Your Education Rights as a Student with Multiple Sclerosis

Jan Pottker, Ph.D.

People of all ages — including children, teenagers and young adults — may be diagnosed with multiple sclerosis. In fact, MS is the leading cause of neurological disease in young adults between the ages of 18 and 26. Students with disabilities who are in either *elementary or secondary schools* (elementary, middle and high school) or who are in *post-secondary schools* (any education enrollment beyond the high school diploma) have education rights and responsibilities. This brochure explains the differences in rights and responsibilities both for students and the schools or colleges they attend.

Students with disabilities should know their education rights and responsibilities in order to be equipped to succeed in all levels of schooling. Maintaining, managing and advancing your education is essential — not just when you are young, but when you must plan for a future as an adult living with MS. Remember that every person has the right to strive for his or her education goals despite having a disability.

In order for you to be considered to have a disability, one or more of your major life activities must be substantially limited by your impairments (*i.e.*, MS, muscular dystrophy, diabetes, epilepsy). Major life activities include the following functions:

- Caring for oneself
- Performing manual tasks
- Seeing
- Hearing
- Eating
- Sleeping
- Walking
- Standing
- Lifting
- Bending

- Speaking
- Breathing
- Learning
- Reading
- Concentrating
- Thinking
- Communicating
- Working

Secondary and post-secondary schools have to consider how an impairment or how multiple impairments affect a major life activity of the student. Schools and colleges may not base their coverage only on how a particular impairment affects a student's ability to learn. They must assess what is needed by students to ensure that they have an equal opportunity to participate fully in all school activities.

The message is clear. Students living with MS have the right to a non-discriminatory education. A student may not be excluded from educational activities solely on the basis of their MS. Many young people find that their MS symptoms and education needs change over time. In fact, an impairment which is episodic or in remission remains a disability if, when in an active phase, it would substantially limit a major life activity. This means that even if your MS is in remission, you retain your disability rights.

Federal Laws Protecting Students with MS

There are several important federal laws and amendments that protect students with disabilities from discrimination in education. The different anti-discrimination laws based on disability are very similar. They focus on whether an education institution's actions and obligations increase equal education opportunities, rather than on the more technical issue of whether a student has a disability. Even if a student does not need special education or related services, a school district still must consider whether the student is entitled to a reasonable modification of its standard policies, practices or procedures.

One federal law is **Section 504 of the Rehabilitation Act of 1973 (Section 504)**, which protects the rights of individuals with disabilities in programs and activities that receive federal financial assistance from the U.S. Department of Education. Section 504 states:

No otherwise qualified individual with a disability in the United States ... shall, solely by reason of his or her disability, be excluded from the participation in, be denied the benefit of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

Another federal law, **Title II of the Americans with Disabilities Act of 1990** (**ADA**), prohibits discrimination on the basis of disability by state and local governments. It protects students with disabilities to the full range of state and local government services, programs and activities (including public schools), regardless whether these entities receive any federal financial assistance.

In 2012, Congress amended once again the Americans with Disabilities Act Amendments Act $(AA)^3$ The AA amends ADA and Section 504 by broadening the potential class of persons with disabilities and by significantly clarifying how the term "disability" is to be interpreted. The AA no longer puts the burden of proof on the student by requiring extensive documentation. The AA has shifted the inquiry from students proving a disability to making the school responsible to students' needs. For example, schools may not consider such mitigating measures as medications, prosthetic devices or assistive devices that are used to eliminate or reduce the effects of impairment in determining whether an individual has a substantially limiting impairment. Nor may a school claim that a student with good grades cannot have a disability. You may not be penalized merely because you are able to successfully cope with your disability.

School districts or universities may be found out of compliance with federal law when they violate any provision of Section 504, the ADA or the AA. Every public secondary school and virtually all post-secondary schools are subject to these laws. Your rights vary according to whether you are in secondary or post-secondary education. In turn, school districts and colleges have different anti-disability discrimination responsibilities to their students. These differences are explained in this pamphlet. There also is a section at the end of this brochure that tells you how

to file a complaint with the U.S. Department of Education's Office for Civil Rights (OCR), which enforces Section 504, the ADA and the AA. Let's look at the rights and responsibilities of students and school districts in elementary and secondary schools, from pre-kindergarten through the senior year in high school.

