

Full Script

Privacy Training Module

Slide 1: (Neera) Title Slide

Welcome to the third module in a series of trainings for health science faculty and administrators: ***Maintaining Privacy: Supporting Students with Disabilities.***

My name is Neera Jain, and I am a Disability Consultant at the University of California, San Francisco and a doctoral student at the University of Auckland. I'm here with Jan Serrantino, Director of the Disability Services Center at the University of California, Irvine.

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Slide 2: (Neera)

Today we will assist faculty and administrators to build on one of our core values: maintaining an environment where all students feel safe, supported and protected, through a better understanding of how to maintain privacy of students' disability information and related needs.

Slide 3: (Neera) Learning Objectives

Through this training module participants will:

- Understand what is meant by privacy.
- Learn the reasons maintaining privacy of students with disabilities is important.
- Recognize how the FERPA 'need to know' rule is relevant as it pertains to communication with other faculty & staff.
- Understand best practices for maintaining privacy of electronic information
- Recognize the importance of making a referral

Please note that this discussion does not cover situations in which faculty and staff may be mandated reporters under state law or university policy.

Slide 4: (Neera) What is Privacy?

Many students raise concerns about how their disability information will be shared. As we explore this topic it is helpful to first clarify what is meant by privacy.

Privacy refers to the student's control over how much information they share with others. As university administrators, we must respect a student's privacy by not

creating a situation where students feel compelled to share information they are not comfortable divulging, for example, through asking students about their diagnosis, about medications they are taking, or whether they need a recommendation for a good therapist.

As university employees, legislation governs how we treat private information once a student has disclosed a disability to us. This includes information such as disability documentation, diagnosis, registration status, and approved accommodations. This information is protected by law.

Slide 5: (Jan) Legal Framework: FERPA

The law that guides our understanding about how privacy of student information should be maintained is called FERPA, or the “Family Educational Rights and Privacy Act.” This is the law that covers education records.

All disability related information is considered part of a student’s education record, and is covered by FERPA. This includes electronic, paper, and any other types of written communication.

Under FERPA, information can be shared for a legitimate educational purpose, commonly known as “the need to know,” and information can be shared to protect health and safety

In the case of disability, the information that faculty “need to know” will generally be focused on the student’s approved accommodations.

In some cases, specific information may be shared about “functional limitations,” or how the student’s disability affects them in the particular setting, as a part of the interactive process to determine appropriate accommodations.

- Unauthorized disclosures of student information **must** be documented and investigated. This can result in the University being held in non-compliance with federal regulations.
- If a complaint is filed, the Office for Civil Rights (OCR) may audit FERPA compliance and require corrective actions.
- Disclosures may also violate state privacy laws and may subject the university and the individual to liability.

Slide 6: (Jan) Why is privacy important?

Aside from the legal obligations, why should faculty care about privacy?

It is important to respect the privacy of students and their documentation to ensure that students feel safe requesting and utilizing their accommodations.

Students with disabilities studying the health sciences often voice concern regarding the “consequences” of registering with disability services, They are especially concerned with how information is shared—who will know about their disability, and who will have access to their documentation.

Much of this concern is rooted in the fear of stigma. Students may fear that they will be treated differently if others know about their disability.

Students may be concerned that others will view their accommodations as an “unfair” advantage.

Students are often concerned about how this information can be used against them in the future, for example, whether it might affect their ability to be licensed, get malpractice insurance, or whether it might become evidence against them in a lawsuit.

Many students also experience a high level of stress related to accessing accommodations and discussing them with faculty. They may forgo using accommodations altogether out of concerns about privacy and confidentiality. This can result in students not disclosing their disability until they are in academic jeopardy or are on the brink of being dismissed.

Slide 7: (Neera) Tips: Guarding Sensitive Information

So, what are some basic things you can do to help guard this sensitive information?

All information that disability services or a student shares with a faculty member **is to be used specifically for arranging accommodations** for the course of study.

Be sure to discuss accommodation letters and logistics of implementing accommodations with students in private. You can do this by making yourself available by email, during office hours, or by appointment to discuss.

Faculty should avoid requesting specific information about a student’s disability. Instead, focus any inquiry on how a student’s learning is affected by their disability.

Do not request a letter from the student’s physician to justify accommodations. If you have questions about the appropriateness of an accommodation, discuss this with disability services.

If a student voluntarily discloses the nature of their disability to you, even if it is obvious, do not disclose it to others.

If a student tries to provide you with their disability-related health records, such as letters from their doctor or other medical evaluations, do not to read or accept them and refer the student back to the office that oversees disability-related resources.

Refrain from discussing a student's disability status and necessary accommodations within hearing range of fellow students, staff, or others who do not have an "educational need to know."

