Statement of Jennifer Mathis

Before the Federal Commission on School Safety

U.S. Department of Health and Human Services

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Secretary DeVos, Secretary Azar, General Sessions, and Secretary Nielson:

Thank you for the opportunity to speak to the Commission concerning the privacy rights of students with mental health disabilities. The privacy protections of the Health Information Portability and Accountability Act, or HIPAA, are extraordinarily important for individuals with mental health disabilities, including students, to have effective access to services. Without the assurance of privacy protections, students are both less likely to seek out help when they need it and less likely to engage openly with mental health counselors or other service providers.

Ensuring that services are available for students with mental health disabilities should be one of our highest priorities. Among adolescents and young adults, the prevalence of major depressive episodes has increased in recent years.[1] Similarly, the prevalence of suicidal thoughts and suicide attempts has increased among young adults.[2] It is important to point out that having a mental health disability does not make a student any more likely to engage in violence toward others. But implementing measures to create a positive school climate, including through

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[1] Ramin Mojtabai et al., *National Trends in the Prevalence and Treatment of Depression in Adolescents and Young Adults*, Pediatrics, vol. 138, no. 6 (Dec. 2016).

[2] Beth Han, *National Trends in the Prevalence of Suicidal Ideation and Behavior Among Young Adults and Receipt of Mental Health Care Among Suicidal Young Adults*, Journal of American Academy of Child and Adolescent Psychiatry, vol. 57, no. 1 (Jan. 2018).

strategies such as positive behavioral interventions and supports, improves academic and behavioral outcomes for all students, including students with disabilities.[3] In colleges and universities, it is critical to implement measures to support students with mental health disabilities—particularly in times of crisis— rather than stigmatizing and penalizing them. For example, encouraging students to seek help or treatment that they may need, making reasonable accommodations to enable students to continue their education as normally as possible, and ensuring the confidentiality of mental health information are all important strategies.

Our schools must have the capacity to offer students with mental health disabilities the services they need to succeed, both at the elementary and secondary school level as well as for college and university students. A number of federal laws afford these students rights—including, for example, the right to reasonable modifications to rules and policies to ensure equal opportunity, guaranteed by the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act. For elementary and secondary public school students, the Individuals with Disabilities Education Act (IDEA) also guarantees a free and appropriate public education, including an educational program that is "appropriately ambitious" and "reasonably calculated to enable a child to make progress appropriate in light of the child's circumstances."[4]

Despite these protections, many students continue to face challenges in getting the help they need. In too many situations, students with mental health disabilities are made to feel unwelcome, and seeking help may result in negative consequences. In one example, the Bazelon

[3] See educational services described in Brief of Former Officials of the U.S. Department of Education as Amici Curiae in Support of Petitioner, *Endrew F. v. Douglas County School District RE-1* (Nov. 21, 2016), at 10-25, http://www.scotusblog.com/wp-content/uploads/2016/11/15-827-amicus-petitioner-FormerU.S.DeptofEduc.Officials.pdf.

[4] *Endrew F. v. Douglas County School District RE-1*, 137 S.Ct. 988, 999, 1000 (2017).

Center represented a college student who voluntarily admitted himself to a campus hospital after his close friend committed suicide, because the student had begun to think generally about suicide. The hospital shared his health information with university administrators and, the next day, while still in the hospital, the student was handed a letter from the university charging him with a violation of the disciplinary code, allegedly for endangering himself. He was suspended from school, barred from entering the campus (including to see his psychiatrist), and threatened with arrest if he returned to his dorm. The student had to sit in a car with a university official while his father and friends removed his belongings from his dorm room. Students learn from these experiences and are far less likely to seek help or disclose important information in the future.

In light of the negative consequences that may flow from the disclosure of protected health information shared in confidence with a treatment provider, it is critical that students be afforded basic privacy protections if we expect them to seek help. As the Department of Health and Human Services observed last year, "[e]nsuring strong privacy protections is critical to maintaining individuals' trust in their health care providers and willingness to obtain needed health care services, and these protections are especially important where very sensitive information is concerned, such as mental health information."[5]

It is precisely for these reasons that HIPAA imposes restrictions on when health care providers can disclose information related to health care services that a person receives. At the same time, HIPAA's privacy rule is "carefully balanced" to allow disclosure of information

[5] U.S. Dep't of Health and Human Services, Office for Civil Rights, HIPAA Privacy Rule and Sharing Information Related to Mental Health (Dec. 2017), at 1.

