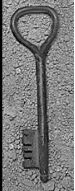


**Keys to
Understanding
and Serving
College Students with
Chronic Illnesses**

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Queens, NY
AHEAD/PEPNet 2010 Conference
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Purpose of Discussion

- **Heighten Awareness of Students with Chronic Illnesses**
- **Student Perspective**
- **Institutional Perspective**




Why?

- **Person → Disability → Diversity → Humanity**
- **American with Disabilities Act - 2008 Amendment Act**
- **Advancements in medicine**
- **Supporting other disabilities**
- **Benefits of a college education**
- **University Business's 30 Smart Business Ideas for Colleges**
- **Deal case by case – but need unified approach**




Awareness

- **Special Assistant to the President for Disability Policy**
- **At New York Mets games**
 - **Health Awareness Days**
 - **6 Days in 2006 compared to**
 - **14 Days in 2010**



Awareness

- **Students with Disabilities**
 - **11% of All Postsecondary Students**
 - **In Colleges and Universities**
 - **40% Increase in New York**
 - **24% Increase in California**



Awareness

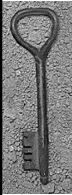
- **Almost half of All Americans live with a Chronic Illness**
 - **7% under age of 18**
 - **6% of those reporting a disability at Colleges and Universities are considered to be health related**

Sources: Center for Disease Control and National Postsecondary Student Aid Study



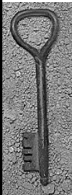
“Not everyone with a disability has a limp, sits in a wheelchair, wheels a portable oxygen tank apparatus, or is ‘obviously disabled’ ”

- Wladman, Cannella, & Perlman,
Invisible and Unseen Disabilities
The Exceptional Parent
Aug/Sept 2009



Awareness


- **Not just for those over 75... It does not discriminate – age, gender, or race**
- **Maybe well or ill at any given time**
- **Seem “invisible” to others**
- **Believed to be “unmotivated”**
- **Very large category, not all areas are known in great detail**



Chronic Illness


One that affects the individual for at least 3 months and is likely to continue in the future.

- Edelman, Schuyler, and White - 1998



Examples of Chronic Illnesses


- Arthritis
- Anemia
- Asthma
- Cancer
- Chronic Fatigue Syndrome
- Celiac Disease
- Crohn's Disease
- Cystic Fibrosis
- Diabetes
- Epilepsy
- Heart Disease
- HIV/AIDS
- Kidney Disease
- Liver Disease
- Lyme Disease
- Migraines
- Muscular Disorders
- Multiple Sclerosis
- Neurological Diseases
- Obesity
- Organ Transplant
- Oxygen Impairment
- Parkinson's Disease
- Seizure Disorder
- Sickle Cell Anemia
- Spina Bifida
- Ulcerative Colitis



Cancer

- **Increase in survival rates for childhood cancers**
 - 45% increase
 - Expectancy of 80% survival rate
 - Acute Lymphoblastic Leukemia (ALL)
 - 4% to 62%
- **Childhood Cancer Survivor Study**
 - Sponsored by the National Cancer Institute
 - Comparison of Survivors with Siblings
 - Graduation rates
 - Employment rates

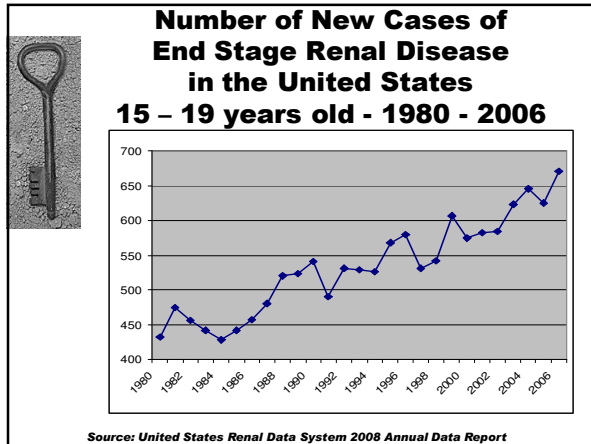
Sources: Gorin & McAuliffe, 2009; National Cancer Institute, 2009; & St. Jude's Hospital

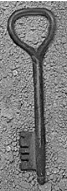


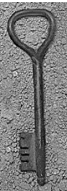
Diabetes

- **Almost 200,000 under age of 20**
- **Type I - ¼ of all newly diagnosed cases are 17 yrs of age or younger**
- **Type II - Increase in children diagnosed**
- **2 million ages 12-19 have a pre-diabetic condition linked to obesity**

