

Practice Brief

The Chronic Illness Initiative: Supporting College Students with Chronic Illness Needs at DePaul University

Lynn Royster
DePaul University

Olena Marshall
DePaul University

Abstract

College students with chronic illness find it difficult to succeed in traditional degree programs due to disruptions caused by relapses and unpredictable waxing and waning symptoms. College disability offices are often unable to help, both because their standard supports are not appropriate and because students with chronic illness frequently do not identify themselves as having a disability. This Practice Brief discusses the need for specific programs tailored to the culture of postsecondary students with chronic illness. The Chronic Illness Initiative at DePaul University is presented as a model for such programs.

People who suffer from severe and debilitating chronic illnesses such as chronic fatigue syndrome (CFS), lupus, rheumatoid arthritis, cancer, or heart disease represent a large segment of the U.S. population.¹ Childhood chronic illnesses are affecting ever more children, and college students are also increasingly unhealthy (Perrin, Bloom, & Gortmaker, 2007; Shieu, 2001). This development has led to rising insurance, health care, and social costs, as well as increased attention to the needs and rights of people with chronic illness in the workplace. However, we believe that the nation's colleges and universities have yet to recognize both the significance of this development and its implications for traditional faculty-student relationships, student support services, and the strict time structures that frame college life. The Chronic Illness Initiative (CII) at DePaul University offers specific, research- and experience-based approaches to serve chronically ill students. These approaches provide a model for accom-

modating the needs of students with chronic illness in the university setting.

In the fall of 2000, U.S. four-year colleges enrolled nearly 10,000 students with health-related disabilities, which included conditions such as severe allergies, cystic fibrosis, cancer, lupus, or multiple sclerosis. Students with these conditions represented 15% of all students with disabilities enrolled as first-time, full-time students in four-year colleges (American Council on Education, 2001). However, this number does not begin to reflect the actual number of students with health-related disabilities in the higher education system. Many do not identify themselves as having a disability and are, therefore, not counted in disability rolls. Others enroll in two-year programs or return after contracting an illness after their freshmen year.

Students with disabilities often experience difficulties related to attaining a postsecondary degree (National Council on Disability, 2003). In addition

to problems that are common to all students with disabilities, students with chronic illness face specific issues such as an inability to qualify for some financial aid options, unpredictable relapses during the term, and the invisibility of their illnesses, which can make them subject to disbelief and claims of malingering. Furthermore, needs of students with chronic illness are often overlooked by college disability staffs who do not understand the waxing and waning symptoms and unpredictable relapses experienced by the chronically ill (Jung, 2003). As Beatty (2001) points out, diseases such as multiple sclerosis, asthma, and lupus are characterized by flares of activity followed by periods of remission. These unpredictable shifts in wellness level lead to loss of spontaneous behavior, uncertainty, ambiguity, loss of independence and control, reduced options for employment, and inability to complete college courses.

In the context of a university, the needs and wants of students with chronic illness tend to differ from the institutional resources and privileges that can be routinely offered. Unlike students whose disabilities can be accommodated through a one-time expenditure of funds and administrative activity (e.g., students who simply need access to a building or require a piece of specialized adaptive equipment), students with chronic illness require accommodations that must continually be negotiated, adapted, and arranged (Jung, 2003). Often, students themselves have little understanding of their illnesses or how to address their illness needs, are not skilled at self-advocacy, and do not know how to find a postsecondary option that will meet their needs. "This lack of information and inability to develop coping strategies in postsecondary settings often results in students dropping out of the educational program," before they can acquire a degree or other credentials for employment (Edelman, Schuyler, & White, 1998, p. 2). This is unfortunate because education, which leads to better paid and more professional employment, is an important social determinant of health and a crucial component in resisting downward mobility for those with chronic, incurable illness (Jung, 2002).

Problem

Support for the health-related educational needs of students with chronic illness plays a large role in whether these students succeed in college. Traditional college and university programs do not systematically offer students accommodations that take into account the unpredictable nature of their chronic conditions, in part because students do not disclose information

about their health conditions, in part because their needs are not well understood. From the students who have joined the CII, DePaul faculty and administrators have learned that students frequently end up distressed academically, financially, and emotionally, having made multiple attempts to attend school that have resulted in strings of withdrawals, incompletes, or failing grades despite often outstanding academic capabilities. Most of the CII students are low-income; yet they have spent thousands trying to attend college, losing much of it because they could not finish courses within the traditional constraints of time and place. The CII was developed to serve this large population of people with health-related disabilities and significant unmet educational support needs.

Students and Location Information: The Chronic Illness Initiative at DePaul University

The CII is a comprehensive educational assistance program that focuses specifically on accommodations for students with chronic illness. The program fits well with DePaul University's mission of providing educational access.² Housed within the School for New Learning (SNL), the CII reaches out to students who, in the words of one student, may have experienced setbacks due to illness but did not lose all hope for a college education. She wrote: "I'm 20 years old and have chronic fatigue, fibromyalgia, and Crohn's disease. In the past three years since I graduated high school, I've tried to go to college twice and always ended up getting sick and never making it."