where necessary to ensure that an individual "receives the best treatment and for other important purposes, such as for the health and safety of the [individual] or others."[6]

While some people have blamed HIPAA for prohibiting disclosure of health information to family members in situations where their involvement would make an important difference, that blame is misplaced. The problems described typically result from the misapplication and misunderstanding of HIPAA. Exceptions to HIPAA's privacy protections allow disclosures to family members in a wide array of circumstances. For example:

- HIPAA allows disclosure in situations where an individual does not object to the disclosure of information to a family member or personal representative, including where the health provider reasonably infers based on the circumstances that the person does not object.[7]
- HIPAA allows disclosure where a health provider believes in good faith that disclosure is necessary to prevent or lessen a serious threat to the health or safety of the person or others.[8] HHS has provided examples of when that may occur—including where a doctor knows from past experience that a person is at high risk of committing suicide when the person is not taking medication at a certain level. In that instance, the doctor may tell the person's family that the person has stopped taking the medication if the doctor believes the family member is reasonably able to prevent or lessen the threat of harm.[9]

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[6] *Id.*

[7] 45 C.F.R. § 164.510(b)(2).

[8] Id. § 164.512(j).

[9] U.S. Dep't of Health & Human Services, HIPAA Privacy Rule and Sharing Information Related to Mental Health, *supra* note 2, at 4.

- HIPAA also allows disclosure in emergency circumstances, or where the individual lacks the capacity to consent or object, and the provider determines that disclosure is in the person's best interests.[10] HHS provides the example of a person who cannot meaningfully agree or object to the sharing of information due to temporary psychosis or the influence of drugs or alcohol.[11]

These exceptions to HIPAA's privacy protections allow disclosure of protected mental health information where it is necessary, including to avert a danger, to deal with an emergency, or to protect the interests of a person who is incapacitated.

Given the focus of this Commission, it is also important to understand that HIPAA's application to children and adolescents in schools is limited—particularly with respect to elementary and secondary school students. Moreover, for all students who are under the age of majority, which in most states is 18, HIPAA has been interpreted as generally allowing disclosures of their health information to their parents.[12] For elementary and secondary schools as well as for colleges and universities, FERPA—the Federal Education Records Privacy Act—may have more relevance than HIPAA.[13] In addition, in both school and other contexts, there are state laws protecting the confidentiality of health and mental health treatment information.

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[10] 45 C.F.R. § 164.510(b)(3).

[11] U.S. Dep't of Health & Human Services, HIPAA Privacy Rule and Sharing Information Related to Mental Health, *supra* note 2, at 3.

[12] *Id.*

[13] U.S. Dep't of Health & Human Services and U.S. Dep't of Education, Joint Guidance on the Application of the Family Educational Rights and Privacy Act (FERPA) and the Health Insurance Portability and Accountability Act of 1996 (HIPAA) to Student Health Records (Nov. 2008), at 3-4, 6-7, 9.

Like federal law, they recognize the importance of affording privacy to encourage treatment, and include commonsense exceptions.

Congress recently considered whether HIPAA interfered with effective treatment for people with serious mental illnesses. After extensive deliberation, Congress ultimately concluded in the 21st Century Cures Act that "[t]here is confusion in the health care community regarding permissible practices" under HIPAA and that "[t]his confusion may hinder appropriate communication of health care information or treatment preferences with appropriate caregivers."[14] To promote clarity, Congress directed HHS to create "adequate, accessible, and easily comprehensible resources relating to appropriate uses and disclosures of protected information under HIPAA" and to issue a guidance clarifying permissible disclosures and addressing a set of specific situations involving families of people with serious mental illnesses.[15] In December 2017, HHS issued this guidance, along with a new set of "Frequently Asked Questions" and other materials specifically addressing HIPAA's application to mental health treatment information.

These resources from HHS would go a long way toward clarifying for providers as well as for individuals and their families what HIPAA actually does and does not permit. They are available online, but have not received much attention or promotion. Much more could be done to ensure that these resources are widely distributed and are used in connection with trainings and other education. We would all benefit from measures to ensure that people understand their rights and providers understand their obligations, so that HIPAA can be implemented in a way

[14] Pub. L. No. 114-255, § 11001(a)(9).

[15] *Id.* § 11003.

that protects both safety and the important privacy rights that are pivotal to good and effective mental health care.