SUCCEEDING AT SCHOOL & IN THE WORKPLACE WITH NARCOLEPSY

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Presentation Outline:

Disability as an individualized assessment

Understanding disability under the Americans with Disabilities Act (ADA)

Understanding Reasonable Accommodations at Work

Understanding Educational Accommodations at School
  - Reasonable v. Unreasonable accommodations
  - Disclosure to employer
  - Medical Professional’s role
  - Accommodation Ideas for Narcolepsy
  - Tips for Success & Additional Resources
What is a disability under the Americans with Disabilities Act (ADA)?

“A physical or mental impairment that substantially limits one or more major life activities; a record of such an impairment; or regarded as having such an impairment.”


“...must be construed in favor of broad coverage to the maximum extent permitted.”

ADA Amendments Act of 2008 (Public Law 110-325, ADAAA)
What is a Physical or Mental Impairment?

A physical impairment is any medical disorder, condition, disfigurement or loss affecting one of the body systems, such as neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genitourinary, immune, circulatory, hemic, lymphatic, skin, and endocrine. A mental impairment is any mental or psychological disorder, such as intellectual disability (formerly termed mental retardation), organic brain syndrome, emotional or mental illness, and specific learning disabilities.

29 C.F.R. § 1630.2(h)(1)-(2)
What is a substantial limit on a Major Life Activity?

Major life activities consist of functions such as caring for yourself, (including bathing, dressing, shaving, preparing a meal, and going to the restroom), performing manual tasks, eating, sleeping, standing, walking, lifting, reaching, bending seeing, hearing, speaking, breathing, learning, reading, concentrating, thinking, communicating, interacting with others, and working.

ADA Amendments Act of 2008 (Public Law 110-325, ADAAA)
What about medications or other mitigating measures?

The determination of disability must focus on whether the individual would be substantially limited in performing a major life activity without the mitigating measure.

ADA Amendments Act of 2008 (Public Law 110-325, ADAAA)
Can narcolepsy and other sleep disorders be considered disabilities by these standards?

ADA Amendments Act of 2008 (Public Law 110-325, ADAAA)

- Added **sleep** as a "major life function"
- Make evaluation in the patient’s **unmedicated state**
Understanding Reasonable Accommodations in the Workplace

• A change or adjustment to a job or a workplace that allows a person with a disability to apply for a job or to perform the essential duties of a job.

• The “essential duties of a job” include more than one function – the duties and skills that are necessary to perform the job.
Examples of Reasonable Accommodations:

• Changing the employee’s work schedule,
• Assigning non-essential functions of the job to other employees,
• Providing the employee with special equipment, devices or software,
• Restructuring the employee’s job,
• Providing the employee with additional training,
• Providing the employee with paid or unpaid leave needed due to the disability
UNREASONABLE Accommodations

Those that would not help an employee perform the essential functions of the job or would pose a significant financial hardship on the employer.

Examples:

• A school bus driver could not reasonably expect an employer to provide an accommodation that he only be required to work after 6pm.

• A paralegal for a small law firm to expect a reasonable accommodation that her employer hire a full time assistant to do those things that she cannot do because of her disability.

_EEOC’s_ Enforcement Guidance: Reasonable Accommodation and Undue Hardship Under the Americans with Disabilities Act
When should an employee disclose to an employer?

• No hard and fast rule
• Before problems arise
• Employee will have to disclose what his or her disability is at this point
• Formal v. informal disclosure
• Employee should be prepared to provide specific reasonable accommodations that he or she is requesting
• A physician’s report/letter may be required. Not full medical history.
How can a medical professional help patients to secure reasonable workplace accommodations?

• Brainstorm accommodation ideas with patient
• A doctor’s report/letter is often an essential part of formal disclosure.
• A doctor’s report/letter helps confirm diagnosis, discusses the symptoms of narcolepsy generally, highlights ways in which the individual is affected, and suggests accommodations consistent with employee’s request to employer
• Balance seriousness of condition with patient’s abilities
Accommodation Ideas for Narcolepsy

Taking Nap Breaks
- A nap during lunch
- Additional breaks to take medication
- An early lunch (10:30am) to take a nap
- A 15-minute naps every 3-4 hours during 9-hour day

Providing Space to Nap
- Providing a “wellness room” for employees
- Providing the new mothers’ nursing room as a nap space with sofa and locked door for naps.
Accommodation Ideas for Narcolepsy

Flexible Scheduling
- Flexibility in arrival time.
- Not scheduling clients back to back.
- Flexible working hours to avoid peak traffic hours.

Work from Home
- Working from home office once or twice a week.
- Providing a laptop and allowed to work from home.
Accommodation Ideas for Narcolepsy

Working Environment
- Not working in “high noise level” area of the workplace since it triggers EDS and cataplexy.
- Providing a more comfortable desk and moved to an area that has a window that gets plenty of natural light.
- Permission to stand or take breaks during meetings.
- When traveling longer than two hours for a business trip, permission to stay overnight at a hotel.

Consistent scheduling
- Moved to the morning or afternoon shift to allow for routine sleep schedule.
- Not required to do “clopening” shifts – closing shift one night and then opening the next morning.
Accommodation Ideas for Employees with Narcolepsy

- Taking Nap Breaks
- Providing Space to Nap
- Flexible Scheduling
- Working from Home
- Working Environment
- Consistent scheduling
- Addressing Cognitive Issues
Tips for Employee’s Success:

1. Foster teamwork with co-workers
2. Improve communications with management
3. Get advice when needed

Additional Resources:

Social Security Administration
State Disability Law Centers
Human Resources Department
Understanding Educational Accommodations at School
Special Education (IEP Plans) versus Section 504 Plans?

