

#4 Guide to Academic Resources for College Students with Idiopathic Hypersomnia

This guide is intended to provide foundational resources for information, direction, and support. Topics include transitioning or returning to campus, understanding ADA at the college level, working with assistive technology, thinking about employment goals, and knowing the education platforms. When linking to the websites within, we suggest you spend time on pages beyond the ones you link to, as many of these sites have an abundance of resources that could be useful.

Please note: Additional Education Platforms will be added to this guide throughout 2019. Stay tuned via SomnusNooze.

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1. Transitioning or Returning to Campus:

- **Best Colleges for Students with Disabilities**
<https://www.ahead.org/students-parents/parents>
The Association on Higher Education and Disability (AHEAD) is highly regarded for its commitment to full participation of persons with disabilities in post-secondary education. It is the professional organization of Disability Service Providers, those professionals on campuses that ensure that students are given the academic adjustments they are entitled to under law. This link to AHEAD addresses a question to which supporters often seek answers: *What colleges are best for students with disabilities?* AHEAD recommends two resources for that information and provides a rationale for them. In addition to providing AHEAD's position on that question, its website is full of useful information and worth your time.
- **Consider College Rankings with Caution:** Stanford University Graduate School of Education has released findings (2018), urging caution about relying on popular sources of college rankings and instead offering three (3) factors to consider when deciding on your choice of school:
<https://www.insidehighered.com/admissions/article/2018/10/15/stanford-study-says-rankings-do-not-point-students-best-college-fit>.

- **The College Board: Ensuring Accommodations on College Board Exams**

<https://www.collegeboard.org/stu-with-disabilities>

This website identifies the tests for which the College Board provides accommodations.

- **“Testing Out” of Classes**

- **Overview of CLEP, DSST/DANTES “Testing Out” Programs**

www.dantes.doded.mil/service-members/ta-alternatives/clep-dsst.html

This site describes the most commonly known “testing out” examination programs.

- **College Board’s College-Level Examination Program (CLEP)**

CLEP – Get College Credit with What You Already Know

<https://clep.collegeboard.org/>

A trusted credit-by-examination program (33 examinations) sponsored by the College Board allows students to “test out” of classes by demonstrating content mastery. CLEP policies vary: not all colleges accept them; some colleges accept credit for a few exams; others accept credit for all of the examinations. Typically, equivalent course credit is granted for passing a CLEP examination.

- **DANTES Subject Standardized Test Program (DSST)**

<https://www.prometric.com/en-us/clients/dsst/Pages/landing.aspx>

This is a form of prior-learning assessment based on standardized, college-granting exams, and it is maintained by Prometric. The exams (38 over six subject areas: Business, Humanities, Math, Physical Science, Social Sciences, and Technology) allow college credit-for-experience at the upper and introductory levels. Passing scores are accepted at more than 2000 colleges for college credit. See getcollegecredit.com for more information.

Note: The American Council on Education (ACE) has evaluated and recommended college credit for the DSSTs. View their recommended minimum scores here:

<http://www2.acenet.edu/credit/?fuseaction=browse.getOrganizationDetail&FI CE=300162>. Policies differ across colleges as to which test scores are

accepted, the number of credits awarded, and the designated academic categories for those credits. The exams are funded for active-duty military and are available as well to adult learners, homeschooled students, and military veterans.

(Source: Bridgewater State University website / www.bridgew.edu)

- **Department of Education (DOE) Resources Related to Postsecondary Education for People with Disabilities**
<http://project10.info/DetailPage.php?MainPageID=202&PageCategory=Postsecondary%20Education&PageSubCategory=>
This site provides informational resources for people with disabilities, their educators, and their supporters.
- **National Center for College Students with Disabilities (NCCSD)**
<http://www.nccsdonline.org/>
This national center is unique in that it is federally funded for college students with all types of disabilities, chronic health conditions, or mental or emotional illnesses. It provides information for supporters, parents, faculty, and others working with college students.
- **Transitioning from High School to Pratt (Institute)**
One Approach to Providing Information, Direction, & Support
<https://www.pratt.edu/student-life/student-affairs/learning-access-center/for-students/transition/>
Pratt Institute in New York provides an online guide for students transitioning from high school to college that encourages students to use resources and know their rights and responsibilities. It addresses these issues: comparison of differences in responsibilities between high school and higher education; the role of self-advocacy in the transition and a self-advocacy plan; discussing accommodations with professors, including what to say and how to say it; and self-advocacy videos from Temple University.