The program was founded in late 2003 by one part-time person, who acted as administrator, advisor, and faculty. This person, one of the co-authors, Lynn Royster, JD, PhD, created the concept for the CII after watching her own chronically ill son try to get an education. Since then, the CII has grown rapidly to recruit more than 200 students, and has expanded its administrative, advising, research, and support staff.

Students who sign up to participate in the CII enroll in degree programs offered by SNL. Nationally known for serving nontraditional students, SNL embodies many features (e.g., commitment to distance learning, a student-centered approach to college education, and faculty and staff skilled at educating students who lead complex lives) that make it a natural home for the CII. Students may earn a BA degree from SNL on campus and via a state-of-the-art distance education program; even the MA program includes some on-line features. The on-line option makes it possible for homebound and even bedridden students to earn college degrees and allows students, faculty, and administrators to

manage relapses and hospitalizations more smoothly. Because the on-line option adds flexibility to the education process, specific class times or the demands of physical travel do not prevent students from taking a class. Not surprisingly, about 80% of the CII students take advantage of this option for all or a part of their degree programs.

Strategy

The hallmark of the CII is respect and compassion for students and a sincere desire to help them. All CII staff members operate from this perspective. CII staff also work to educate faculty and staff about issues related to chronic illness so that they may respond appropriately and compassionately. By actively advocating on students' behalf, CII staff help both students and faculty to avoid the misunderstanding and mistrust that many students have experienced prior to coming to DePaul. At the core of the program are student support services, which aim to accommodate students' health-related needs as they pursue undergraduate and graduate degrees at DePaul's SNL. The staff include a director, an advisor/assistant director for student services, and a research associate (all part time) as well as several student workers, each of whom is engaged for a few hours each week to perform administrative tasks, develop an instructional video about the CII, create a financial aid resource guide, and serve as a buddy. The CII is also forming a Family and Friends Group that will engage additional volunteers. One parent of a CII student is working part-time for the CII as a public awareness coordinator.

Student Support Services

Although chronic illnesses encompass a wide range of symptoms and health conditions, they share an important characteristic: an unpredictable waxing and waning course of illness with recurring relapses and hospitalizations. Unlike more traditional and better understood disabilities that can be addressed by specific solutions, such as wheelchair access, hearing aids, or readers, chronic illnesses require ongoing flexible accommodations. For this reason, CII services assist students with health crises and the administrative burdens that arise from them, including college financing. CII staff work with the school's faculty and administration to craft exceptions to traditional policies when necessary.

Several specific supports are offered. A special CII advisor advocates for students with chronic illness, coordinates their questions and accommodations, acts as

a liaison between students and faculty, and minimizes administrative issues that can be overwhelming for an ill person. This advisor also works closely with the financial aid office to help navigate the confusing maze of financial aid options.

The CII has an endowed scholarship of \$57,000 and also receives occasional annual scholarship donations from other sources. It offers an annual service award to a person (usually a student) who has supported the program. The CII employs students with chronic illness to provide them with work experience and with additional income that helps offset education costs. The CII staff networks with internal student support services at DePaul and with community providers (ranging from support groups to service agencies) to help CII students take advantage of external supports.

CII staff members pay attention to the social integration of CII students, whether they attend classes on campus or online. The staff design academic and social events that allow students to validate their experiences, discuss effective strategies for managing illness and college, or simply build new relationships. A special program for 18 to 23-year-olds called Inside Track helps students adapt to the college environment and acquire skills that their older peers have developed. The CII's Buddy Program links each new student, regardless of age, to an experienced CII peer. Each fall, the CII conducts a meet-and-greet gathering for all students, setting a stage for social and academic interactions throughout the academic year. Two new programs pioneering fall 2007 are a counselor-led support group, and a peer discussion forum. Other social interaction venues, such as interactive guest chats, are in the works.

The CII director has designed and teaches a new undergraduate course on self-determination and self-advocacy and is planning a course on disability issues. Such courses serve a dual purpose: They engage CII students and also inform others about disability issues, disability rights and advocacy. For example, a student who took an advocacy and self-determination course began an active veterans group at DePaul as part of his class project.

Outreach

To reach potential students and serve others enrolled at DePaul, the CII has developed networks among disability-related groups, private and governmental service agencies, and counselors in high schools and community colleges. For example, the Chronic Fatigue Syndrome, Fibromyalgia, and Chemical Sensitivity Coalition of Chicago, the Chronic Fatigue

and Immune Dysfunction Syndrome Association of America, the Lupus Foundation of Illinois, the Pediatric Network, the National Association for the Mentally Ill, and the Multiple Sclerosis Society have all worked with DePaul on disability-related issues. These and many other groups (a) direct parents, potential students, and education and medical professionals to the CII via web links and publications; (b) advise the CII on research, disability services, and community resources; and (c) participate in an annual symposium on higher education and health-related disability issues. So far, the CII has hosted three successful symposia (May 2005, 2006, and 2007), whose audiences have evolved from local to national. The symposia bring together community service agencies, government agencies, hospitals, other colleges and universities, high school guidance counselors, patient support groups, experts on chronic illness, students, and parents.

