



Higher Education Options Expand for Students with Chronic Illnesses

by Marilyn Gilroy

For many years, the doors of higher education were closed to those with chronic illnesses, such as multiple sclerosis and cancer, primarily because of the issues associated with managing these diseases. Today, however, chronically ill students often want the opportunity to be in the intellectually stimulating environment of the college classroom despite their physical conditions.

“These are individuals who decades ago would not have been college students, but now they are,” said Patricia Fennell, president and CEO of Albany Health Management Associates and author of several books on managing chronic illness. “And their numbers are increasing.”

The Centers for Disease Control and Prevention reports that one in 10 Americans suffers from chronic illnesses. Last year, *JAMA: The Journal of the American Medical Association* said the prevalence of chronic illnesses among children and adolescents has reached 7 percent of that population.

As chronic illness in college students becomes more prevalent, faculty and administrators are scrambling to create appropriate policies and support services. Fennell runs webinars and online workshops to help college officials understand requirements and options for chronically ill students, who are enrolling in college at record numbers. The first concept she introduces to her audience is an explanation of the difference between static and dynamic illnesses and disabilities.

“Static conditions, such as blindness and deafness, are fixed and do not change that much,” she said. “But chronic illness such as

asthma, Crohn’s disease, lupus, rheumatoid arthritis, or illnesses with frequent hospitalizations, including cancer or heart disease, have an unpredictability about them because the symptoms ebb and flow.

“Although these students might have days that are relatively free of symptoms, there are other periods when a severe flare-up can trigger the inability to attend class and complete coursework.”

These problems can make it difficult, if not impossible, to meet the requirements of a conventional college program.

Fennell says the educators she works with are searching for guidance in answering several key questions including: 1) how do we adapt our pedagogical approaches to help these students? and 2) how do we keep them in school?

“I try to make administrators understand the experience of chronically ill students by giving them a cognitive map of what they and their families go through,” she said. “Then I ask them to think about their colleagues at work who are managing diseases such as diabetes, cancer and other conditions which cause them to have times when they need to be away from the job.”

Fennell is making the point that rules have changed about what it means to be chronically ill and how we accommodate these individuals in the workplace. In addition, there are laws in place now to protect people with health issues. In higher education, those laws are clear that we must deal with students who have visible and invisible illnesses, she adds.

For colleges in universities, there are significant challenges to integrating these individuals

into a college-level program of studies and helping them cope with the rigors of campus life. Without support services, students with illnesses can get frustrated and lose time and money if they have to drop out of courses.

In an article on WebMD titled “A College Guide to Chronic Disease,” several physicians spoke about the strains of campus life that can place students at risk for making existing chronic illnesses even worse as they try to meet the demands of their studies and social activities. The situation is exacerbated because many of these students are away from their parents and doctors who have supported them and served to reinforce care regimens.

Dr. Robert Winfield, director of the University Health Service at the University of Michigan, pointed out that students occasionally battle more than one chronic disease, such as epilepsy and irritable bowel syndrome. He noted that “as stress levels mount before midterms and the approach of finals, we find that anxiety, depression and sleep deprivation can take their toll on those trying to manage a chronic illness.”

Faculty members also feel the strain because they are not trained to negotiate all of the extenuating problems these students present to course requirements and teaching styles.

That is why Fennell advocates a multilayered approach, beginning with clear communication to students in orientation materials.

“Colleges should encourage students to self-identify and point out the advantages of doing so. This way administrators can put in place the resources, including staff, that need to be available to deal with actual, real numbers,” she said.

“And faculty should try envisioning these students under the umbrella of diversity because they are a population representing a subculture of needs within the institution.”

Above all, Fennell encourages faculty and administrators to recognize that the situation is “urgent” because it exists right now and needs attention.

“Chronically ill students require policies and services that differ from those offered to students with traditional, acute disabilities such as blindness and paraplegia,” she said. “How we accommodate them will make the difference in their chances for career success through achieving a college degree.”

Chronic Illness Initiative at DePaul University

DePaul University has been ahead of the curve in trying to meet the needs of chronically ill students.

In 2004, DePaul launched its Chronic Illness Initiative (CII), which provides access to higher education for students age 24 or older who are disabled by a chronic illness. Housed in the university’s School for New Learning (SNL), staff and faculty provide individualized attention for students who have complex lives. They are committed to helping these students achieve their educational goals.

