:9
show 22:4 78:16 92:7 99:19
shown 18:13 19:9 20:11
shows 8:14 80:15 81:5
shut 29:10 74:16
shy 25:22 30:12
side 31:8 39:9,15
sides 108:8
significance 36:18
significant 16:1 32:7 67:10 69:20 80:5,17 90:20 109:12
signs 53:9 92:7
silencers 9:7
similar 46:4 48:5 48:13 68:17
similarly 57:1 83:7
simple 40:22 49:21,22
simply 36:3 39:16
single 66:19
sit 27:9 59:15
site 17:9 18:7
sites 41:22 42:7
sitting 49:1
situation 26:3 32:21 51:18 55:9 79:19 104:20
situations 58:19 61:3,11 64:16 78:16 95:17,19 96:6
six 24:18 31:5 38:13 54:2
sixty 17:5
size 4:7
skill 32:1
skills 18:9,11 25:18 46:16 113:7

slid 28:7
slightly 54:20
slipped 26:12
smoking 25:9 34:13
social 18:10 20:10 22:1,18 29:5 30:14,15 32:14 35:22 52:11 78:9 78:21 81:4 87:22 96:10
societal 47:15
society 86:7 94:6
solicit 4:5
solution 49:22
solutions 41:1
son 28:6 73:18
sonja 2:15 75:13
sonja's 103:6
sophisticated 35:13
sorry 15:15
sort 44:8 50:18 100:3 102:17
sorts 102:16 103:5
sound 30:15,17,18 30:20,21
sounds 53:6 105:5
speak 23:6 24:4 56:6
speaker 23:19 33:8 55:20 65:21 75:13 85:16
speakers 2:3 4:21 5:1,4 7:1,6,16 55:17,18 56:22 75:12 107:20
speaking 4:21 14:16 23:22 33:13
special 36:15 76:16 80:17 111:15
specialized 89:2
specialty 16:16
specific 64:16 83:1 90:12 105:14,17
specifically 64:20 79:3
specifics 85:7
spectrum 50:11
speech 83:5
spite 30:16
spoke 26:21
spontaneously 41:5
staff 12:17 76:10 76:19 78:6,21 79:6 80:21 82:11 108:7
stake 22:17 94:1
stakeholder 106:9
stakeholders 86:19 93:6 94:19 102:15 103:8
standard 77:19 95:10,14 105:10 105:21
standardized 4:8 104:16,22 105:8
standards 42:11 82:19 92:2
standing 83:4 95:2
start 10:18 104:1
started 17:3 54:21
starting 40:11 46:7
starts 29:4 66:18
state 8:15 12:5 13:9 23:21 33:11 42:16 63:16 67:2 68:11 76:1 78:9,9 85:5 106:14,16,20 106:21 107:7,16
statement 78:19 80:18,22 81:2
statements 2:19
states 7:21 16:11 33:19 37:18,19 63:7 82:17 109:3
statistically 72:1
statute 77:12 84:9 85:1 100:21 101:12 103:14
statutory 70:10,21
stay 32:4 45:2
step 70:10 76:19 109:12,14
steps 12:13 13:2 36:14 111:20
stigma 15:19 28:14 32:15 48:4 92:13
stigmatizing 57:14
stimulants 38:16
stone 98:6
stoneman 3:15
stonewalling 69:10 70:3
stoney 24:9
stony 53:16
stood 69:12
stop 12:18 53:10
stopped 26:5 62:4
stops 53:8
stories 111:18
story 67:14 75:8 96:19 99:19
straight 21:19
strategies 57:7,20
strengthen 42:11
stress 19:10 29:9 46:10,16 95:18
strict 90:18
strike 89:20
striking 16:21
striving 11:14
strong 43:3 50:18 60:6 87:13
struck 96:19
struggle 5:16
struggles 73:20
student 13:3 26:11 26:19 52:17 57:4 59:1,3,7,15 66:11 67:9 77:5 78:7 79:17,18 80:6,16 80:20 81:3,4 82:5 82:13 83:20 84:6 86:11 89:17,21 90:2,3,6 91:8 92:5 93:4 106:15,15,17 110:7
student's 81:13,14 81:16 82:8
students 3:8,12,22 5:12 11:14 12:16 15:14,18 16:3 17:1,20 18:11,21 19:14 20:3 21:5 21:18 22:20 24:18 46:10,15 47:21 48:2 52:13 53:1 56:7,11,14,18 57:9,10,12,15,17 57:22 58:3,5,11 58:17,19 59:18 60:2 63:6,6 68:2 68:12,15 76:3,11 76:20 77:9 78:5 78:12,22 79:6,11 80:21 82:10 84:15 85:21 87:12 88:16 89:8,15 90:1,14 91:12 92:3,7,10 92:16,19,22 93:1 94:10,13 98:16 110:6
students’ 86:22 94:4
studied 22:10 29:17
studies 33:20 44:8 44:9 45:20