Sources: National Institute of Health, 2008 & Center for Disease Control, 2008



- 
- End Stage Renal Disease (ESRD)**
- **Between 1980 and 2006, 55% newly diagnosed cases of End Stage Renal Disease for those 15-19**
 - **Increase of 10% of those 15-19 living with ESRD**
 - **Decrease in the mortality rate of those 15-19 from 28% to 17%**
 - **Probability of death of those receiving a living related transplant after 10 years has decreased from 11% in 1980 to 4% in 1996.**
- Source: United States Renal Data System 2008 Annual Report

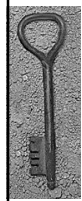
- 
- Celiac Disease**
- **Lifelong**
 - **Digestive Disorder**
 - **Gluten**
 - **Wheat products**
 - **Affects 1 out of every 133 people (children and adults)**
- Source: Celiac Disease Foundation, 2008



Crohn's Disease & Ulcerative Colitis

- **Inflammatory bowel disease**
- **30,000 newly diagnosed each year**
- **Mostly 15 - 35 years of age**
- **University of Michigan Study**

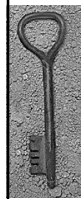
Sources: Crohn's and Colitis Foundation, 2007



Asthma

- **Millions of children are affected by asthma.**
- **Asthma accounts for 14 million lost days of school missed annually.**
- **Asthma cases more than doubled since 1980**
- **7th most prevalent health problem for College Students**

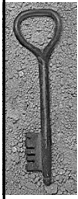
Sources: Center for Disease Control, 2006 & National College Health Survey, 2006



Obesity

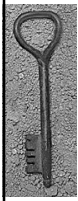
- **1/3 of college students**
- **Increases the risk of developing high cholesterol, hypertension, asthma, respiratory ailments, orthopedic problems, depression and type 2 diabetes**
- **Increase in the percentage of adolescents age 12-19 who are overweight**
- **Heavier children are even heavier than in the past**

Sources: 2008 National College Health Survey & 2007-08 National Health and Nutrition Examination Survey



“There are millions of people out there ignoring disabilities and accomplishing incredible feats. I learned that it’s not the disability that defines you, it’s how you deal with the challenges the disability presents you with. And I’ve learned that we have an obligation to the abilities we DO have, not the disability.”

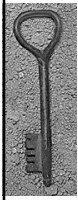
- Jim Abbott (former Major League Baseball Player)



Student Perspective


- **43% do not consider that they have a disability**
- **About 1/3 have not notified their institution**
 - **Not common on campus to identify**
 - **“I never thought...”**
 - **“I would have...”**

What can we do about this?




Student Perspective

- **Characteristics**
 - **Chose school**
 - **Academic Reputation**
 - **Closeness to home**
 - **During 1st year or Admission Process**
 - **Residence**
 - **Commuter**
 - **On campus**
 - **Fall behind in credits**



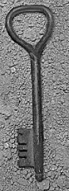
Differences

- Absences
- Reduced Course Load
- Need more administrative assistance
- More time involvement
- Change in nature of assistance
- Unique requests




Student Perspective

- Communicating Condition
 - Faculty
 - Administrators
 - Students
- Adjustment to college
- Management of condition




Student Perspective

- Side effects
 - Tiredness
 - Weight loss/gain
 - Mood changes
 - Nausea
 - Ability to concentrate
- Interfere with
 - Social Life
 - Extracurricular Activities
 - Academic Performance
 - Scheduling of Classes




Student Perspective

- **Offices contacted**
 - **Disability Student Services**
 - **Dean's Offices/Academic Advisors**
 - **Facilities**
 - **Campus Ministry**
- **Positive**
 - **Sensitivity**
 - **Willingness**
 - **Satisfaction**



Student Perspective

- **Issues with**
 - **Where to obtain information**
 - **Securing medical services**
 - **Schedules**
- **Negative**
 - **Asked for a "Buddy"**
 - **Provided more information than received**
 - **Not receiving housing accommodations**
 - **Encouraged to Drop out/change majors**




Student Perspective

- **Recommendations to other students**
 - **Self Advocate**
 - **Educate Faculty/Admin/Staff**
 - **Make their illness a priority**
 - **Achieve Balance**
 - **Do what is "right" for you**
 - **Reduce Stress**
 - **Lessen the credit load**
 - **Self Identify**
 - **Discuss with your physician**



Institutional Perspective


- **Half have specific policies for students with Chronic Illness**
- **Communication to**
 - **HS Advisor**
 - Web Site
 - One on one conversations
 - Publications
 - **Parents and Students**
 - Open House
 - Invitations to Presentations
 - Publications
 - Web Site
 - One on one conversations/ Meetings
 - Orientation
- **In Course Syllabus**
How can we enhance this?