A class should never be informed that a student has a disability, except at the student's request.

Slide 8: (Neera) Maintain an environment where students with disabilities....

In summary, while meeting our legal obligations is important, maintaining a high standard of privacy also serves to maintain an environment in which students with disabilities feel respected, safe, supported, and protected.

We recommend maintaining a high level of vigilance to avoid inadvertent disclosures. In short, treat student information as you would that of your patients.

Demonstrating respect, and strict adherence to protocol, also encourages a professional standard for students to emulate as they interact with patients.

Slide 9: (Neera) Review Question

Now, let's review what we've learned so far with a question.

Why is maintaining privacy of students with disabilities important?

- a) Disability-related information is protected by FERPA, and so is only to be shared for a legitimate educational purpose.
- b) Many students hesitate to access disability supports because they are concerned about who will have access to their personal information
- c) The university may be investigated if a student's disability-related information is breached
- d) Taking care with how we handle personal information helps to create a safe and supportive environment for students with disabilities
- e) **All of the above**

Slide 10: (Neera) Answer

The correct answer is e, all of the above – all are important reasons to maintain privacy: because students are concerned about sharing their personal information, only share what is necessary for an educational purpose. If you believe privacy of a student has been breached, it is important to contact the FERPA officer at your institution.

Slide 11: (Jan) What and when do others need to know?

Faculty often find themselves in situations where information about a student has to be shared in order to implement accommodations, and they are unsure how to proceed. So, what constitutes a legitimate educational purpose, and what information may be communicated to others?

Let's review some examples:

1. Co-instructors are jointly responsible for providing accommodations. They should receive the accommodation letter and be aware of the student's approved accommodations.
2. Exam proctors only need to know the student's name and approved accommodations relevant to the exam.
3. Colleagues who are planning for future courses need to know the number of students requiring testing accommodations to plan for exam space (but not the names). This is particularly important as students can choose **when** to use their accommodations and may wish to **opt out** of accommodations for a particular course or clerkship for a number of reasons.
4. Preceptors only need to know the approved on-site accommodations, not why the student requires them, nor do they need a copy of the accommodation letter.

You can see that the information to be shared is carefully selected based on the person's role in the student's education. If you ever have any doubt about what to share with whom, consult with disability services.

Slide 12: (Jan) Electronic Communication

Now, let's talk for a moment about electronic communication.

In this digital age, the ease of communication and portability of devices can result in inadvertent breaches of confidential information. Email is particularly vulnerable to breaches of privacy.

Faculty must pay close attention to how they store disability-related information, such as accommodation letters, to ensure that they are not visible or accessible to

others. They should also refrain from placing these letters in a shared drive that may be accessible to others.

It is critical that emails are sent to the intended recipient, that all information contained in the email is necessary for everyone receiving it. Follow your institution's policies and mark this communication as "secure" or "confidential." **Remember that emails seem like a private means of communication and they may also later serve as evidence in legal matters so be cognizant of what you are communicating and writing.**

Slide 13: (Jan) Tips for Guarding E-Information

What are some ways to protect private electronic information?

1. **Do not leave student disability information visible** on your computer desktop, or in any printed format that others can see.
2. **Letters of accommodation should be filed in a safe place** and disposed of securely at the end of the term.
3. **When you send an email to a group of students**, even if they are all registered with Disabilities Services, **blind copy (bcc) all recipients** so they cannot access each other's information, or better yet, send separate emails to each student.
4. **Beware of email threads.** Before forwarding an email to a new participant, or adding a new receiver to an email, look back through the full email thread to ensure it does not include confidential information. Or, better yet, start a new email and copy in only the specific, relevant information and people to ensure confidential information isn't accidentally shared.

Slide 14: (Jan) Review Question

Now, let's review what we have learned so far with a scenario:

A student provides you with an accommodation letter from Disability Services, but their disability is not obvious. The student has been struggling and you are concerned about how to best support their learning.

What is the appropriate response?

Slide 15: (Jan) Review Question

Should you:

- a) Ask the student to bring a letter from their doctor with more specific information about their disability so you can fully understand what barriers they might be facing.
- b) Explain that you are supportive of their use of accommodations, and discuss how they will be implemented in your course.

- c) Ask the student if there is anything you can do to support their disability-related health care treatment.
- d) Explain that in order to understand their needs, you'll need to read up on their disability. Ask the student for their diagnosis so you can look for any helpful information about teaching students with that condition.

Slide 16: (Jan) Answer

The correct answer is b) Explain that you are supportive of their use of accommodations, and discuss how they will be implemented in your course.

The best way to support a student is to provide the approved accommodations, and remain focused on educational objectives of your course. It is always appropriate to refer students to other supports on campus, for example: learning resources, disability services or counseling.