study 8:14 40:7,10
sub 52:19
subcommittee 68:19 69:22
subject 8:4
submitted 78:19
subpoena 81:6
substance 35:4 52:20 108:18,21
substantial 89:4 95:16 96:7 105:11
substantially 91:7
succeed 58:1
succeeded 67:18
success 20:17
sued 10:7 70:20
suffer 9:3
suffering 30:10 36:13
sufficient 95:11
sufficiently 90:10
suffolk 24:11
suggest 40:14
suggested 51:13
suicidal 57:1
suicide 6:7,8 31:7 31:8,11 34:11,16 47:5,13 49:5,14 50:5,15 57:2 59:3 59:4 62:1 73:4,10 73:13
suicides 23:5 51:6
summarize 40:17
summary 20:14
support 11:9 17:17 21:4 22:18 41:15 46:6 57:12 67:1 73:12 86:4 88:8 90:22 93:7
supported 43:6 85:2
supporting 89:21
supportive 76:11
supports 18:6 27:19 30:7 57:8 84:18 87:14
supremely 72:16
sure 45:13 51:11 95:6,7 98:18 99:21 101:17 103:22 104:4,12 107:2,7,8 111:3,8
surprising 37:5
survey 18:20
susceptible 89:2
suspended 25:5 26:11 54:1 59:11
suspensions 19:3
suspicion 92:7
sustain 87:14
switch 25:15 29:6
symbol 27:3
symptomatic 31:21
symptoms 19:10 28:2 29:8 36:9 46:17 67:5 72:5 74:6
system 8:14,16 15:18 21:4 28:21 39:7 47:15 74:9 84:17 102:15 111:2
systems 9:11 13:12 17:17 46:6 51:13 111:1

t

table 13:6
take 12:13 13:2 28:14 76:19 99:9 104:1,10 105:18 111:21
taken 55:4 83:9 113:3,9
takes 25:18 101:5
talk 12:21 66:9,22 67:15,19 68:5 72:18 105:2,4,15
talked 102:2
talking 14:22 25:19 56:2 95:18
talks 104:17
tangible 109:14
tantrums 25:13,17 27:13
target 88:21
task 25:15
tasks 25:15
taught 9:13
taunting 78:22
teach 46:15
teachers 3:22 9:20 20:3 22:21 27:16 35:19 36:3 48:2 51:16 87:2 103:7 109:8
teaches 18:10,11
team 20:9 51:20 52:9 74:13 110:2
teams 13:16 51:15 52:4
tech 77:17
technical 22:7 77:22 82:22 84:19 93:9,12 108:19 109:1,3
technologies 86:4 87:3
technology 78:2 86:6 87:8 102:13 108:20
teen 28:14
teenagers 72:11 73:3
teens 28:10
tele 20:11
tell 48:10 62:3 69:9
tells 81:3 97:9
temper 27:13
temporary 62:14
ten 109:2
tend 37:13
tens 102:3
term 27:19 39:8 44:9
terms 47:20 52:19 53:19 54:4 81:12 94:18 100:2 105:20
terrific 99:2
test 91:5
testify 85:20
testimony 14:4,7 54:18 65:17 68:20 69:1 86:12 106:16
thank 5:1,2 7:9,16 8:1,3 9:16 10:9,11 10:15,21 11:10 13:21 14:1,2,13 14:19,20 23:6,10 23:11 24:3 28:4 32:20 33:2,3,4,14 33:16 43:9,12,16 43:17 45:10 51:8 54:15,16 55:3,3,7 56:3,5 65:14,15 66:3,4 67:17 75:6 75:7,16,18 85:12 85:18,19 94:11,15 95:7 96:16 98:19 98:19 100:17,19 102:9 103:20,20 106:7 107:19,20 108:4,6 109:22 110:1,4,9,10,13 111:5,9,12 112:4 112:5
thanking 10:18
thanks 111:15
that's 4:11
theft 88:20 89:3
theme 8:9

