

LIVING WITH PARALYSIS

Navigating and Transitioning to College with Paralysis



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REEVE FOUNDATION

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This guide has been prepared based on scientific and professional literature. It is presented for the purpose of education and information; it should not be construed as medical diagnosis or treatment advice. Please consult a physician or appropriate healthcare provider for questions specific to your situation.

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Introduction

Students with paralysis and mobility impairments share many of the same questions as their non-disabled peers when exploring colleges (academics, campus culture, financial aid, services), and they also have a unique set of considerations to take into account, including physical accessibility, access to care, and accommodations. Data indicates that approximately 19% of college students in the United States are students with disabilities¹. This number includes: learning disabilities, ADD, mental health conditions, chronic health conditions, and physical disabilities. Additionally, approximately 7% of the college students who report having a disability indicate that they have a physical disability/mobility impairment². Although colleges are required by federal law to accommodate students with disabilities, the way in which accommodations are administered varies from college to college. The aim of this publication is to provide guidance and support for young adults with paralysis and mobility impairments as they prepare to transition to college.

Background: Federal Laws – Section 504, IDEA, and ADA

It's important to understand the differences in the laws that govern K-12 education and college. There are three main laws that students and families should be familiar with. The first is the Individuals with Disabilities Education Act (IDEA). This is a law that governs special education services

in the K-12 setting for students with disabilities and provides for free and appropriate public education and services. Students who are receiving accommodations under IDEA, typically have an "IEP" (Individualized Education Program) that outlines their accommodations and services.

Acronyms

- ADA:** Americans with Disabilities Act
- DSO:** Disability Support Office
- FERPA:** Federal Educational Rights and Privacy Act
- IDEA:** Individuals with Disabilities Education Act
- IEP:** Individualized Education Program
- OT:** Occupational Therapist
- PCA:** Personal Care Attendant
- PT:** Physical Therapist
- SSI:** Supplemental Security Income
- SSDI:** Social Security Disability Insurance
- VR:** Vocational Rehabilitation

1. U.S. Department of Education, National Center for Education Statistics. (2019). Digest of Education Statistics, 2017 (2018-070).

2. Raue, K., and Lewis, L. (2011). Students with Disabilities at Degree-Granting Postsecondary Institutions (NCES 2011-018). U.S. Department of Education, National Center for Education Statistics. Washington, DC: U.S. Government Printing Office.

The next law is Section 504 of the Rehabilitation Act of 1973 (Section 504). It provides protection against discrimination on the basis of disability and applies to both high schools and colleges. K-12 students who receive accommodations under Section 504 may have a “504 Plan”. This is a plan that outlines what accommodations the student receives. Section 504 also applies to the college setting, however, a student’s 504 Plan from the K-12 environment may not directly transfer to the college setting in terms of the types of accommodations that a college offers. It’s important to note that private schools have to adhere to Section 504 and remove barriers to education, but private schools do not have to provide accommodations and services under IDEA, like the ones that may be included in an IEP.

In the college setting, IDEA is no longer an applicable law. Colleges provide “reasonable accommodations” for students with disabilities as defined by the Americans with Disabilities Act (ADA) and protection from discrimination as outlined in Section 504. One big difference between high school and college is that in college the student has to be engaged in the “interactive process” and request their own accommodations, whereas in the K-12 setting, parents are usually advocating and driving the conversations and requests. Parents no longer have a role in the accommodations process once the student has matriculated to college.

SELF-ADVOCACY

Many students and parents are not prepared for the changes that take place around accessing disability supports and services in college because there is a large shift in the role and responsibilities of the student. Here are some major differences:

High School: The school takes the lead in arranging accommodations. For example, if the student gets extra time on tests the school knows and makes those arrangements.

College: The student has to engage in the “interactive process” and request accommodations. The interactive process requires the student to meet with a counselor in the Disability Support Office (DSO) and provide documentation of a disability/health condition. Example: If the student needs extra time on tests, most colleges have a process to request to take an exam with extra time in a testing center which typically involves making the request at least seven days prior to the exam.

High School: Teachers identify when the student needs support. Teachers can connect with parents and share information.



If I have learned anything throughout my college experience, it is that I have to be an advocate for myself.”

-Ian Malesiewski

<https://www.ChristopherReeve.org/blog/life-after-paralysis/college-during-the-coronavirus>

College: The student has to be proactive in seeking out support by going to office hours, hiring tutors, and taking advantage of the services the college offers. Additionally, professors and administrators are restricted by the Family Educational Rights and Privacy Act (FERPA), a federal law, which prevents university personnel from sharing information such as grades, class schedules, and disciplinary action, with parents. Students and families that opt to allow parents to access this information will need to sign a release form, typically with the college’s Registrar.

Students and parents are often caught off guard by this shift. It’s important to start talking about this transition with the student early, and start to allow them to develop independent living and self-advocacy skills.

Essential Skills

Students will need to be able to effectively articulate their needs and discuss their disability when they are in college. Self-advocacy, the ability to understand and communicate one’s needs, is key. These are the essential self-advocacy skills that students need to support their successful transition:

- Knowledge of their disability
 - Able to name and describe condition(s)
- Understand how their disability impacts them
 - Able to discuss how their disability(ies) impact their ability to participate in school, daily living, and programs.
- Know what accommodations they need (academic, residential, transportation, programmatic)
 - Identify their “functional limitations” and consider how they are impacted in each setting they may encounter in college, and identify accommodations that will support them.
- Able to communicate their needs



- Able to identify who they should speak with and effectively communicate their needs
- Understand their rights and responsibilities under the law
 - A general knowledge and understanding of the Americans with Disabilities Act and Section 504, and the application of these laws in the college setting.

