



NATIONAL **BLEEDING DISORDERS** FOUNDATION



HEDI: Equitable Education: Support for Young Adults Navigating Higher Education

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HEDI: Equitable Education:

Support for Young Adults Navigating Higher Education

As young adult students transition into higher education environments through community college, trade school, vocational school, college, or university, the importance of advocating for themselves is critical to their success.

This document outlines the process of maximizing tools for individuals living with serious, chronic health conditions. Some students may have had accommodations through grade and high school attained by their parents or guardians. In higher education, it is the responsibility of the young adult student to initiate the process in higher education. The federal law **Family Education Rights and Privacy Act (FERPA)** protects the privacy of students, therefore under confidentiality rules, parents and guardians are not able to gain information on the student without their written consent (U.S. Dept. Education FERPA). It is the responsibility of the student to request assistance and support. This tool is a guide and template for navigating accommodations. NBDF strongly recommends young adult students seek support and assistance from their health care team and support system for optimal success in this process.

Disclosure

Plan ahead: Disclosing medical needs during the school admission application process provides opportunities for specific protection under the U.S. Department of Education Office for Civil Rights (**U.S. Dept. of Education**). This can start at the beginning of the education process through the application to the school, or after acceptance and enrollment. The process may take up to four weeks or longer. Starting earlier in the process will help expedite access to tools and resources when needed. The young adult student may not need the accommodations, however starting the process early prepares everyone for coordinating services.

Coordinate care: Young adults should talk to their bleeding disorder health care team such as the Hemophilia Treatment Center (HTC) or doctor's office to discuss how to create and provide medical documentation. In some instances, an HTC travel letter can be used as documentation. The social worker or nurse can help.



Important Laws Defined:

Americans with Disabilities Act

The **ADA** does not contain a definitive list of medical conditions that constitute disabilities. Instead, the ADA defines a person with a disability as someone who (1) has a physical or mental impairment that substantially limits one or more "major life activities," (2) has a record of such an impairment, or (3) is regarded as having such an impairment.

504 Plan

U.S. Rehabilitation Act of 1973 outlines that any organization or institution, including schools, receiving federal money cannot discriminate against people with disabilities.

ADA U.S. Department of Justice

Title IX

Title IX (nine) of the Education Amendments of 1972 protects people from discrimination based on sex. "No person in the United States shall, on the basis of sex, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any education program or activity receiving Federal financial assistance".

US Dept. Education Title IX



Higher Education Office of Access & Learning Accommodation (OALA):

Each school receiving federal funding is required to have a policy and procedure for creating Accessibility and Accommodations.

They also will have an office addressing equity and Title IX. These are often called “ the Office of Institutional Equity & Title IX”. Sometimes these are separate offices, other times they are in the same office, depending on the institution.



Office of Institutional Equity:

The office for Institutional Equity administers equitable policies, procedures, and response to incidents of sexual misconduct, bias, and discrimination. All higher education institutions are required to offer an Office for Institutional Equity if they are receiving federal funding.

What is a medical accommodation plan?

Accommodations: Federal laws allow for accommodations and accessibility for individuals with serious chronic health conditions under the Americans with Disabilities Act (ADA) with appropriate medical documentation.

Assistance: Each institution receiving federal funding is required to provide staff to help with this process. The department assists with creating a plan to help adjust the student's education curriculum if/when they have a condition that prevents them from accessing education with the other students. This can be referred to as an Individualized Healthcare Plan, Individualized Education Plan (IEP) or a 504 plan. In this document, this plan is called an Accessibility & Accommodation Plan.



Why is it important:

Easier access: Creating an Accessibility & Accommodation Plan for daily tasks of getting to class or before issues arise is incredibly important. In the daily life of a student, distance to walk to class may be challenging, use of assistive devices such as crutches or a wheelchair may have barriers. In the event of an unexpected bleed or hospitalization is incredibly important. Creating the Plan allows timely adjustment to the student's routine to adjust to the change in routine. Many students may have had a plan in grade school or high school. This is the same process; However, it does need to be initiated by the young adult student at the new school or institution because it does not transfer. Some schools may require it to be submitted every semester. To help with the process, some higher education schools/institutions may provide an advocate or social worker to help the student navigate the process.



What documentation is required?

Requirements

Students will need to complete a form that will include demographic information, medical information, and may have portions that need to be completed by the medical clinical care team.

Clarification

Documentation needs to be provided by the student because it is confidential. The information provides information on how to classify the condition or impairment.