Elementary and Secondary Schools: Pre-school, Elementary, Middle and High Schools

Elementary and secondary schools, in contrast to higher education, have an obligation to identify students within their jurisdictions who have disabilities and who may be entitled to aids and services. The Section 504 regulation requires a school district to provide a "free and appropriate education" (**FAPE**) to any qualified students with a disability, regardless of its nature or severity. To ensure the provision of FAPE to school age children, a school district must establish standards and procedures for the evaluation and placement of students who need (or are believed to need) special education and/or related aids and services. The school uses tests, as well as teacher input, to evaluate the students' needs. After a school district identifies the education and related services needed by a student with a disability, it must develop a documented plan such as a Section 504 or an individualized education program (**IEP**) for the student. The school district must provide the services stated in the student's plan. The documented plan helps guarantee that your right to an appropriate education are met under Section 504 and the ADA.

If you are a student with a disability and have unique needs, your school district must meet your individual education needs as they do the needs of a non-disabled student. Your documented plan, such as a Section 504 or IEP, must reflect your school's evaluation and placement process. The district must prevent misclassification or inappropriate placement. A student with MS may have different needs at different times during schooling. Your documented plan must be flexible to meet these changing needs. If you need such services as regular or special education, or related aids and services, your school must provide them.

Auxiliary Aids and Services

There are many different kinds of auxiliary aids and services that your school (and later, college) may be required to provide. Some examples of these are listed below. These examples do not indicate that your school must obtain them for you, just as this list does not capture every example of auxiliary aids and services.

- Providing a school bus that stops directly at the residence of a student with a disability
- Providing recording devices or taped texts
- Providing Braille calculators, printers or typewriters
- Providing assistive listening systems
- Providing specialized gym equipment
- Providing calculators or keyboards with large buttons
- Providing a reaching device for library use
- Providing sign language interpreters
- Providing telecommunications devices for the hearing impaired
- Equipping school computers with screen-reading voice recognition or other adaptive software or hardware

When your special needs are evaluated, your secondary school must make sure that trained professionals administer the specific evaluation tests you take, and that these tests are valid for you by accurately reflecting what the test is supposed to measure. Your school should not place you in a class or program solely on the basis of an intelligence test. Both Section 504 and the ADA prohibit students with disabilities from being discriminatorily assigned to segregated classes or facilities. Even where a school district does not believe that a student needs special education or related services, it must still consider whether the student is entitled to a reasonable modification of its standard policies, practices or procedures. The school must also conduct periodic re-evaluations of your skills and abilities in order to meet your current needs. In addition, students who were in the past determined not to have a disability now in fact may be found to have a disability due to the broadening requirements of the ADA Amendments Act.

Your parents or guardians must be able to examine your records and to be notified of any evaluation or placement action. Parents or guardians must also be allowed a

formal hearing if they disagree with a school's decisions about your placement. If your parents or guardians disagree with the hearing decisions, your school must make a review procedure available to you, and your parents or guardians.

The services you receive because you have a disability related to MS must be comparable to the quality of services provided to non-disabled students. Your teachers must be trained in the instruction that you need, and this instruction must be held in accessible facilities. Appropriate materials and equipment must be available to you. Students with MS who are otherwise able must not be barred from participating in extracurricular activities or non-academic services merely on the basis of their disability. These activities and services may include physical education and recreational athletics, recreational activities, groups or clubs, health services, transportation, referral to agencies that provide assistance to students with disabilities, and student employment.

If, for a valid reason, you require programs or facilities not available at your home school, you still have the right to a free and appropriate education. Your home school is responsible for valid costs involved with your transfer to and education at another school, whether it is public or private. Your home school must take into account the distance between your house and the alternative school.

Your career counseling must be based on your abilities rather than on your disabilities. School counselors and other staff must not advise students to make any education choices that restrict career objectives merely on the basis of any disability that you might have as a result of MS.