There are a few ways to support students in developing these skills. First, if the student has an IEP or a 504 plan, include the student in the meetings related to their accommodations. Families can support the student in learning about their disability and their needs. Often, parents will work with counselors and therapists to assist in this area, since students may be more receptive to someone other than their parent. Most states have transition support guides that can be found online. These guides typically outline what skills a student can work on during 9th-12th grade to support a successful transition.

It's also important to find ways to let the student build their executive function and independent living skills. Here are a few ideas on how to foster these skills early on:

Conversations with Healthcare Providers:

- It can be challenging for parents to hold back from directing the conversation during medical appointments. However, the student should learn to ask questions and speak for themselves. This will help the student develop independence and self-advocacy skills. In

order to practice letting the student converse with the healthcare provider, families can:

- Ask the healthcare provider to direct questions to the student to enhance the student's ability to monitor health and self-advocate.
- Let the student handle the entire appointment by themselves.
- Support the student in creating a list of questions/concerns prior to each appointment.
- Rehearse the appointment with the student.

Medication Management:

- As students move toward living independently, they will need to be able to manage their own medication. It's important for students to have a system in place to monitor their medication. Those systems should be adopted before they go to college. In order to foster these skills, families can:
 - Assist the student in setting up a medication management app or calendar to support the student in identifying when to take medication and how much and when they need to call for a refill. (Please note that many apps also have a section where users can track how the medication makes them feel. This can be beneficial data).
 - Get the student a pill box and identify a specific day that the box gets filled (such as every Sunday).

Healthcare Appointments:

- Families start making doctor appointments for their child a few days into their infant's life! It can be a hard habit to break, 18 or so years later. Nevertheless, parents will eventually have to let the student take the reins and make their own appointments. In order to transfer this responsibility to the student, families can:
 - Support students in scheduling their own appointments. Students should have a sense of their calendar and commitments, and be able to call to schedule an appointment independently.
 - Co-construct a script and practice what the call might entail.
 - Make sure the student has relevant health insurance information in a handy location.
 - If the student has a recurring appointment, be sure they have a system in place for tracking and scheduling their appointment. Apps and electronic calendars can be very helpful.

The more practice that students can get with self-advocacy, executive function, and independent living skills while they are supported at home, the more successful they will be in navigating college.

HOW TO PREPARE: THE ROLE OF THE REHABILITATION CENTER

If your paralysis is long-standing as college approaches, you may want to consider outpatient rehabilitation to improve your functional and independent living skills. These skills may include wheelchair transfers, fine motor skills, core strengthening, and stamina building. This may help you be better prepared for living on your own at college.

For those who are newly injured or paralyzed, this section explains the key people who can help you return to or prepare for college. Look at the roles of various rehabilitation team members and consider how they can help you in your goal of returning to or entering college. Ask if the rehabilitation center has a person who can liaise with schools. Typically, this person has the title of “Education Coordinator,” but that may vary from center to center.

The Education Coordinator can:

- Support the student with college visits and connect them to the Disability Support Office (DSO)
- Assist the student in identifying accommodations
- Provide guidance on the other types of supports the student may need in the college setting

During the student’s time in rehabilitation they will work with physical and occupational therapists (PT/OT).

The PT/OT can:

- Identify the student’s “functional limitations”
 - Develop a list of functional limitations
 - Consider how these limitations may impact the student’s mobility in the classroom and in a residential setting
 - Assist the student in determining their individual support needs (care attendant, assistive technology, etc.)
 - Provide documentation for the student to use when the student is requesting accommodations

Working collaboratively with the team at the rehabilitation center can help the student make sure they have the best systems and supports in place. Once the student is accepted to a college, they may also want to consider coordinating with the college’s DSO and bringing their OT to the

campus to do an on-site evaluation with the student. This can be particularly helpful if the student plans to live on campus. The evaluation may identify modifications and requests that can be made to the DSO.

HOW TO PREPARE: THE ROLE OF THE HIGH SCHOOL

When the student is in high school there will be opportunities to engage with the high school counselor and have conversations about the college search and selection process. However, not every high school counselor is equipped to assist students with physical disabilities in thinking through their specific needs. Students and families will need to be prepared to create their own questions and do their own research.

If the student has an IEP, transition planning will be a part of the IEP process. It will be critical for the student to engage in the IEP process to better understand their needs and accommodations so that they can be an effective self-advocate in college.

If the student has a 504 plan, they will not receive transition services to support them with the transition to college. Students with 504 plans will need to dedicate time and think through the types of transition supports and accommodations that they may need in order to live independently and be successful in college.

College Counselors/Independent College Consultants

College counselors are typically a great source of information on what the different colleges offer, and they can help identify the best academic fit for the student. They may not be as well versed in issues related to students with physical disabilities transitioning to college. Ask the college counselor if they have worked with students with physical disabilities before. If they have not, they may be able to point you to other consultants or resources. Some families may choose to seek out the support and guidance of an independent college consultant. Independent consultants can also offer information on different schools and work with the student to find the right college fit.