theory 101:3
therapy 19:16
there's 10:4
thing 26:18 99:17 103:2
things 12:2 25:16 27:10 35:18 47:3 48:13,20 49:2,7 49:16 53:20 73:11 79:7 94:17 97:17 99:7,8,16 102:22 110:22
think 8:5,9 9:8,17 10:2 36:14 38:8 43:8 44:11,13 45:4,9 47:11 49:10,11,15,18 50:1,4 51:8 52:1,8 52:14 54:7,13 59:3 75:8 94:15 95:15,21 97:18 99:1,4,14,17 100:1,10,12 102:6 102:17 103:3,16 105:19 106:8,8,12 106:22 107:15 110:20
thinking 31:18 74:16
third 36:21 42:11 51:6 55:1,8,14 112:6
thirds 38:22
thirsty 106:10,11
thought 25:11 96:7
thoughtful 85:14
thoughts 52:3 57:1 97:16
thousand 76:6
thousands 102:4
threat 51:15 52:4 52:7,15,17 53:7 54:4 61:18 62:6 79:3 80:5,7 82:3 82:13 84:7 90:15 90:20 91:14,19 95:16 96:8 105:18
threatened 59:13 79:3
threatening 25:11
threats 24:20 52:22 53:17 78:15 90:11 91:10 92:9 94:3
three 6:6 7:2 14:6 17:22 19:13 21:9 22:16 31:4 32:6 37:16 39:14 40:13 41:2 76:6 107:21
thresholds 105:4
thrive 23:3 76:12
tier 18:2,17 19:6 19:13
tiered 17:17 21:4 46:5
tiers 17:22
time 44:20,22 51:9 60:17 67:20 79:2 80:2 87:8 89:14 91:2,11 104:20 106:4 108:2 110:15
timely 78:1
times 14:8 37:17 55:12 57:13 77:14 90:9
timidly 67:17
tip 19:12
today 4:19 5:8 6:19,22 7:6,17 8:9 10:17,20 11:11 12:11,22 14:6,16 14:21 23:6 24:4 56:6 66:5 71:15 76:22 78:18 84:13 86:12 94:20 107:21,22 108:5,9 108:15 110:2,3,9 110:15 111:16 112:4
today's 85:20 108:10
today's 13:22
told 67:14 68:8 69:15
tolerate 29:7
tools 98:10
top 19:14 40:7
topic 6:19 10:17 23:15,17
topics 7:2
total 34:20
totality 91:4 92:1
touched 97:19
tourette's 40:3
town 8:21
tragedy 3:15 32:15 72:20 84:15
tragic 77:3
trained 22:9 37:9
training 4:15 18:9 22:6 41:22 70:11 75:2 93:11 101:20 102:16,17 108:19 109:4,7
trainings 65:7
trainor 2:15 75:14 75:16,17 85:12 95:8,15 100:19 101:3 106:7
transcriber 114:1
transcript 114:3
transfer 108:20
transparency 89:10
trauma 19:8
traumatic 19:10 46:10,16
travel 38:1
treat 28:10 29:18 35:12 37:10
treatable 32:8
treated 5:20 28:17 30:16,22 34:6 38:3,14,16,17,21 39:13,14 45:1,2 53:1,11,12
treating 44:15 45:5
treatment 6:2 9:14 15:7 16:12 17:1,4,6,7,8 19:15 19:16,20 22:9 24:5 28:15,18 30:3 31:4 34:5,19 35:3 36:7,12,16 36:21,22 37:7 42:13 45:8 49:6 49:19 54:12 57:16 60:1,20 63:17,21 64:2,9,21 67:20 70:18 71:2 83:8 83:10 98:2
treatments 9:15 16:19 19:13 21:7 21:8 31:1,22,22 32:14,16 46:12
treaty 1:10
trends 33:20
trial 16:18 44:18 44:18
triangle 18:1,2,16 18:17 19:12
triggers 72:10
truancy 35:18
true 113:6
truly 25:6
trump 3:14
trust 15:11 60:7 87:14,15 92:19 93:2
try 14:7 105:15 110:17
trying 40:16 45:5 97:1 105:20 106:4