If you do not show clear signs of a disability, you may have heard someone comment, "You don't look as if you have MS." But some of us living with MS may have such hidden disabilities as fatigue, which may not be apparent to education professionals. However, Section 504 protects students with hidden disabilities just as it protects students who have disabilities that are easily recognized.

For example, students with fatigue may be wrongly perceived as lazy if they cannot study or concentrate on their schoolwork. They and their parents or guardians have the right to notify school counselors or others of their hidden disabilities so that they receive appropriate services in and out of the classroom. If

you have MS-related fatigue, you may need to take your more difficult classes in the morning rather than in the afternoon. If you have difficulty walking or climbing stairs because of fatigue or a walking impairment, you should be given more time to travel between classes, or be allowed to use an elevator normally restricted to teachers, or be given a special parking space that is close to your school building.

Applying to College

There is no reason that high school students with MS should not continue education beyond the high school diploma. Your education after high school may include career and technical schools, two-year colleges or four-year colleges and universities. Later, you may wish to apply to graduate or professional universities. Undoubtedly, you will take high-stake standardized tests as part of your admission process for college or any other post-secondary school.

Some students with MS may have a disability that puts them at a disadvantage when they take standardized tests. Federal law allows a student with a disability to ask for needed changes to testing conditions as long as the changes requested do not fundamentally alter what is tested or create undue financial or administrative burdens. If you need a testing accommodation, you should contact the organization that administers the any exam needed for college admission. For example, the standard tests for college admission are the SAT (administered by The College Board) and the ACT (administered by ACT, Inc.). You will need to provide the test-maker with documentation of your disability and explain your need for any changes in testing conditions.

Testing Accommodations

Some examples of testing accommodations are:

- The use of a sign-language interpreter for spoken directions
- Preferential seating
- Large print
- Tape-recorded responses
- Entering answers in the test booklet for you
- Fewer questions on each page

- Small group setting
- A private room
- Testing over several sessions
- Extended testing time
- Frequent breaks
- Braille

Generally, colleges and universities are not permitted to make pre-admission inquiries about your disability status. Nor are you required to inform the college of your disability during the admission process. When you apply to college or graduate school, a post-secondary school may not ask you such a question as "Describe your health" or "Have you been hospitalized for a medical condition in the past five years?" The only time a college or university is permitted to make a pre-admission inquiry about your disability status is when the college is taking remedial or voluntary action because of its past history of disability discrimination. Nor are you ever required to notify your college of your disability before or after college admittance unless you need academic adjustments, accessible housing or other accessible facilities, or disability-related aids and services.

If you meet the essential requirements for admission, a college may not deny admission simply because you have a disability. Nor may you be denied admission to a particular major or program within the college simply because you have a disability. For example, you may not be denied admission to medical school merely because you have MS. However, a college or university may deny admission to any student, disabled or not, who does not meet essential requirements for admission such as grade point average.

A post-secondary student with MS has rights and responsibilities just as an education institution has its own rights and responsibilities. The best thing that you can do for your future is to know your disability rights as you travel upward through your school years. Post-secondary schools must provide you with academic adjustments, including auxiliary aids and services, to ensure that they do not discriminate on the basis of disability. The responsibility of post-secondary schools toward students with disabilities differs significantly from those of school districts, even though Section 504 applies to them both. The more that you know about your responsibilities before you go on to college, the better are your chances to succeed.

Academic Adjustments and Auxiliary Aids and Services

Unlike elementary and secondary schools, your college is not required to provide you with a free and appropriate education. Instead, these higher education schools must provide appropriate academic adjustments to ensure that that they do not discriminate on the basis of disability. There are many different kinds of academic adjustments and auxiliary aids and services that your college may be required to provide. Some examples of auxiliary aides and services are listed earlier in the *Elementary and Secondary Schools* section of this brochure. These examples and the ones that follow do not indicate that your college must obtain them for you, just as this list does not capture every example of academic adjustments and auxiliary aids and services. Some examples are:

- Arranging for priority registration
- Reducing your course load, even if it means attending college part-time
- Substituting one course for another
- Providing readers
- Providing videotext displays
- Providing television enlargers
- Providing talking calculators
- Providing electronic readers
- Providing telephone handset amplifiers
- Providing closed caption decoders
- Providing open and closed captioning
- Providing voice synthesizers
- Providing a reaching device for library use
- Providing raised–line drawing kits
- Providing sign language interpreters
- Providing telecommunications devices for the hearing impaired
- Providing extended time for testing
- Offering you a TTY in your dormitory if other students are provided with telephones

Colleges are not required to provide such personal devices and services as help in bathing, dressing or other personal care; readers for personal use or study; or tutoring. However, if your college offers tutoring to the general student population it must ensure that tutoring services are also available to students with disabilities.

As when you were in elementary and secondary school, you may try contacting your state vocational rehabilitation agency to assist your college in providing auxiliary aids and services.

Colleges and universities may not treat a foreign student with disabilities differently than American students. In addition, post-secondary colleges or universities must provide auxiliary aids and services for a non-degree student who may be auditing classes or otherwise are not working for a degree.

If you will need assistance of any kind, it is useful to let your college know about your disability needs as soon as possible so that you are assigned to accessible facilities and receive needed academic adjustments and auxiliary aids. It is up to you to inform your college that you have a disability and need academic adjustments. Post-secondary schools are not required to identify you as having a disability nor are they required to assess your needs. That responsibility is your own. Do not wait until you have taken an examination or turned in an important paper and are dissatisfied by your grade before informing the college of your disability.

You must also follow reasonable procedures to request an academic adjustment. Look at your college's website or ask a staff member who specializes in assisting students with disabilities. Any college admissions or administrative staff member should be able to identify this person for you. Please remember to request any academic adjustments that you need from your college as early as possible, as some adjustments and services may require more time than others to provide.

Keep in mind that if you seek academic adjustments or auxiliary aids and services, each college or university may set its own reasonable standards for documentation to demonstrate disability and need. However, the college's standards must comply with Section 504 and the ADA. Try to work with the staff at your post-secondary school so that they understand your needs. Be friendly rather than adversarial.

Of course, your IEP or Section 504 plan will help identify services that were effective for you in elementary and secondary school; however, your IEP or Section 504 plan generally is not sufficient documentation to support either the existence of a current disability or the need for academic adjustment. You may be asked to provide additional documentation as your needs may now be different from when you were younger.

If you offer documentation that is considered insufficient by your college, its officials should tell you in a timely manner what other information is needed. If you need a new evaluation, you and your parents are responsible for paying for it. Your state vocational rehabilitation agency may assist you with these costs if you qualify under its financial guidelines. It is also important to note that your post-secondary school does not have to lower or substantially modify its essential academic requirements in order to meet your needs.

If you request a specific auxiliary aid, your college should give your specific request primary consideration. The college can opt to provide alternative aids or services if these are deemed effective. However, your college may refuse to give you an aid or service that would fundamentally alter the nature of its program or activity. It also may refuse to provide an aid or service if that provision would place an undue burden on the college.

Students with disabilities may not be charged more for participating in programs or activities than students who do not have disabilities. In general, colleges may not condition their provision of an academic adjustment on the availability of funds. Nor may post-secondary schools refuse to spend more than a certain amount of money to provide appropriate academic adjustments. Neither can they refuse adjustments because other providers of services may exist, although your college may help you obtain reimbursement from such outside agencies as a state vocational rehabilitation agency. The college retains ultimate responsibility for providing aids and services and for any costs associated with providing them.

You should also tell your post-secondary school if you believe that the academic adjustments that you have been provided do not seem to be effective. Work with your schools the best you can to resolve any problems. If you believe that your education institution is not complying with Section 504 or the ADA, contact the staff person who specializes in compliance with federal anti-discrimination laws. These staff members may be called the Section 504 Coordinator, the ADA Coordinator, or the Disability Services Coordinator.