College Fairs

Students will have opportunities to attend college fairs either at their school, in their school district, in their surrounding area, or online. College fairs typically host a number of college admissions representatives.



Fairs are usually held in high school gymnasiums or convention centers. Recently, more organizations and schools have been offering online college fairs where students can connect with admissions representatives from different colleges in a virtual setting.

Questions to Ask Prior to Attending a College Fair:

- Is the location of the college fair accessible?
- Is there a process for requesting an accommodation if needed?
- When attending a virtual college fair, ask if the platform is accessible for screen readers and speech-to-text software.

A Note About College Admissions Staff:

College admissions staff may not be well-versed in the needs of students with disabilities. Students and families should be prepared to ask questions of the admission staff at the college fair. However, if the student is interested in that specific school, the student should follow up and connect with the DSO to get specific information related to disability services on campus. It's also important to remember that the process for requesting accommodations in college is separate from the college admissions process. The admission staff do not share information with the Disability Support Office and vice versa.

College Tours

Students with paralysis and mobility impairments should try and visit the campuses of the schools that they are interested in attending. This will give the student a better sense of how accessible the campus is for them.

1. Contact the admissions office

- Ask if the admissions office is accessible (this is not always a given).
- Ask for specific instructions on how to enter the building if the accessible entrance is not at the front of the building (common at “historic” campuses).

2. Ask if the tour is accessible. If there are specific things that the student needs in order to be able to access the tour and the tour materials (sign language interpreter, audio system, large print, electronic copies of materials, a golf cart, etc.) be sure to request those in advance. Here are some sample questions to ask:

- Is the tour wheelchair accessible?
- Has the tour guide been trained to navigate the campus’s accessible routes?
- Are you able to send me the tour materials electronically in advance?
- Are there videos shown as part of the tour? If so, are they captioned?

3. Ask about the tour length

- Some campuses are quite large and/or topographically challenging. If the student is not using a power device, they should get a sense of the tour length to make sure they are prepared.

4. Make an appointment to meet with the DSO

- Meet with a counselor to discuss the process for requesting accommodations.
- Ask to be connected with current students who have physical disabilities.

Note: Universities that receive federal funding must be ADA compliant. However, compliance varies, and what is considered “compliant” may not meet the specific needs of the student.

Virtual College Tours

Many colleges offer virtual tours through a variety of online platforms. These tours offer students the opportunity to explore schools that they may not be able to go and see in person. While virtual tours do expand a

students' ability to explore schools from the comfort of their own home, it can be challenging to get information related to physical accessibility, and to get a sense of the ways in which people with disabilities are supported and engaged on campus through a virtual tour.

Unfortunately, virtual tours do not always show how students with physical disabilities would access a building, or what accessibility features are present (push buttons, tactile features, or signage). Virtual tour attendees see the front/interior of a building, but the accessible entrance might be on the side or back of the building, and not featured on the virtual tour. Although colleges are required to be compliant with the ADA, there are varying levels of compliance, with some schools even working to go beyond compliance.

If the student is interested in the college, and a virtual tour is the only option, there are some ways to get the information that they may be seeking without visiting the campus in person.

- Contact the Disability Support Office and have a conversation about the types of accommodations that the student is seeking and the support they offer.
- Ask to be connected with other students with physical disabilities on campus.
- Contact the Student Health Center and the Student Counseling Center to ask about the types of services that they offer on campus.



HOW TO PREPARE: VOCATIONAL REHABILITATION'S ROLE

Rehabilitation services are available through the state and are referred to as Vocational Rehabilitation (VR) services. State VR agencies receive funds from the federal government because of the Rehabilitation Act of 1973, and the Department of Education oversees the program. The purpose of the VR program is to assess, plan, develop, and provide services to people who are eligible for VR in order to prepare recipients for higher education and employment. VR can assist in job placement, provide support to increase independence and integration into the workplace and the community.

In order to be eligible for VR, students must have a physical, mental, emotional, or learning disability that is a real barrier to employment or accessing higher education. Additionally, students who receive Supplemental Security Income (SSI) and/or Social Security Disability Insurance (SSDI) and/or they are in special education programs, receive accommodations in school, or have a severe health condition may be eligible. It's important to know that VR service is provided to only a small percent of people who may be eligible. Because funding is not available to serve everyone, students with the most severe disabilities are prioritized. Each application for eligibility is evaluated on a case-by-case basis.

In high school, students who meet the eligibility requirements can request VR services. Families can request that a VR counselor attend IEP/504 meetings. Involving VR early in high school as a part of the transition planning process, can be beneficial to the student and the state VR agency, who may be able to better predict resource and funding needs the earlier students engage with VR.

What can VR do?

- Work with the student to help them find a college appropriate to their needs and professional goals.
- Assist the student in identifying possible scholarships. Frequently, this is done collaboratively with the high school counseling staff.
- Support the student in identifying the types of accommodations that they may want to request in college, and once the student is accepted, they will assist the student in connecting with the college's Disability Support Office.
- Provide the student with financial assistance, assistive technology, and/or access to aids for daily living.

INJURED IN HIGH SCHOOL OR COLLEGE

It can be challenging for students and families to determine how best to move forward with education if the student has been injured during high school or college. School re-entry may look different for individual students. Some students may want to try and continue to stay at pace with their classmates, and others may choose to proceed more slowly.