The length of the condition:

- **Permanent:** People living with a bleeding disorder have a permanent health condition. This means they live with the condition throughout their entire lifetime. An Accessibility & Accommodation Plan should be considered for the main bleeding disorder diagnosis.
- **Temporary:** Medical issues such as a bleed are considered “temporary”, meaning it’s a shorter time frame of a specific incident that causes medical treatment and need for time in the healing process.
- **Can it be both?** Yes. The limitations associated and functional impairments from the health condition is specific to the student. It’s best to talk to your healthcare team about how to outline your specific needs.

Requested Accommodations

- Students can ask for accommodation based on their medical needs; however, this does not guarantee they will receive the accommodation. They will work together with the institution to create a plan. Accommodation varies between institutions and may also be different depending on the type of request and the type of class.
- Students should consider experiences that they have had in the last two years of previous schooling to consider what may be requested. Examples may include:
 - History of hospitalizations
 - Joint bleeds limiting mobility
 - Pain with mobility including issues with hemophilic arthropathy
 - Frequent and persistent nose bleeds
 - Fatigue from anemia impedes the ability to get to the classroom and attend class.
 - Medication use, need for access to refrigeration

An example of a request for accommodation may include a request for extra time in between classes, parking access closer to buildings to limit walking, or joining the class through video conferencing. Some accommodation requests may include talk to text document creation due to limited mobility. The accommodation will also vary based on the subject matter of the class and requirements for participation.



What to consider:

- What is your current treatment plan for routine, preventive care, and emergency care? How would that be challenging if you were in a classroom setting away from your home medicine?
- Discussing the treatment plan with your care team while creating the Accommodation request is important to consider all options.



When to submit documentation:

Plan ahead! It can take up to six to eight weeks to complete the request! Create a timeline by working backwards from the start of the semester.

Student Timeline: The student will need to find out where the Accommodation requests are filed with the institution, what the form is, and complete the document.

- Once a student is accepted and enrolled into the higher education program, the student should start the process for requesting an Accessibility & Accommodation Plan.
- Need help? Use your resources and network! Non-profit organizations in the community including Chapters are a great resource! Resources listed below.

Healthcare team timeline: Working with your healthcare team to understand how long it will take to work together on to create the request is important. Health care providers will need two to four weeks to process request.

Institution/School timeline: The process takes time, and there are several steps to process it in the system. The process can take two to four weeks; sometimes longer.

- Students should not wait until there is a medical issue to file a request. They can file a request for a plan proactively and may not use it depending on their healthcare needs. It is important to note accommodation is not able to be provided retroactively.

What is the process:

Students should review the school's student handbook for guidance. The process is different at each school; however, it will generally contain the following steps:

1. Once the student is accepted to the higher education institution, they should notify their health care team. The health care team should be involved in the creation of the Accessibility & Accommodation Plan.
2. The student should discuss this process with the health care team at least two months before school begins.
3. The health care team may need time to review documentation and the request.
4. The student will complete the documentation and submit it to the school for review.
5. The students will meet with a representative of the school to discuss their needs and request for potential accommodation.
6. The institution will review the request and determine if the request is approved. Determination of reasonable accommodations will be considered, which may include alternative plan of accommodations with consideration of the tasks and requirements of the subject and class, and the potential limitations of the student.
7. A determination letter will be sent to the student with the outcome of the decision.
8. The student has the right to appeal against the decision if they are dissatisfied with the outcome.
9. The school may notify the instructors of the student. Some institutions will require the instructor to review, sign and return the plan to the OALA office.
10. It is the responsibility of the student to notify the instructors of the Accessibility & Accommodation Plan. The student should proactively communicate with all instructors at the beginning of each semester by requesting an appointment during office hours. Email communication is also recommended to provide documentation of communication.
11. Accommodation letters expire, and it is the student's responsibility to renew in compliance with the rules of the school.



Commonly requested accommodations include (but are not limited to):

- Extended time on exams and extra time to get to classes
- Use of laptops for tests and exams
- Use of calculators for tests and exams
- Course notes from other students or the instructor
- Permission to make audio recordings of class
- Reduced course load
- Priority registration
- Scheduling assistance with navigating distance on campus.
- Accessibility to audio recordings.
- Remote attendance accommodation (attending class by live video).



Independence and Self Advocacy:

Throughout the student's educational experience, parents or guardians most likely have assisted with the plan for accommodations or medical need in school settings.