- Differences Between K-12 Services for Success and College Services for Access**
Rights and Responsibilities of College Students

By Catherine Carlson, Director of Office of Accessibility Services,
 Columbia-Greene CC, SUNY Permission granted 7.2.17

High School	College
The applicable law is the Individuals with Disabilities Education Act or IDEA.	The applicable law is the Americans with Disabilities Act (ADA) of 1990, and as Amended, and Section 504 and 508 of the Rehabilitation Act.
IDEA is about success.	The ADA is about access.
Fundamental modifications of programs and curricula are required.	No Fundamental modifications are required – only academic adjustments.
Education is a right and must be provided in an appropriate environment to all individuals.	Education is not a right – students must meet certain admission criteria.
The school district is responsible for identifying a student’s disability.	Students must self-identify.
The school district develops Individualized Education Plans (IEPs) to define educational services.	Student must identify needs and request services – no IEP exists and is not considered sufficient documentation, although the Plan, together with a Psycho-educational Evaluation, may be considered sufficient if it clearly outlines the functional challenges of the disability and/or establishes a history of accommodations.
The school district provides free evaluations.	The student must obtain evaluations at his/her own expense.
Student is supported by parents and teachers.	Student is responsible for seeking assistance from the Disability Services Office, which exists to ensure equal access to students with disabilities.
Primary responsibility for arranging modifications belongs to school.	Primary responsibility for self-advocacy and arranging academic adjustments belongs to the student (who may seek assistance from Disability Services).
May have received modifications to the school’s behavior code.	Expected to abide by college’s code of conduct, regardless of disability.
Personal Services and equipment for medical and physical disabilities are provided by the school district (i.e., Personal Care Attendant).	No personal services or equipment are provided – however, the Disability Services Office may assist the student in obtaining such services or equipment.
Parent advocates for student.	Student must advocate for self.

- **PowerPoint Presentations**

- ***Transitioning to College with a Sleep Disorder: Regulations and Beyond***
<http://www.hypersomniafoundation.org/wp-content/uploads/Transitioning-to-College-with-a-Sleep-Disorder-Schultz-Nelson-Tuttle.pdf>

Presenters: Dr. Susan M. Schultz (Associate Professor of Special Education) and Dr. Christine Nelson-Tuttle (Associate Professor of Nursing), St. John Fisher College Rochester, NY. Permission granted June 30, 2017

Two professors, one of whom has a loved one in college with a diagnosis of a central disorder of hypersomnolence, developed this PowerPoint Presentation. She understands as a supporter what living with excessive daytime sleepiness (EDS) is like; and both understand as professors what it takes to work with students who have disabilities.

- ***Education Essentials for Students with Idiopathic Hypersomnia***
http://www.hypersomniafoundation.org/wp-content/uploads/Education-Essentials-for-Students-with-IH-Boston-2017-M.King_.pdf
Presenter: Mary A. King, EdD, Hypersomnia Foundation Board of Directors; Hypersomnia Foundation Regional Conference, Boston, June 4, 2017

This presentation introduces the audience to the Foundation's program of guides for K-12 and College students with IH, with an emphasis on information, direction, and support.

- **Office of Civil Rights, U.S. Department of Education**

<https://www2.ed.gov/about/offices/list/ocr/index.html>

This link brings you to the home page for the Office of Civil Rights (OCR), which provides access to the laws that protect students.

- **Vocational Support Services**

<http://www.fda.gov/downloads/AboutFDA/WorkingatFDA/UCM277757.pdf>

There are off-campus services that can help the college student with idiopathic hypersomnia. Because IH is a recognized disability, your state vocational rehabilitation services office may arrange for a vocational counselor and provide **supportive services through all levels of schooling**, including some services not provided on campus under ADA law. For example, campuses are not required to provide personal coaches or personal aides, but vocational rehabilitation offices may provide such services. The link above provides a list of the state rehabilitation offices, where you can find information about academic and employment support services.

- **Medical Alert Card**

Campus administrators advise that students with IH carry medical information on their person so that in the event of a medical emergency, first responders are more likely to interpret the symptoms of IH accurately. The Hypersomnia Foundation has created a Medical Alert Card (MAC) for such purposes and also advises the use of smart phone medical alert apps.

<https://www.hypersomniafoundation.org/introducing-our-new-medical-alert-card-for-ih-patients/>

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2. Understanding the ADA at the College Level

- **United States Department of Justice**

<http://www.usdoj.gov>

This Federal government website provides information on disability rights.

- **Students with Disabilities Preparing for Postsecondary Education**

<https://www2.ed.gov/about/offices/list/ocr/transition.html>

The Office of Civil Rights enforces Section 504 of the Rehabilitation Act of 1973 (Section 504) and Title II of **the Americans with Disabilities Act** of 1990 (Title II).