One main factor that impacts how the student can move forward in their education is their physical ability post injury. Depending on the impact of the injury the student may have to learn or relearn:

- Activities of daily living skills
- How to use assistive technology (i.e.: text to speech software, note taking software/devices, audio books, etc.)
- How to navigate the physical school environment using a wheelchair/mobility device (classrooms, building access, and bathrooms)

For the student there may also be social factors or implications that guide their decision-making process. They may want to stay connected and on track with their peers. The fear of social exclusion can be very real for students, so it's important to be understanding of the student's desire to keep up with their friends. Families may want to connect with a therapist, counselor, or healthcare provider to discuss these issues, and consult with other families who have been through similar experiences.

If the student is in high school:

Families should connect with their school and school district to explore the possibilities. Additionally, the rehabilitation facility may have some resources that can be used to support students as they consider returning to high school. Families will want to work with the school counselor or special education coordinator to determine what accommodations and services the school can provide. It's important to remember that public schools provide accommodations and services under IDEA and Section 504, and that private schools only provide accommodations under Section 504 (they cannot discriminate against a student with a disability). Students may opt to re-enter completely, re-enter taking less classes, continue with remote education and/or a hybrid of home and hospital learning, or take time off. Families will need to work with their school or school district to provide documentation and determine the best path forward.

If the student is in college:

If the student is injured in college, there are a few things to navigate in the short term. First, the student and family should connect with the student's academic dean to inform them of the injury and rehabilitation plan. Depending on the point in the semester that the injury and rehabilitation occur, the student may opt to withdraw, or take an incomplete for the semester (with the ability to make up the missing work in the future). When a student is ready to return they may choose to re-enter completely (full-time), re-enter with a reduced course load (reduced credit hours), transfer to an online program, take courses at a college/community college closer to home with the goal of returning to their previous school, or take time off (withdraw). Once the student determines that they would like to return to college, they should work with their rehabilitation center and healthcare providers to determine their accommodation needs and gather documentation. Then the student should contact the DSO to request accommodations (refer to the "Accommodations" section). If the student decides that they want to go to college part-time, they may have to request part-time status as an accommodation (some college programs do not allow part-time status). Additionally, part-time status can impact the student's financial aid, so the student should also connect with the financial aid office to make that determination.



SELECTING A COLLEGE

When starting the process of exploring colleges, high school students typically work with a college counselor at their school, or a college consultant. Many students perform research independently or with their families. Most students start the process by considering their interests. Once the student has determined what their interests are, that can lead them to determining a course of study or major. Students can pair down the colleges they are interested in by finding out if a college has the major that they are interested in pursuing. Students should also think about how they like to learn. Do they prefer hands-on work or research? Lectures or discussions? Small group work or writing papers? Students can look at the college's website, read course descriptions, check out reviews of professors, and begin to determine if that college is the right academic fit. Students should also look at the average GPA and standardized test scores of the most recently accepted class. This will help them know if admission is achievable.

Learning about the culture on campus is another important consideration for all students. Thinking about whether the student wants a small or large campus, looking at the average class size, an urban campus or a campus in the country are all factors to think about. Many students use their personal interests, such as sports, arts, or politics to gauge whether a college will be a good fit for them. Try and visit the campus and speak with current students. Students may also want to do a bit of online research to learn about the culture on campus, and read the student newspaper.

Finances are a concern for many families. Many colleges offer financial aid packages and scholarships which students may be eligible for. Students and their parents will need to complete a **Free Application for Federal Student Aid (FAFSA®) form** — found at <https://studentaid.gov> — to apply for financial aid for college or graduate school. Colleges make most of their grant and scholarship decisions based on the FAFSA results. It is important to apply early and to know the deadlines. There are scholarships that are specifically available for students with disabilities, including specific scholarships for students with paralysis and mobility impairments. However, it's important to be realistic about what the family can afford so that the student doesn't take on an unreasonable amount of debt. State colleges and universities may cost less than a private college but there may be less financial aid and endowment monies available. It is

important to explore all options. If you disagree with the college's financial aid decision, you can file an appeal for reconsideration. Information on how to file a financial aid appeal can be found at Swift/Student: <https://formswift.com/swift-student#whatsanappeal>.



Is it feasible to go to school here? Will all my personal needs be addressed?"

- Taylor Price

[https://www.ChristopherReeve.org/
living-with-paralysis/for-parents/higher-education](https://www.ChristopherReeve.org/living-with-paralysis/for-parents/higher-education)

Considerations for Students with Paralysis and Mobility Impairments

Beyond the general considerations outlined above, students with paralysis and mobility impairments face considerations beyond what their non-disabled peers may be thinking about. The elements that are outlined below are meant to provide guidance, and not to deter a student from considering a specific college. The items in this section are specifically related to issues and concerns that students with paralysis and mobility impairments may have. It's important to remember that colleges may be able to offer support and/or accommodations to mitigate some of the challenges a student may encounter. That's why it's always important to connect with the Disability Support Office to ask questions before making a determination on whether the student wants to apply to or attend the college.

Physical Conditions

One factor that may be important for some students, are the physical conditions on campus. When students go on a tour, they are usually visiting the campus during spring or summer, but those aren't the only seasons! Students should think about the weather year-round, and explore the campus/area terrain.

When considering the weather conditions, students should ask:

- Does the area get a lot of snow/ice and/or rain?
- Does it get very hot/humid in this area?