106:5
turn 10:13 17:13 23:14 24:2 43:14 95:3 96:10
turned 16:22
two 16:18 18:17 19:6 22:6 23:18 35:8 38:22 47:3 48:6 55:17,18 67:16 75:12 78:18 78:22 79:7,11
types 22:13
typewriting 113:5
typical 67:9 81:15
typically 61:5 66:18

u

u.s. 33:22 34:6
ucla 14:14 20:6
uh 49:9 98:12 100:8 101:8,9 104:1 106:7
ultimately 25:5 64:5 67:13 73:9 103:10
unable 88:22
unacceptable 74:22
unaffiliated 89:17
unambiguous 70:1
unauthorized 89:16
unavailable 38:7
unaware 41:6
uncertainty 39:8
uncomfortable 26:3
uncomplicated 27:9
unconstrained 91:18
underemployed 6:14
undermine 86:11
understand 13:10 13:17 22:18 44:12 48:18 54:5 63:3 65:10,11 107:8
understanding 46:9 47:22 78:11 82:18 96:2 102:6 108:3
understatement 69:10
undertreated 33:22
undertreatment 35:6 38:9
unemployment 16:9
uneven 42:14
unfortunate 67:14
unfortunately 3:17 21:1 40:22
unfunded 84:18
unified 15:13 20:7
unintentional 6:10
unique 65:19 72:14 86:14
uniquely 72:16
united 7:21 16:11 33:19 109:3
universal 18:2,4,8 20:22 21:5 46:21 74:21
universities 57:11 63:12 66:12
university 15:4 20:5 23:22 33:11 58:3 59:6,8,16 67:2,11,16 68:9
unmanageable 25:20
unmedicated 44:21
unmet 21:16
unmotivated 26:12
unnecessarily 38:21
unnecessary 82:3
unreasonable 88:5
unspecified 40:8
unsure 81:8
untangle 106:5
untethering 92:1
untreated 28:2 38:2
unwelcome 58:20
upfront 67:19
uphold 101:10
upset 27:14
urban 37:13,18 38:5
urge 41:12,20 43:5 85:3 93:4,14
urged 91:16
urges 84:21
use 7:3 13:19 18:14 20:8 24:1 33:17 35:4 38:9 39:1,5 42:18 43:7 43:22 50:16 86:13 87:16,16 88:3 104:7 105:14 108:18
useful 52:5 97:13 106:2
user 70:4
uses 64:13
usually 105:18
utmost 7:14 94:2