- **ADA Q & A: Section 504 & Postsecondary Education - PACER Center**

<http://www.pacer.org/publications/adaqa/504.asp>

Pacer is a Minnesota-based Parent Training and Information Center funded by the U.S. DOE (Offices of Special Education). This website assists families and college students in understanding the protections provided by the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act. Below are some of the questions addressed by this website.

- *How does the ADA affect postsecondary schools? Admissions requirements?*
- *What are the differences between the ADA and Section 504?*
- *What should I do if the instructor refuses or neglects to make the accommodations I requested? What if informal attempts to resolve the problem are unsuccessful?*
- *Does the ADA provide funding for students with disabilities?*

- **Rights of Students with Disabilities in Higher Education**

www.disabilityrightsca.org/pubs/530901.pdf

This website provides the guide *Rights of Students with Disabilities in Higher Education*, prepared by *Disability Rights California*, California's Protection & Advocacy System. Among the questions addressed by this guide are:

- *Do the ADA and Section 504 cover professional, trade, vocational, and technical schools?*

- *Is my college or university's admissions office permitted to ask me about having a disability in the application or interview process?*
- *When and how do I file a complaint with the Office for Civil Rights of the U.S. Department of Education (OCR)?*
- *Are there any federal laws that protect me from retaliation?*

- **Academic Adjustments**

Transition of Students with Disabilities to Postsecondary Education: A Guide for High School Educators

<https://www2.ed.gov/about/offices/list/ocr/transitionguide.html>

Source: U.S. Department of Education, Office of Civil Rights, *Transition of Student with Disabilities to Postsecondary Education: A Guide for High School Educators* (2011)

Although this guide is not intended for college students or their supporters, the information may prove very useful to understanding the admissions process, post-admission documentation of a disability, and the critical importance of attitude, self-advocacy, and preparation.

In this guide, the term “academic adjustments” refers to modifications to the following: nonessential academic requirements; reasonable changes to policies, procedures and practices; and the provision of auxiliary aids and services necessary for individuals with disabilities to participate in, and benefit from, the postsecondary education program.

Quoting verbatim from this government guide:

Academic adjustments are defined in the Section 504 regulations at 34 C.F.R. § 104.44(a) as:

[S]uch modifications to [the] academic requirements as are necessary to ensure that such requirements do not discriminate or have the effect of discriminating, on the basis of [disability] against a qualified... applicant or student [with a disability]... Modifications may include changes in the length of time permitted for the completion of degree requirements, substitution of specific courses required for the completion of degree requirements, and adaptation of the manner in which specific courses are conducted.

Academic adjustments also may include a reduced course load, extended time on tests and the provision of auxiliary aids and services. Auxiliary aids and services are defined in the Section 504 regulations at 34 C.F.R. § 104.44(d), and in the Title II regulations at 28 C.F.R. § 35.104. They include note-takers, readers, recording devices, sign language interpreters, screen-readers, voice recognition and other adaptive software or hardware for computers, and other devices designed to ensure the participation of students with impaired sensory, manual or speaking skills in an institution’s programs and activities. Institutions are not required to provide personal devices and services such as attendants, individually prescribed

devices, such as eyeglasses, readers for personal use or study, or other services of a personal nature, such as tutoring. If institutions offer tutoring to the general student population, however, they must ensure that tutoring services also are available to students with disabilities. In some instances, a state VR agency may provide auxiliary aids and services to support an individual's postsecondary education and training once that individual has been determined eligible to receive services under the VR program.

- **Determining Disability**

- **Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities**

- <https://www2.ed.gov/about/offices/list/ocr/transition.html>

- This publication explains the rights and responsibilities of students with disabilities who are preparing to attend postsecondary schools and addresses a number of questions, including the following, quoted verbatim:

- ***“What documentation should I provide?”***

- Schools may set reasonable standards for documentation. Some schools require more documentation than others. They may require you to provide documentation prepared by an appropriate professional, such as a medical doctor, psychologist, or other qualified diagnostician. The required documentation may include one or more of the following: a diagnosis of your current disability, as well as supporting information, such as the date of the diagnosis, how that diagnosis was reached, and the credentials of the diagnosing professional; information on how your disability affects a major life activity; and information on how the disability affects your academic performance. The documentation should provide enough information for you and your school to decide what is an appropriate academic adjustment.”*

- ***“Once the school has received the necessary documentation from me, what should I expect?”***

- To determine an appropriate academic adjustment, the school will review your request in light of the essential requirements for the relevant program. It is important to remember that the school is not required to lower or waive essential requirements. If you have requested a specific academic adjustment, the school may offer that academic adjustment, or it may offer an effective alternative. The school may also conduct its own evaluation of your disability and needs at its own expense. You should expect your school to work with you in an interactive process to identify an appropriate academic adjustment. Unlike the experience you may have had in high school, however, do not expect your postsecondary school to invite your parents to participate in the process or to develop an IEP for you.”*