As young adults transition to adulthood, it becomes the student's responsibility in higher education to initiate, educate, advocate, and request accommodations. Parents and guardians do not have access to this process without signed consent from the young adult/student. Parents and guardians are not able to talk to the school/institution without consent from the student. If they are involved in the application for Accessibility & Accommodation Plan, the student will be required to provide written consent and disclosure for their confidential information.

It is the student's responsibility to discuss their Accessibility & Accommodation Plan with their instructors at the beginning of the semester before they may need to request accommodation. Students should schedule an appointment during office hours with the class instructor. Summarizing the request in an email at the beginning of the semester is also recommended.





Unmet Needs:

If a student has an Accessibility & Accommodation Plan in place, and their needs are not being met:

1. Appeal to OALA office.
2. Discuss the concerns with their Advisor and/or Career Counselor. This may include an involvement with the Dean.
3. If the needs are not addressed, the student should contact the Ombudsman, often referred to as Ombuds at the school. Their role is to serve as a neutral party to solve problems and resolve conflicts with students and faculty in compliance with the school's policies and procedures.
4. If the needs are not addressed, the student should file a grievance with the Office of Equity.
5. If the needs are not addressed, the student should contact the Provost. A Provost is the chief academic officer of the university who reports directly to the President.
6. If the issue is still unresolved, the student and their family may consider legal counsel.

Access and Accommodations for Mental Health Services:

NBDF Mental Health Definition:

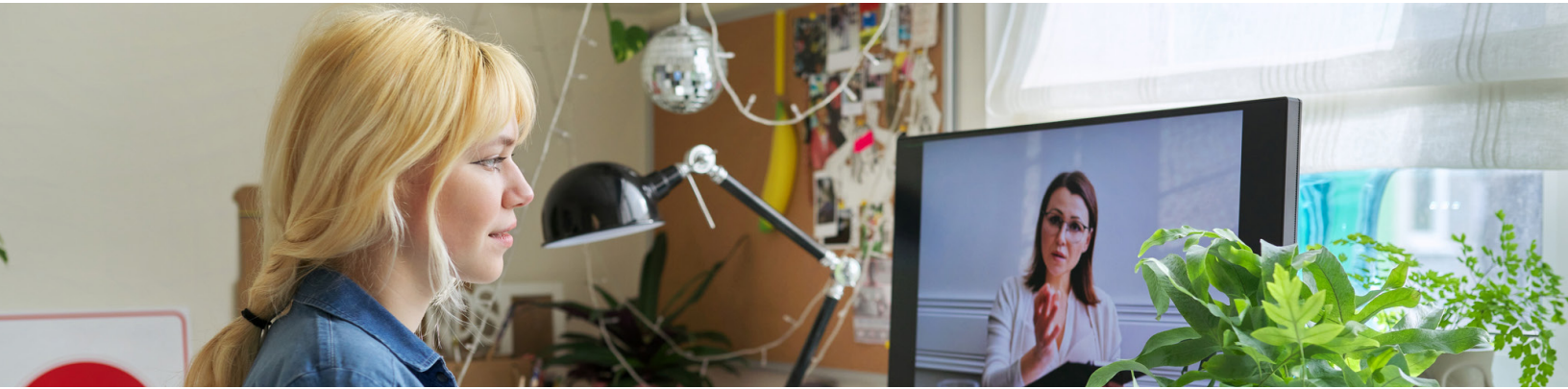
Mental health is a combination of someone's emotional, psychological, spiritual, and social wellbeing. It varies from person to person and may be impacted by life events. Intense or hard life situations may have a negative effect on mental health resulting in the inability to do usual day-to-day routines.

Mental health is as important as, and is connected to, physical health. It requires ongoing attention. Tools, resources, and treatments are available. Talk with your healthcare team about the best treatment for you. Tools and resources can be found through the National Bleeding Disorder Foundation (NBDF) & Hemophilia Federation of America (HFA).



Mental health professional or HTC provider:

Students living with a serious chronic health condition such as bleeding disorders may experience mental health needs, especially transitioning into a higher education learning environment.



It is important for the student to discuss mental health needs with their health care team, including the mental health professionals at the hemophilia treatment center, behavioral health care team, or primary care provider. Higher education institutions do provide supportive services to students in a variety of programming. The student may consider utilizing these resources for optimal care. If the student is seeking accommodation or support, they will be required to file a request like the process outlined above. The process may be different and may include coordination between mental health providers at home and the mental health providers at the educational institution. It is important that the student/patient's medical record reflect their updated care, including mental health. This will most likely include additional consents for release of information and coordination due to HIPAA and medical confidentiality laws **(U.S. Dept. Health and Human Services).**

Mental health services for all students are usually provided by the college's health department through counseling services. Mental health care includes psychological, emotional, and social well-being as it relates to other functions such as cognition and perceptions. Transitions in young adulthood with life experiences including school, work, social and family relationships can add complexity of stress, which can impact mental health. The student's Accessibility & Accommodation Plan may include mental health services and support.