Individualized Education Program (IEP) plans:
• geared toward Special Education and placement outside of the regular classroom

Section 504 Accommodations:
• geared toward accommodations within the general education classroom.
Understanding 504 Plans for Narcolepsy

• Public school districts and other institutions of higher education receiving Federal Financial Assistance must provide a “free appropriate public education” to each qualified student with a disability.

  Section 504 of the Rehabilitation Act of 1973

• Extended to a wide range of state and local government services, programs, and activities (including public schools) regardless of whether they receive any Federal Financial Assistance.

  Title II of the Americans with Disabilities Act of 1990
What is a Free Appropriate Public Education?

May include education in the regular classroom, education in the regular classroom with supplemental services and/or special education and related services. It cannot cost the child’s family any extra money, and must be designed to meet the student’s individual educational needs to the same extent as the needs of nondisabled students are met.

Section 504 of the Rehabilitation Act of 1973
Who Qualifies?

• Students generally between ages 3 and 22 years of age and must have a disability

• Disability is a physical or mental impairment that substantially limits one or more major life activities; a record of such an impairment; or regarded as having such an impairment

  Title II of the Americans with Disabilities Act of 1990. 42 U.S.C. S121 01 et seq

• Sleeping as major life activity

• Assessment made without medication or ameliorating factors

  ADA Amendments Act of 2008 (Public Law 110-325, ADAAA)
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ADA Amendments Act of 2008 (Public Law 110-325, ADAAA)
“Hidden Disabilities”

• The Office of Civil Rights has also acknowledged that some students have “hidden disabilities” that are not readily apparent to others.

• Invisible disabilities may not be obvious, but if they substantially limit that child’s ability to receive an appropriate education

• Examples include certain learning disabilities, diabetes, epilepsy and allergies.

Who initiates the Section 504 process for accommodations?

- Anyone can refer a child for consideration for evaluation under Section 504, including a doctor, parent, teacher or school nurse.
- If a child is experiencing chronic problems at school and interventions are proving unsuccessful, and a disability is suspected, the school has an obligation to refer the child for an evaluation.
Who determines if a student qualifies under Section 504?

• “Placement decisions are to be made by a group of persons who are knowledgeable about the child, the meaning of the evaluation data, placement options, least restrictive environment requirements, and capable facilities.”

• Without a definitive “list” of qualifying conditions, school administrators and teachers must use their collective, professional judgment to make the determination

• Does not mention parents as being part of the committee
What information is used in conducting a Section 504 evaluation?

- Must consider **multiple sources** of information
  - Doctor’s letter
  - Grades
  - Teacher’s reports
  - Information from parents and medical providers
  - Standardized test scores
  - Discipline reports
  - Attendance records
  - No formalized testing is required under Section 504
What accommodations would best help a student with narcolepsy succeed?

• There is no list of approved accommodations.
• Generally, the student eligible under 504 (and not Special Education) will remain in the regular classroom.
• The Section 504 committee determines the student’s needs on a case-by-case basis, in accordance with the nature of the condition and what that child needs to have an equal opportunity compared to non-disabled students of the same age.
What accommodations would best help a student with narcolepsy succeed?

**Note-Taking:**
- Allowed to choose to anonymously assign a classmate to take notes and use their notes as well in order to grasp concepts better.
- Allowed to take notes and teachers also provide copies of their notes.
- Using a “smart pen” that records audio with writing.

**Day-to-day in classroom:**
- Snacking in class if stomach is upset from medication.
- Providing tutors who understand if student is late – knowledgeable about difficulties with sleep and EDS.
- Ability to participate in extra-curricular activities such as Volleyball and Cross Country running.
- Opportunities to revise material at a time that suits child better.
Extracurricular Activities

• Includes counseling, physical education and/or athletics, transportation, health services, recreational activities, specific interest groups and clubs

Standardized Testing

• ACT and the College Board (for SAT) have different requirements

• Receiving Section 504 accommodations or Special Education IEP accommodations at school will not guarantee accommodations, but may be helpful
College and Graduate School

At the postsecondary level, a qualified student with a disability is a student with a disability who meets the academic and technical standards required for admission or participation in the institution’s educational program or activity.

Provides appropriate academic adjustments and auxiliary aids and services that are necessary to afford an individual with a disability an equal opportunity to participate in a school’s program.

How can a health care provider best support patients in the Section 504 process?

• Evolving process through diagnosis, medication adjustments, identifying with the term “disability”
• Brainstorm accommodation ideas with patient and parents early on
• Ask exploratory questions:
  
  *Are short naps helpful?*

  *Does the student have trouble waking up in the morning?*

  *Is cataplexy an issue at school?*

  *Trouble retaining information from classroom lectures?*

  *Are there behavioral issues?*
How can a health care provider best support patients in the Section 504 process?

- A doctor’s report is an important part of the Section 504 review documentation
- Educates the Section 504 committee on the symptoms, current treatment options and effects on quality of life
- Highlights the individual’s unique strengths and challenges
- Suggests specific accommodations to best meet the student’s individual needs
Accommodation ideas for students with narcolepsy

- Managing EDS and Nap Accommodations
- Note-Taking
- Day-to-day in classroom
- Absenteeism
- Homework
- Class Schedule
- Alternatives to standard classroom
- Testing/Final Papers
Tips for Success

1. Address concerns in advance of problems arising
2. Put everything in writing when interacting with school district
3. Secure a full report from doctor, not just parents’ input on child’s illness

Additional Resources
Disability.gov
Children’s Law Center
College Board & ACT websites
US Department of Education, Office of Civil Rights
References


ADA Amendments Act of 2008 (Public Law 110-325, ADAAA)