It's important to be realistic about the potential obstacles to accessing classes and services on campus. For example, if the student chooses a school in a snowy area, they should also think about the time it will take them to put on winter gear, and they should connect with the DSO to ask about snow clearing and accessible transportation services during inclement weather. Some schools have underground tunnels that students use to get around, other schools will prioritize clearing the snow around buildings where they know that students with disabilities are living or need access to. It's critical to know what to expect before the first day!

The other weather-related consideration has to do with the student's ability to regulate their own temperature. If the student chooses a school in a hot climate, it may be challenging when trying to travel to class. Students and families should consider weather/climate as a factor in college choice, and discuss their needs with the DSO to see if there are ways to mitigate concerns.

Another area of consideration is campus terrain. Hilly campuses, or campuses where buildings are spread far apart, may be more challenging to navigate when using a wheelchair. If the student is using a manual wheelchair, they may want to think about how they feel after navigating around campus. If the student is able, they should tour the campus prior to applying. "Historic" campuses may have brick or cobblestone walkways, which can also be tricky to navigate, whereas, newer or updated campuses may have more consistent, flat pavement. Some colleges do offer accessible transportation (bus or golf cart) between buildings. Additionally, the student may be able to request classroom relocation as an accommodation. (See the "Accommodations" section)

Distance from Home

The distance the college is from home may be another factor in the student's choice. This can impact many areas of the student's life, including medical treatment (doctors and therapists), and support structures.

Here are some questions to consider when thinking through the medical implications:

- Will the student be able to maintain access to the same doctors and specialists? If not, are there doctors and specialists on campus or near campus that they can connect with?
- Will the student be able to receive mental health services on or near campus? If the student needs mental health services, it's important to



connect with the college's counseling center to ask about how often and how many times a student can be seen there before they refer them out to an off-campus provider.

- Are telehealth options available either through the university, or through insurance?

Students may want to explore colleges that have a hospital on or near campus, or select a college close to home where they can continue to see their current doctors.

The student will also need to consider the steps they would take in the event that their chair breaks down, the Personal Care Attendant (PCA) doesn't show up, or if they think they will just need more general support from friends and family at home. Here are some ideas on how to mitigate potential issues if the student chooses a school that is not close to home:

- Identify a local wheelchair repair company. Make provisions to keep a manual chair on hand if possible.
- Think about how the student can get back home. Will they need a car on campus (note: this may not be allowed without an accommodation)? Is there other accessible transportation that they can utilize to get home?
- Identify any friends or family who may live in close proximity to the school and would be willing to assist if an issue arose.

DISABILITY SUPPORT OFFICE (DSO)

Every college has a DSO or a disability services coordinator. This distinction typically depends on the size of the school. The DSO may have a different name. Here are some examples:

- Disabled Student Services
- Access Center
- Accessibility Services
- Disability Support Services
- Academic Resource Center

The role of the DSO and coordinator is to ensure that the college meets their obligation to provide access to students with disabilities in accordance with federal law. This usually includes:

- Determining “reasonable accommodations” to support students with disabilities
- Facilitating accommodations for students with disabilities

This may also include:

- Advising and training faculty and staff on disability-related issues and accommodations
- Acting as a resource on issues related to disability with other university departments
- Providing academic support for students with disabilities and/or the general student population

Students and families should read the DSO’s mission statement to get the most accurate understanding of how the specific college’s DSO approaches their role. It can usually be found online at the DSO’s website. If the student determines that they are interested in the school, they should reach out to the DSO prior to applying to set up an appointment for a conversation. If the student is going on an in-person tour, they may be able to schedule an appointment on the same day as the tour. Otherwise, the student can ask to speak with a DSO counselor via phone or video chat. It’s helpful to have a conversation with the DSO prior to applying to the college so that the student can compare the services and supports that different colleges offer. Additionally, these conversations can give the student a sense of the people in the DSO, and assist them in determining if they feel supported working with the counselors in that college’s DSO.

It's important to understand that the DSO is separate from the admissions department. Information that a student may share with the DSO prior to acceptance and enrollment is not shared with the admissions department. Conversely, disclosure of a disability to the admissions department does not automatically get shared with the DSO. Lastly, disclosure of a disability in the admissions process (when applying to the school) is not mandatory.

During the College Search Phase

When a student with paralysis and mobility impairments connects with the DSO, the student will want to ask about specific accommodations and get a sense of the role of the DSO and the support they provide at that college. The level of support and the care with which accommodations are given and administered varies from college to college. It's a good practice for the student to prepare for a conversation with the DSO by having a list of questions and potential accommodations written down prior to meeting with the DSO counselor. It's important to note that accommodations apply to nearly every aspect of college life. If the college is offering something to the general student population, it should be accessible for all students in order to be compliant with federal laws.

After Enrollment

Once the student has been admitted, there is a process for requesting accommodations in college. It requires the student to "self-disclose" to the DSO. Many colleges have an online process for requesting accommodations, which can be accessed through the DSO website. At other colleges, the self-disclosure process starts with the student either emailing the DSO, or visiting the office in person and meeting with a counselor. The student will need to be able to talk about their disability(ies) and provide documentation of a disability.