Students may have had an individualized education plan (IEP) in high school or grade school. This plan does not transfer into the higher education system. The student must request a new Accessibility & Accommodation Plan when entering a new educational institution.

Mental health code:

It is important to understand that student/patient mental health information, diagnosis and treatment are protected by the **Health Insurance Portability and Accountability Act (HIPAA) of 1996**. This ensures confidentiality, protecting the student's privacy. Health care providers are bound by a **code of ethics** that governs them to keep all mental health information and records confidential.

Mental Health Laws & Policies: Below are some recent laws/policies as it relates to access to quality care and treatment pertaining to mental health:

Students with mental health disabilities are protected by federal civil rights laws, including **Section 504 of the Rehabilitation Act of 1973 (Section 504)** and the **Americans with Disabilities Act of 1990 (ADA)**. These laws require K-12 schools and postsecondary institutions to provide students with an equal opportunity to learn, free from discrimination, including during public health crises. Section 504 and the ADA require schools and postsecondary institutions to make decisions about how to respond to students at risk of self-harm based on an assessment of each student's circumstances rather than on fears, generalizations, or stereotypes about mental illness. In making these decisions, schools and postsecondary institutions generally must provide students who have mental health disabilities with reasonable modifications to school policies, practices, and procedures, as appropriate for an individual student. Public elementary and secondary schools must also provide students with disabilities a free appropriate public education, also known as FAPE,



after an evaluation, as described in the Section 504 regulations. When schools and postsecondary institutions do not meet these responsibilities, the U.S. Department of Education's Office for Civil Rights (OCR) and the U.S. Department of Justice's Civil Rights Division (CRT) can help by enforcing these Federal laws that protect students from discrimination based on disability. A college student with bipolar disorder has been struggling with anxiety and is hospitalized for a suicide attempt. Without conducting an individualized assessment, the college's academic dean visits the student in the hospital and informs him that the college's policy requires an immediate medical leave whenever a student is hospitalized for reasons related to mental illness.

Mental health accommodations:

Mental Health accommodations vary by educational institution. This may include, but is not limited to:

- Test accommodations
- Waivers and substitutions
- Parking passes
- Access to instructor or classmate notes
- Assistive Technology (ability to attend class virtually may be an option)
- Adjusted Attendance Policy



State specific mental health support:

Mental health code is also state specific and may differ depending on the state that the student attends school in and one cannot assume that rights and privileges are the same from state to state. The student (and their support system) must inquire at the college/ university or research the state specific laws.

U.S. Department of Justice, Civil Rights Division. US Department of Education, Office for Civil Rights. Oct. 2021.

Resources:

[U.S. Department of Educational Rights and Privacy Act \(FERPA\)](#)

[U.S. Department of Education Office for Civil Rights](#)

[U.S. Department of Civil Rights of Students with Hidden Disabilities and Section 504](#)

[Congress.gov H.R. 5654 Higher Education Mental Health Act 2021 117th Congress](#)

[Civil Rights Data Collection Office of Civil Rights, U.S. Department of Education:](#)

[Americans with Disabilities Act: Guide to Disability Rights Laws:](#)

[National Bleeding Disorder Foundation \(NBDF\) Steps for Living](#)

[National Bleeding Disorder Foundation \(NBDF\) Chapter Network:](#)

Students traveling away from home for education should consider contacting the local Chapter to learn about programs, peer support, and services.

[Hemophilia Federation of America \(HFA\)](#)

[Parent to Parent USA- Support for Parents of Children with Disabilities](#)

[National Disability Rights Network- Resources](#)

[The Resource Library Mental Health Coalition:](#)

[National Institute of Mental Health \(NIH\)](#)

[National Alliance on Mental Health \(NAMI\)](#)

[The Trevor Project: LGBTQ+ Mental Health Resources](#)

[American Indian College Fund: Supporting Your Journey Mental Wellness for Students](#)

[Mental Health Matters Too](#)

[Psychology Today](#)

This resource was created by the NBDF Health Equity, Diversity, and Inclusion Champion program with community involvement and review of Lived Experience Experts.

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