Cecilia Reyes, who has multiple sclerosis, experienced the benefits of CII after struggling with traditional classes. Reyes first tried taking mainstream courses at DePaul, but despite her best efforts, she was either late for class or absent because of the flare-ups and limitations of her illness. But she did not want to give up or, as she said, “let the illness take over.” Through the initiative, she was able to complete her coursework and earn a degree in psychology.

According to Reyes, the school is like a family where students support each other despite disabilities. When she graduated, she was “thrilled” to hear her name called at commencement. She walked across the stage without any assistance and received her diploma as her parents, siblings and grandmother looked on.

The roster of students served by CII is diverse. One student, Gilliam Trumbull, had six surgeries during her three years at DePaul but

maintained a 3.2 average. Lacey Wood came to DePaul from California after two organ transplants. And Matt Morgan finished his degree despite being bedridden for most of his senior year with chronic fatigue syndrome. Terry Fulton, 53, returned to DePaul to complete her bachelor’s degree in social work, something she termed “an impossible dream.”

The initiative owes much of its creation to Dr. Lynn Royster, a SNL visiting professor, who watched for years her son, a victim of chronic fatigue syndrome (CFS), labor unsuccessfully to

of the initiative. Royster holds a law degree from George Washington University and a doctorate in conflict resolution and rhetoric from the Union Institute.

“After I began to teach at SNL, I saw a way that the program – which already had features that could make learning accessible to students with chronic illnesses – could be modified to eliminate some of the additional roadblocks chronically ill students face,” she said.

Royster’s efforts are supported by research showing the extent of illnesses such as her son’s chronic fatigue syndrome. According to a study conducted by Leonard Jason, a DePaul psychology professor, more than 800,000 people nationwide have CFS. But the initiative also serves those afflicted with other illnesses, such as multiple sclerosis, fibromyalgia, Gulf War Syndrome and rheumatoid arthritis – all of which are characterized by chronic relapses and fatigue.

“With chronic illness, a person’s condition can change radically during the semester,” said Royster. “It varies from student to student.”

CII gives these students flexible time requirements that allow them to earn degrees at their own pace. They can make up courses without being restricted by the normal two months other students have to complete a class after dropping out. They can take as much time as necessary to earn a bachelor’s degree without penalty because there are no minimum credit requirements for enrollment. Students may take as many or as few courses as they can handle.

No physical presence on campus is required. Students can obtain a DePaul degree online but may attend in-person classes if they wish to do so. Royster said

that one-half of CII students do come to campus because they want a classroom experience.

“Although it is enormously difficult for some of them, it also makes them feel validated,” said Royster.

Other features of the initiative include competence-based degree requirements that recognize learning in different settings; special advisors to help students plan and execute studies;



Patricia Fennell, President and CEO, Albany Health Management Associates

earn a college degree. Royster analyzed her son’s plight and worked to develop a program that would help others who suffer from chronic illnesses but want to go to college.

“I watched as my son, who is now in his 30s, struggled to go to college, only to be thwarted over and over again by severe relapses, heavy bureaucratic requirements and uncomprehending faculty,” said Royster, director and founder

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and informed faculty who are trained to understand and respond effectively to the needs of students who may appear slow but are, in actuality, ill.

“No one in the country offers a program like this,” Royster points out. “Typically, disability offices are trained to deal with more traditional disability needs, such as wheelchair access, readers for the blind and hearing aids. The disabilities we address are not totally solved with technological aids. Students who benefit from CII may be perceived as unmotivated when, in reality, they are wrestling with real health problems that seriously impact their ability to complete a conventional program.”

As a means of increasing awareness and sharing information, DePaul has held an annual Chronic Illness and Postsecondary Education Symposium for the last six years.

“It brings people together to share information about chronically ill students and gives us the opportunity to learn more about what we are doing and how we can do it better,”



Dr. Lynn Royster, Visiting Professor, School for New Learning, DePaul University

said Royster.

The 2010 symposium featured presentations from and about artists of all kinds,

including painters, dancers, actors and musicians, who offered perspectives on chronic illness.

Royster and her colleagues often hear the same questions and concerns about serving chronically ill students that Fennell encounters in her seminars.

“Faculty and administrators worry that they will be inundated with students and that they cannot handle their needs,” said Royster. “But I tell them these students also deserve an opportunity to get a college degree that will help them support themselves.”

She knows that many in the academic community would rather not deal with these students and their problems.

“You cannot ignore these students and hope they will go away,” she said. “I ask faculty and staff to see this as creating something that serves the needs of the institution as well as the needs of the students.”