Know what you 'need' that will allow you to be healthy, successful and have fun while enrolled in college. These needs to discuss with your college may include caregivers, medical equipment, and accessible housing"

- Taylor Price

<https://www.ChristopherReeve.org/blog/life-after-paralysis/the-path-to-employment-paved-with-dreams-choices-goal>

ACCOMMODATIONS

Below is a list of the types of accommodations that students with paralysis and mobility impairments should consider asking the DSO about prior to admission. The DSO's replies to the students' questions may inform the student's college search process. They may choose not to apply to, or attend a specific school if they know that they won't get the accommodations and services they need. This list covers academic, housing, transportation, programmatic, and recreational accommodations. It's important to remember that campus life is not just restricted to the classroom and the residence hall and that all of these areas are covered under federal law. (Note: there may be other accommodations that the student should request. Be sure to connect with the student's therapists and counselors to determine the student's specific needs).

Classroom Accommodations to Ask the DSO About:

- Priority Registration
 - Because it may take the student more time to prepare in the morning, and more time to get places on campus, ask about the process for securing priority registration to allow the student to choose class times that allow them enough time to get to class.
- Classroom Relocation
 - Is there a process to request that the student's classes are in buildings that are close together? Can you ensure that the most accessible classroom locations (entry level floors, ADA compliant, easy access) will be considered for the student? Can the student visit the classroom locations prior to the schedule being finalized?
- Classroom Furniture
 - What is the process for requesting accessible desks and modified classroom equipment?
- Alternate Formats
 - If the student needs course materials in a PDF or screen reader enabled format, and/or electronic copies of textbooks, ask about how the DSO facilitates this process.
- Ability to Record Lectures
 - If the student is unable to type/write they may need to request the ability to record lectures. Ask about the college's policies around recording.

- Notetaker
 - If the student needs a person to take notes for them, does the college use a peer-based (another student) system, or do they hire a professional notetaker or use assistive technology to capture notes? What is the process for receiving notes?
- Ability to Use Assistive Technology (AT)
 - If the student needs to use speech to text software to write papers and take exams, does the school offer access to the software? Also, if the student is using AT during an exam, how does this process work?
- Extra Time
 - Students may need extra time to complete exams and coursework. Ask about the process for requesting extra time for coursework and exams.

Housing Accommodations:

Students with paralysis and mobility impairments who want to live on campus will need to connect with the DSO and the housing department to get a sense of the housing options on campus. Typically, colleges have a process for requesting housing accommodations that is separate from the request for academic accommodations. These requests are usually due in late May or early June, in the summer before the student's first year. In most cases, these requests are evaluated by the DSO and the housing department. It's a good idea to create a list of items that the student will need in order to make sure that the residence hall (dorm) room is accessible for them. If the student is in the college search phase, they can ask if it's possible to see an accessible room when they go on a campus tour. If that is not possible, students can ask to see pictures of accessible residence hall rooms, including building entry and accessibility features.

Here are some accommodations that students may want to consider requesting:

- ADA accessible room: "ADA accessibility" refers to technical compliance as stipulated in the ADA. Students should be specific in their request and ask for the accessibility features that work for them. For example, if the student needs keyless entry, due to hand mobility challenges, the student can make that request. Some residence hall rooms have private bathrooms and others have a shared "community" bathroom. If the student needs a private bathroom to be able to easily maintain hygiene and privacy, be sure to request it. The student may also be able to request a shower chair or bring their own. Upon touring the room or



moving in, if the room does not meet the student's needs, the student should communicate with the DSO about the things that don't work for them, so that the DSO can work to find a resolution.

- **Location:** There are a few considerations in terms of location. Some students may want to be on a lower floor or entry level floor in order to be able to easily access their room and in case of emergency evacuation. Additionally, students can request a centralized location on campus or a location that will put them closer to their classes or the dining hall.
- **Residence Hall Furniture:** Standard residence hall rooms usually come with a bed, a desk, and a closet/dresser. If the student needs an accessible desk or modifications to the space (lowering clothing bars, removing furniture, etc.), this is an accommodation that can be requested. If the student needs a hospital bed, they will need to request that the bed in the residence hall be removed. Some colleges can provide hospital beds or equipment for self-transfer, but at most colleges, the onus falls on the family to supply their own hospital bed. Hospital beds can sometimes be rented from local home health supply companies.

- **Personal Care Attendant (PCA):** Under Title II of the ADA, colleges are not required to provide personal care services as an accommodation. If the student needs a full time PCA for daily living and hygiene, the family will need to hire the PCA themselves. Typically, universities will allow the PCA to share a room with the student at no additional charge. If the student would like a joined room or some other configuration, they will need to discuss that with the DSO and housing offices. (See the section on PCAs)



Transportation Accommodations:

Many universities offer both on and off campus shuttles and buses for students in order to facilitate movement on campus, allow access to surrounding cities, and provide transportation to off campus events. Students who need accessible transportation should connect with the DSO and inquire about the accessibility of campus transportation. Some schools offer accessible golf carts specifically to support the transportation of students with physical disabilities around campus. Ask the DSO about what types of accessible transportation may be available.