Slide 17: (Neera) Scenario

Now, let's work through another scenario together:

A student was reluctant to disclose his disability and access accommodations. When registering with the DS office he was assured that information about his disability would be kept private. Later the student overheard you speaking to his clinical supervisor about the accommodations he would be using while on the ward. The student complains to disability services about what he heard.

Slide 18: (Neera) Was privacy breached? Why or why not?

Was privacy breached? Why or Why Not?

This scenario is a common occurrence in clinical settings and we understand that faculty may forget that the hospital environment is not a completely private setting. In this situation the clinical supervisor may have a "need to know" that is legitimate and serves to support the implementation of accommodations in that setting. FERPA allows disclosure, however, the fact that the student was able to overhear the conversation suggests that it was held in an open setting. Imagine the impact if the student's peers had also overheard the conversation.

It is critical that we take the time to step into a private space to discuss disability related needs. Doing so will help promote a culture of respect for privacy that will increase students' comfort disclosing their disability and using related services.

Slide 19: (Neera) How to resolve the situation?

So how might we work to resolve this situation?

In this case, the faculty member should consider apologizing to the student, and reassure them that in future, accommodation needs will be discussed in private spaces.

Review your campus best practices for maintaining privacy of disability information.

Finally, any breach, no matter how small, should be reviewed with your FERPA officer to report the situation per campus policy.

Slide 20: (Jan) Making necessary referrals

There will be times when you need to refer students who have disclosed their disability to you, who you suspect have a disability, or who may be experiencing difficulty and need support.

The most important thing for faculty to do is to support the student, explain that you will not repeat the information shared, and direct them to the resources available on campus.

As a faculty member, you are considered an agent of the institution. As such you are **required** to notify students who disclose a disability to you of the formal campus procedures for accessing disability accommodations. If a student is struggling and you suspect they may have a disability you are encouraged to refer them to your disability services office or the designated resource as directed by your institution.

When faculty communicate their support and encouragement to utilize services, students tend to follow through. For example, you may say that in your experience, other students have found the office to be helpful, and that it will not be a problem to provide accommodations once approved. This will aid in developing a culture of inclusion rather than perpetuating the stigma that often accompanies using accommodations.

Make it a practice to follow up with the student to provide referral information in writing. It is valuable to create a paper trail in the chance that the student does poorly as a result of not accessing accommodations. You may offer to contact disability services, with student's permission, to make the initial introductions.

If concerns arise about patient safety or student wellness, follow your campus policy to make the necessary referrals.

Slide 21: (Jan) Scenario

Now, let's review another scenario:

A student confides in you that she was recently diagnosed with a mental health disability and is struggling with her medication, maintaining attendance, and studying. She wonders if a leave of absence is needed, or what other options might be available, but is worried about others knowing about her diagnosis.

Slide 22: (Jan) How might you respond?

How might we honor the student's need for privacy while connecting her to the appropriate campus resources?

It is important to know that many students believe they have to disclose detailed information about their wellness to multiple faculty and administrators in order to access accommodations, leaves of absence, or other academic adjustments. Working under these assumptions, students may choose to “stick it out” placing their health and academic progress in jeopardy.

Students may not know what supports exist to help them identify options.

Faculty should encourage students to meet with disability services, who will discuss a range of supports that may be available, including the possibility of a leave of absence. Explain that disability services can clarify how privacy is maintained – without requiring students to provide extensive details to multiple faculty and administrators.

In this way we reassure students that private information is maintained within the disability services office, and communicate our willingness to work together to put the right supports in place.

By making the student aware of the available resources, we encourage students to place their wellness first and show our support in that effort.

Slide 23: (Neera) In Summary

To summarize what we have talked about in this training:

- Maintaining and respecting privacy about students' disability related needs is important to ensure students receive needed supports and to build a culture of inclusion where *all* students feel safe, supported, and protected—which is one of our core values.
- Limited information may be shared with colleagues for legitimate educational purposes
- Demonstrating respect and strict adherence to protocol for privacy encourages a professional standard for students to emulate as they interact with patients.

Slide 24: (Neera) References

This training was informed by the following resources:

- The Family Educational Rights and Privacy Act of 1974
- The 2015 article “Qualitative analysis of the barriers college students with disabilities experience in higher education, by Hong, published in the Journal of College Student Development.”
- The chapter “Professionalism and Communication About Disabilities and Accommodations” by Meeks, Jain, Aceteson, and Phair from the edited book, The Guide to Assisting Students with Disabilities: Equal Access in Health Science and Professional Education, Springer Publishing.
- The 2003 article “Out of the disability closet: Strategic use of perception management by select university students with disabilities” by Olney and Brockelman, published in the journal “Disability & Society”.