v

value 100:4
variety 19:17 102:10
various 4:16 36:22 77:11
vast 73:8
vendors 102:14
verbal 29:9
verdi 2:16 85:17 85:19 94:14 95:9 100:19 101:11,16 101:17 102:9 104:1
versus 17:2,7
viability 93:21
vice 85:17
victim 72:20 88:18
videos 99:8
viewed 37:4
viewpoints 23:18
violate 10:6 80:14
violation 59:8 70:20 80:9 81:21 101:2
violence 4:17 8:7 18:22 19:2 32:18 57:5 66:10 72:1 77:3 79:2,7,15 80:7 81:18 83:15 84:2 111:21
violent 3:7 24:19 52:7,22 71:17,19 92:7
virginia 77:17
visit 18:7
visits 4:3
visually 102:21
vital 74:20 85:22 93:9
voluntarily 59:1
voluntary 41:7,13
vulnerable 13:20 90:1

w

wait 38:1
waiting 22:4 30:8
wake 89:11
walk 21:19

walked 48:8
wall 98:6
walls 67:7
want 7:7,16 8:3 12:1,11 27:4 32:20 97:14 104:11,13 111:12 111:15
wanted 24:21 26:10 51:10 98:22 103:22
warn 100:9
warning 12:4 53:9
washington 1:11 85:18
way 9:17 25:15 35:14 45:7 47:10 50:22 54:8 64:22 65:12 74:1 92:5 94:16 104:22
ways 11:8,22 17:13 21:12 23:7 52:2 87:11 99:22 102:10 105:19 110:22
we've 24:12 40:3 43:13 44:7 46:18 50:12 52:1 53:21 54:13 94:20 97:18 102:1
wealth 110:15 111:16
web 106:13,21
website 70:6 98:11 99:6 102:1
weight 39:10
weird 26:22
welcome 3:3 14:10 55:7
welfare 42:20
went 90:21
we'll 12:21 14:6,8
we're 5:14 12:2
we've 8:8 9:5 12:3
whip 98:6
wide 17:16 51:5 61:8
widely 65:6
wider 99:8
widespread 38:9
williams 2:22 94:22 95:3,6 96:16 107:12,17 111:7,8
willingness 60:8
wind 101:8
withdrawal 35:22
withdrawn 26:15
withdrew 26:6
withheld 73:21
withhold 70:17
wonder 97:3,12 104:16 105:22
wondered 45:17
wonderful 23:10
word 48:7,17
words 17:5 53:7 70:6 79:12 96:9 101:8 107:6,10
work 3:21 4:19 11:7 13:4,9 15:15 15:16 21:18 23:4 41:16 52:3 68:5 76:8 77:2 78:8 85:11,21 95:21 98:7 104:17 105:11 110:2,8 111:19
worked 27:17
worker 52:11
workers 20:10 22:1,22
workforce 21:11 21:22 22:8
working 3:19 8:10 66:15 67:20
works 32:13
world 80:15 99:4 99:16
worldwide 27:7
worried 24:20 31:6
worries 92:12
worry 87:9
worse 16:8 73:2 89:2
worship 48:16
worst 104:20
wouldn't 9:17
wounded 73:2
written 69:1 102:19,21
wrong 49:22
wrongful 88:13
wrote 26:21

x

x 2:2

y

yeah 46:1 51:11 53:5 97:18 100:7 101:11 102:9
year 3:14 18:22 34:17 38:13 60:6 73:2,3 79:1
years 15:12 34:14 42:4 53:18 56:22 66:9 77:4 88:22 89:20 103:3
yep 107:18
york 23:22 24:11 33:11
young 6:18,21 20:21 23:3 31:12 33:21 34:10 35:7 35:12 36:3,6 38:19,20 39:6,12 40:1,4,10,17 41:10,14 44:1,10 49:13 50:6,7,12 51:6 56:20 57:2 66:14 67:22 71:2 72:11 73:4,5 74:11 88:21 109:15
younger 50:17
youth 3:7 6:3,9 16:11,14 17:5 18:18 22:12 28:16 34:16 39:2 41:4