Programmatic Accommodations:

Students with disabilities are able to request accommodations in order to be able to attend on campus events. One way to determine if making events accessible on campus is a priority to a college is to see if event flyers and promotions have an accessibility statement informing people who they can contact if they are seeking an accommodation. Students can look for this when they are on in-person tours, and check on the

campus events section of the college’s website. Many, but not all, colleges require accessibility statements for campus events. A few examples of these types of accommodations include:

- Accessible seating and companion seating
- Preferential seating
- Holding the event in an accessible location

Recreational Accommodations:

Students can also request accommodations related to campus recreation services and activities (including clubs and school sponsored social activities). This includes access to the campus fitness center and student center (See section on “Recreational Activities and Campus Events”). While the buildings themselves are required to be ADA compliant, often the spaces are not accessible, and do not offer ways for students with disabilities to be able to enjoy amenities and socialize with peers. A few examples of accommodations include:

- Accessible changing area
- Pool chair lift
- Rearranging fitness center equipment to allow for access
- Adaptive fitness equipment
- Adaptive furniture
- Adaptive gaming equipment

PERSONAL CARE ATTENDANTS

Students who need assistance with daily living, such as bathing, toileting, dressing and other personal care will need to retain the services of a Personal Care Attendant (PCA). ADA, the law that provides for “reasonable accommodations” in college and in the workplace, does not require universities to provide PCAs (read more about “Auxiliary Aids and Services” at <https://www2.ed.gov/about/offices/list/ocr/docs/auxaids.html>). DSOs will usually have information on the college’s PCA policy on their website. Be sure to review the policy. It will likely include information on housing, and information on how the PCA can register with the university so that they can have access to the residence hall. College policies differ as to whether the PCA can have access to services on campus such as libraries, fitness



centers, and dining halls if they are not accompanying the student. If the college's policies do not include this information, consult the DSO.

Students who need a PCA have a few options. They can hire an independent PCA, use a home-health agency to hire a PCA, or use a friend or a family member as a PCA. The cost of a PCA varies throughout the country. Families will need to consider their options, which might include: private pay, Medicaid, or insurance. This resource from the Family Caregiver Alliance provides details on the pros and cons of each of the options outlined above, and outlines guiding questions for students and families to use when interviewing PCAs: <https://www.caregiver.org/hiring-home-help>.

As of June 2020, there are only two colleges in the United States that have residential living programs that include PCAs. Those schools are:

1. The University of Illinois at Urbana-Champaign:

<https://www.disability.illinois.edu/living-accommodations/beckwith-residential-support-services-nugent-hall>

2. Wright State University in Dayton OH:

<http://www.wright.edu/diversity-and-inclusion/disability-services/personal-assistance-station>

At these schools, the PCAs are typically nursing students who are working as a PCA to further their education. This means that the PCAs are typically the same age as the students they are supporting.

If the student is considering using an agency to hire a PCA, they may want to ask the DSO if they keep a list of local home healthcare agencies. Although colleges cannot recommend a specific agency, they often keep lists of local agencies on hand. Students should also ask the DSO to connect them with any current students who have PCAs. This way, they can get an idea of what it's like to have a PCA on campus. Sometimes, students are able to share a PCA (if needs do not overlap or conflict). Students may also choose to hire several part-time PCAs, and often they can facilitate the hiring of these PCAs through the school of nursing or a physical or occupational therapy program. There are pros and cons to hiring individual PCAs and to using an agency. It's important to consider all the possibilities, including potential challenges with all the options.

There are a few things that students can do to prepare for hiring a PCA:

1. Write out the care needs

- Write down all of the support the student needs in a 24-hour cycle starting with waking up. This will be helpful when hiring a PCA so that they can understand the needs and expectations. This may include dressing, washing, transferring, and eating.

2. Write out specific instructions

- If the student needs care that is technical or specific, write out a step by step process and/or create a video for the PCA to use. This might include things like nighttime breathing machines, physical manipulations, and medication administration.

3. Consider the other areas where the student may need support

- The student may also need support with things such as laundry, grocery shopping, and socializing.

Having these things written out can facilitate the conversation with the PCA and assist in providing clear expectations.



As an undergraduate at the University of Albany, I relied heavily on the Office of Disabled Student Services and my Vocational Rehabilitation counselor. They helped guide me to a field of study where I would thrive and continued to advise me, even at my first job”.

- Sheri Denkensohn-Trott

<https://www.ChristopherReeve.org/blog/life-after-paralysis/finding-employment-where-you-will-thrive>

RECREATIONAL ACTIVITIES AND CAMPUS EVENTS

Students with paralysis and mobility impairments like to have fun and exercise just like their non-disabled peers. If a student is interested in sports, fitness, recreation, and campus events, there are a few things that they should be aware of. First, both the ADA and Section 504 have a provision for “auxiliary aids,” which means that it is the college’s responsibility to provide aids, including specialized gym equipment, interpreters, closed captioning, and more. Additional information can be found at this link. Second, in order to receive these aids, students need to follow the process to request an accommodation. This typically starts with the DSO, but will likely include other departments on campus.

Sports and Fitness

Students who are looking to play collegiate adaptive sports either at the intercollegiate or club level will want to identify schools that offer these programs. It can be challenging to find an up-to-date list of programs because there is no one governing body. Here are a few resources to help with the search:

- 1. American Collegiate Society of Adapted Athletics (ACSAA): Colleges/Universities that Offer Adapted Sports**
- 2. GRIT: Collegiate Adaptive Sports Guide**
- 3. AbleThrive: 21 Colleges with Adaptive Sports Programs**



If the student is interested in a specific sport, it's best to contact the college's athletics department and the DSO for the most current information.