Initial Information

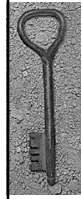
- **Obtaining**
 - **Disabled Student Services**
 - **1 on 1 meetings**
 - **Social worker/physician**
 - **Faculty Member**
 - **Web Site**
- **Dissemination**
 - **1 on 1 meetings**
 - **1 on 1 telephone**
 - **Web Site**
 - **Publications**
 - **Orientation**
 - **Open House**

How can we make this better?



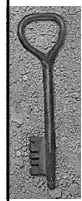
Important Activities

- **Peer to Peer Mentoring**
- **Workshops**
 - **Health Management**
 - **Stress Management**
 - **Coping**
 - **Healthy Eating**
 - **Life Balance**
 - **Emergency Situations**
 - **Time Management**
 - **Social Adjustment**



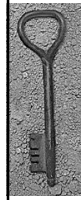
Important Activities

- **Services to have**
 - **Access to information on campus accessibility**
 - **Priority Scheduling**
 - **Flexible Scheduling**
 - **Lighter course load**
 - **Faculty and Peer Tutoring**
 - **Faculty approved extensions**
 - **Early access to course syllabus**
 - **Ability to take breaks during class**
 - **Recommendations of alternative classes**




Institutional Perspective

- **Peer to Peer Mentoring**
 - **Not widely available**
 - **Examples of activities**
 - **Dinner/lunch meetings**
 - **Guest Speakers**
 - **Social Events**
 - **Focus Groups**
 - **Day Trips**
 - **Frequency of meetings decided by students**
- **Workshops**




Institutional Perspective

- **Examples of Housing Accommodations**
 - **Tour with Res Life to see best fit**
 - **Own Cooking Area - Celliac**
 - **No Charge for Boarding - Celliac**
 - **Own refrig/microwave**
 - **Lock for own suite**
 - **Dorm with A/C - Asthmas**
 - **Adjustment of Cleaning materials used in Dorms**
 - **Single Rooms**
 - **Rooms with Private Baths**
 - **Attendant Services Program**




What Has Worked

- **Team Approach**
 - **Notify Key Individuals**
 - **Share schedules**
- **Trying to develop greater awareness on campus and understanding**
- **Communication to university community**
 - **Informal conversations**
 - **E-mail responses**
 - **Letters/e-mails**
 - **Web Site/web announcements**
 - **Presentations to faculty**



What Has Worked

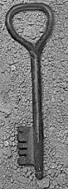
- **Faculty/Admin/Staff Training**
- **Clear procedures**
- **Establish emergency plans before hand with faculty**
- **Video Taped classes**
- **Web cams/podcasts**
- **Flexibility due to illness/disability attendance policy**
- **Priority scheduling**



What Has Worked

- **Find ways to help these students succeed**
- **Communicate to students that accommodations can change**
- **Role playing/coaching sessions**
- **Handout to manage Chronic Health Issues and Education**
- **University handicapped parking permits granted**


Other Examples?



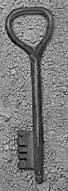
Wish List

- **Students**
 - Support Group /Peer Mentoring
 - Educate entire community
 - Market the services of DSS to students
 - Better Food Services
 - Assist Distance Learning Students
 - Early access to course syllabus
 - Knowledge to take other courses
- **Institutions**
 - Private room
 - Workshops
 - Peer to peer mentoring
 - Transportation
 - Access to professional knowledge on CI
 - Access to campus medical facility
 - Increased online courses

How can we meet these needs?




“the better the students can discuss their needs and set up a plan of action, the smoother the process works and the better academic success the student has”




In Conclusion

- **Collaborate and Communicate**
 - Outreach
 - Training
- **Expand the definition of “Disabilities”**
- **Mentoring and Support Programs**
- **Might take more time, but worth it**
- **Nature of assistance**
- **Encourage students to talk with Faculty members even when well**
 - Give examples of why this is important



“Life is not a matter of holding good cards, but of playing a poor hand well.”

- Robert Louis Stevenson






Questions &



Answers



Thank you!