Any post-secondary school must have an established grievance procedure. The grievance procedure must allow you to raise your concerns fully and fairly. It also must provide for a prompt and equitable resolution of complaints. If you believe

that your college's grievance procedure has not adequately addressed your concerns, or if you wish to pursue alternative methods to address your questions as to whether the grievance procedure was equitable, you may file a complaint through the Office for Civil Rights at the U.S. Department of Education. Or, you may bring suit in court against your college. Please realize that if you are able to work successfully with college administrators, your needs may be met more quickly than if you rely on filing a federal complaint or suing in court.

Make Yourself an Advocate for Your Education Rights

Know your rights. The most essential factors in your educational success will be your advocacy on your own behalf and your positive attitude. Know your anti-discrimination civil rights and work collaboratively with the disability coordinator at your school or college. Understand your strengths and weaknesses as well as any limitations that you may have. Know something about how MS affects you. Be able to communicate what you need to overcome the effects of your disability and which adjustments might work for you in specific situations.

Be prepared. Remember that students with disabilities should expect to complete all course requirements. In order to meet such course requirements as assignments and exams, you will need to identify the essential academic and technical standards that are required for admission and necessary for your chosen program or major. Students with disabilities should understand that while federal disability laws guarantee them an equal opportunity to participate in education, these laws do not guarantee that students will achieve outcomes such as outstanding grades or an automatic graduation diploma or degree.

Check with your high school counselor before you enroll in classes. All students applying to higher education are expected to meet that institution's essential standards. Students with disabilities must take a high school curriculum that will prepare them to meet these college standards. If you need assistance, talk to your high school guidance counselors or state vocational rehabilitation agency counselors to help plan your curriculum.

In high school, focus on math, science, writing and computer skills. The ability to write well and to have good science and math skills are important education factors. If you need assistance in improving your study skills, talk to your counseling staff. In addition, learning computer skills will be essential to your life, in school and out of school. If you have a disability-related issue that interferes with learning computer skills, assistive technology can help you.

Take summer preparatory classes. If you are planning to enter a college or university after high school, consider taking a preparatory program. Some post-secondary education colleges and university have summer programs in which students can participate while they are still in high school or after high school graduation. This type of program would ease your transition to college. Your high school counselors can assist students with disabilities by identifying local preparatory programs.

Be involved. Many students experience social isolation in their first year of college. If possible, become involved with campus activities. Be sure to attend orientation programs and become involved with the clubs or activities in which you are interested.

Your education is key to your success and pleasure throughout your life. Any disability you experience need not prevent you from gaining a full and satisfying educational experience. Know your rights and responsibilities, take advantage of the assistance available to you and rely on the counsel of those who have traveled this path before you. You are not alone and, with hard work, you can succeed!

¹ The U.S. Department of Education's regulation implementing Section 504 of the Rehabilitation Act of 1973, 34 C.F.R. Part 104, as amended.

² The U.S. Department of Justice's regulation implementing Title II of the Americans with Disabilities Act of 1990, 28 C.F.R. Part 35, as amended.

³ The Americans with Disabilities Act Amendments Act of 2008, Pub. L. No. 110-325, 122 Stat. 3553 (2008).

How to File a Complaint with the Office for Civil Rights (OCR), U.S. Department of Education

You may file a complaint based on disability by going to OCR's website, which is www2.ed.gov/ocr. Then type in the words "File Complaint" and click. The website will take you to a different page. On that page, click on the first link, which is "How to File a Discrimination Complaint with the Office for Civil Rights."

If you do not own a computer, the Internet is usually available from your public library, and free email accounts are available from several large providers.

You may also contact OCR by telephone, TDD, fax and email.

Telephone: 1-800-421-3481 TDD: 1-877-521-2172 Fax: 1-202-453-6012 Email: OCR@ed.gov

Jan Pottker received her Ph.D. in Sociology and Education from Columbia University and was named *alumna emerita* by the University of Maryland. She is the author of eight books and is a popular public speaker. Before retirement, Jan worked 30 years for the Office for Civil Rights, U.S. Department of Education. She and her husband are members of the Project RESTORE Board at Johns Hopkins University Medicine and they have two adult daughters. Jan, too, lives with MS.



National Multiple Sclerosis Society

nationalMSsociety.org

For Information: 1 800 FIGHT MS (1 800 344 4867)