If the student is hoping to work out on campus, they will want to check out the campus fitness center in person.

Although the fitness center is required to be ADA compliant, often that does not mean that it is usable for every student with a disability. Here are some considerations when touring or asking about the fitness center:

- Location
 - Can the student reach the location independently?
- Workout Equipment
 - Does the facility have adaptive workout equipment?
 - Is there enough space around the equipment to maneuver any aids the student requires (e.g.: a wheelchair, cane, or other support device)?
- Locker Rooms
 - Is there an accessible changing room?
 - Is there an accessible shower and toilet?
- Pool
 - Does the pool have a chair lift and are all staff trained to use it?
- Fitness Classes
 - Does the facility offer adaptive fitness classes?
 - Are instructors trained to modify based on varying abilities?

If there is something that the student needs in order to be able to workout, the student can request an accommodation through the DSO. The DSO will likely work with the campus recreation department who will provide a reasonable accommodation.



Campus Events

College is a time when students have access to many types of engaging activities including, concerts, speakers, and sporting events. Unfortunately, accessibility is not always at the forefront when campus events are planned. Students may want to ensure that they will have equal access to all of the events that a college offers. Some colleges have integrated the accommodations process into all of their campus events (athletics, student groups, speakers, etc.) and require an “accessibility statement” on all advertisements, while other colleges do not require information for people who are seeking accommodations to be included on event advertisements. The “accessibility statement” provides the student who is seeking an accommodation with the contact information of the person or department hosting the event and allows the student to request an accommodation. When “accessibility statements” are not on event advertisements, it puts a burden on the student who may need an accommodation in order to attend to track down the organizer and explain their need for an accommodation. When the student is touring a campus, they can look at the flyers for events and see if they have an “accessibility statement”. The same activity can be conducted online by looking at the campus events calendar for the past year and selecting individual events to see if there is a way to request accommodations for attendees. Students who need accommodations (preferential seating, accessible seating, PCA access, accessible transportation) should also ask the DSO about the college’s process for requesting accommodations at college events.

Conclusion

With the right structures, supports, and accommodations students with paralysis and mobility impairments can be successful in college. Using the considerations outlined in this document can help mitigate some of the issues that students with paralysis and mobility impairments may face in college.



Photo by Louie Favorite, Courtesy of Shepherd Center

RESOURCES

If you are looking for more information on transitioning to college with paralysis or have a specific question, Reeve Foundation Information Specialists are available Monday through Friday, toll-free at 800-539-7309 from 9 am to 5 pm EST.

The Reeve Foundation offers comprehensive resources and booklets on hundreds of topics related to living with paralysis, including:

Christopher & Dana Reeve Foundation: Choosing a College to Best Fit Your Child's Needs blog <https://www.ChristopherReeve.org/living-with-paralysis/for-parents/higher-education>

Christopher & Dana Reeve Foundation: College During the Coronavirus blog by Ian Malesiewski <https://www.ChristopherReeve.org/blog/life-after-paralysis/college-during-the-coronavirus>

Christopher & Dana Reeve Foundation: Fact sheet on Education for People with Disabilities: <https://s3.amazonaws.com/reeve-assets-production/Education-for-PWD-8-20.pdf>

Christopher & Dana Reeve Foundation: Selecting and Hiring a PCA: <https://www.ChristopherReeve.org/blog/daily-dose/selecting-and-hiring-a-pca>

Additional resources about transitioning to college with paralysis:

Accessible College: <https://accessiblecollege.com>

Accessible College provides one-on-one consultation with students with physical disabilities and health conditions and their families focusing on their transition to college and determining accommodations in college. The Reeve Foundation is sponsoring a limited number of consultations with Accessible College so that there is no charge to the student or their family for the service. Please call 1-800-539-7309 and ask for a Reeve Information Specialist to get started with this offer.

AbleThrive: 21 Colleges with Adaptive Sports Programs: <https://ablethrive.com/activities/21-colleges-adapted-sports-programs>

American Collegiate Society of Adapted Athletics (ACSAA): <https://www.acsaaorg.org/resources.php>

Family Caregiver Alliance: Hiring In-Home Help: <https://www.caregiver.org/hiring-home-help>

FinAid: Financial Aid for Students with Disabilities

Several scholarships for students with disabilities as well as financial aid resources <https://finaid.org/otheraid/disabled>

GRIT: College Adaptive Sports Guide: <https://www.gogrit.us/news/2015/12/14/the-complete-guide-to-collegiate-adaptive-sports>

Shepherd Center: University Accessibility: A 12-minute video that promotes the idea that education can continue after spinal cord injury. Colleges have disability resource offices that can help students with disabilities navigate college. <https://www.youtube.com/watch?v=qF59-wfnl2A&feature=youtu.be>

University of Illinois at Urbana-Champaign's Division of Disability Resources and Educational Services (DRES)/Beckwith Residential Support Services (BRSS): <https://www.disability.illinois.edu/living-accommodations/beckwith-residential-support-services-nugent-hall>



U.S. Department of Education: Auxiliary Aids and Services for Postsecondary Students with Disabilities: <https://www2.ed.gov/about/offices/list/ocr/docs/auxaids.html>

Wright State's Office of Disability Services: Personal Assistance Station: <http://www.wright.edu/diversity-and-inclusion/disability-services/personal-assistance-station>



We're here to help.

Learn more today!

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