- **Additional questions addressed in the publication “Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities” include the following:**
 - **May a postsecondary school charge me for providing an academic adjustment?**
 - **Who has to pay for a new evaluation (if I need it for another disability or for IH)?**
- **Disability Discrimination Resources - US Department of Education**
<https://www2.ed.gov/about/offices/list/ocr/disabilityresources.html>
This website provides a number of informative disability discrimination resources by the Office for Civil Rights (OCR), including policy guidance information (*Dear Colleague letters*), technical assistance materials, and varied other resources.
- **Office for Civil Rights**
<http://www.ed.gov/ocr>
The OCR website provides resources that underscore the importance of equal access to education and educational excellence through the enforcement of civil rights.

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3. Working with Assistive Technology

- **Auxiliary Aids and Services for Postsecondary Students with Disabilities**
<https://www2.ed.gov/about/offices/list/ocr/docs/auxaids.html>
Source: *Auxiliary Aids and Services for Postsecondary Students with Disabilities: Higher Education's Obligations Under Section 504 and Title II of the ADA. (1998).*
This pamphlet reviews the obligations of higher education institutions to serve students with disabilities and includes answers to frequently asked questions. The sections that follow are drawn verbatim from this publication.

Postsecondary School Provision of Auxiliary Aids

“The Section 504 regulation contains the following requirement relating to a postsecondary school's obligation to provide auxiliary aids to qualified students who have disabilities:

‘A recipient . . . shall take such steps as are necessary to ensure that no handicapped student is denied the benefits of, excluded from participation in, or otherwise subjected to discrimination under the education program or activity operated by the recipient because of the absence of educational auxiliary aids for students with impaired sensory, manual, or speaking skills.’”

The Title II regulation states:

“A public entity shall furnish appropriate auxiliary aids and services where necessary to afford an individual with a disability an equal opportunity to participate in, and enjoy the benefits of, a service, program, or activity conducted by a public entity.

It is, therefore, the school's responsibility to provide these auxiliary aids and services in a timely manner to ensure effective participation by students with disabilities. If students are being evaluated to determine their eligibility under Section 504 or the ADA, the recipient must provide auxiliary aids in the interim.”

Postsecondary Student Responsibilities. “A postsecondary student with a disability who is in need of auxiliary aids is obligated to provide notice of the nature of the disabling condition to the college and to assist it in identifying appropriate and effective auxiliary aids. In elementary and secondary schools, teachers and school specialists may have arranged support services for students with disabilities. However, in postsecondary schools, the students themselves must identify the need for an auxiliary aid and give adequate notice of the need. The student's notification should be provided to the appropriate representative of the college who, depending upon the nature and scope of the request, could be the school's Section 504 or ADA coordinator, an appropriate dean, a faculty advisor, or a professor. Unlike elementary or secondary schools, colleges may ask the student, in response to a request for auxiliary aids, to provide supporting diagnostic test results and professional prescriptions for auxiliary aids. A college also may obtain its own professional determination of whether specific requested auxiliary aids are necessary.”

Examples of Auxiliary Aids

Some of the various types of auxiliary aids and services may include:

- Taped texts
- Note takers
- Interpreters
- Readers
- Videotext displays
- Television enlargers
- Talking calculators
- Electronic readers
- Telephone handset amplifiers
- Braille calculators, printers, or typewriters
- Closed caption decoders
- Open and closed captioning
- Voice synthesizers
- Specialized gym equipment
- Calculators or keyboards with large buttons
- Reaching device for library use
- Raised-line drawing kits
- Assistive listening devices
- Assistive listening systems
- Telecommunications devices for deaf persons

“Technological advances in electronics have improved vastly participation by students with disabilities in educational activities. Colleges are not required to

5. Knowing the Education Platforms

- **4a: Online Education**

This guide (which can be separately accessed at this link:

<https://www.hypersomniafoundation.org/wp-content/uploads/4a-Online-Education.pdf>) has been developed for students who are thinking about online

education, whether living off or on campus. It informs the student about how to make informed decisions about online courses and programs, provides suggestions for learning online (*Tips and More Tips*), includes comments by students of all ages (*In Their Own Words*), and includes the “tips” faculty are given for instructing online courses (*A Peek Behind the Professor’s Door*).

- **4b: Experiential Education** (in progress)

Stay tuned via SomnusNooze ... Additional platforms will be added throughout 2019!

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**Approved by the Hypersomnia Foundation Board of Directors and
Reviewed by separate education legal counsel.**

**Vetted by college students with IH. Special appreciation to Jessamine Griewahn-Okita, BA for her
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