Through its extensive collaborations and public awareness efforts, the CII reaches program beneficiaries (students, potential students, parents, employers, educational institutions, and disability groups) well beyond DePaul. Because most ill students find the distance education program very accessible, the program serves CII students all over the country. It has recently received inquiries from Canada, Thailand, England, Italy, and Ireland. In recent months the program has received, on average, five inquiries per week from potential students. About 50% of such inquiries result in people applying to the CII.

Rapidly growing CII enrollment, reflecting a considerable demand for chronic illness-related services, has moved DePaul University to expand the breadth and depth of services and outreach, build internal and external partnerships, and undertake efforts to build national awareness about the capacities and needs of people with chronic illness among employers, colleges, universities, and the public. The CII has also raised more than \$60,000 in scholarship funds and more than \$80,000 in program funds to support the services provided to students.

Infrastructure Development

One of the most important, yet least heralded, aspects of the CII has been the development of an administrative structure to support the services offered to students with chronic illness and integration of the CII into the administrative and budget structures of the university. From its founding, CII obtained support and approval from the dean of the SNL and the faculty organization, who recognized that the issue of chronic illness was connected to the School's mandate to edu-

cate non-traditional students and reflective of DePaul's Vincentian mission to serve the disadvantaged.

Outcomes

The CII has brought about several important positive outcomes. First, awareness of and interest in the program have increased, as evidenced in accelerating inquiries from parents, potential students, and counselors, and in growing college enrollments (from 50 students in 2005 to more than 200 students in 2007). Local and national illness-related groups enthusiastically support the CII. Media have also praised the program in detailed publications about the educational needs of college students with chronic illnesses. Most recently, two articles appeared in the *Chicago Sun-Times* (Newbart, 2007, pp. 12 & 13), highlighting the program and several of its students, and both *Inside Higher Ed* and *University Business* have featured it.

As an academic support program just approaching its four-year mark, the CII is beginning to generate sufficient longitudinal data on student academic performance, retention, and progress toward degrees to allow for valid comparisons with other reference groups such as the general undergraduate population or the non-CII student population within the SNL. The DePaul University Office of Institutional Planning and Research has generated some preliminary comparisons that cast CII student performance in positive light. The end-of-year grade-point average (GPA) for CII students of 2.31 is comparable to that of the non-CII students (2.06). The inactive not-passing rates for CII students are lower than those for non-CII students. Overall, CII students are more likely to continue to their second academic year than non-CII students: Average first-year retention rate for CII students was significantly greater than the average first-year retention rate for non-CII students. Five students have graduated with BA degrees. Finally, in addition to helping students to get an education, the CII has provided work opportunities to several students, thus showcasing their abilities and giving them much needed job experience and extra income.

Implications

Given the increased incidence of and national attention to chronic illness, the CII's targeted educational support program is likely to be one that other American colleges and universities may have to adopt. Growing numbers of young people with illnesses such as asthma and diabetes, war veterans returning from the Middle

East with permanent health-related problems, and increasing numbers of adults returning to school will swell the numbers of such students. The CII combines compassionate attitudes and specific methods within a flexible program to help students with chronic illness succeed in college and builds public awareness about the needs and capabilities of this population.

References

- American Council on Education. (2001). *College freshmen with disabilities. A biennial statistical profile*. Retrieved September 11, 2007, from http://www.health.gwu.edu/files/active/0/college_freshmen_w_disabilities.pdf
- Beatty, J. E. (2001). Chronic illness identity in the workplace. Submitted to the Gender and Diversity in Organizations Division for the 2001 Conference of the Academy of Management. Retrieved July 12, 2004, from http://www2.bc.edu/~beattyjc/ci_acad_4-24-01.html
- Edelman, A., Schuyler, V., & White, P. (1998). Maximizing success for young adults with chronic health-related illnesses. Transition planning for education after high school. American Council on Education. Health Resource Center. Retrieved September 11, 2007, from <http://eric.ed.gov>
- Jung, K. (2003). Chronic illness and academic accommodation: Meeting disabled students' "unique needs" and preserving the institutional order of the university. *Journal of Sociology and Social Welfare*, 30(1), 91-112.
- Jung, K. (2002). Chronic illness and educational equity: The politics of visibility. *National Women's Studies Association Journal*, 14(3), 178-200.
- National Council on Disability. (2003). People with disabilities and postsecondary education. Retrieved September 11, 2007, from <http://www.ncd.gov/newsroom/publications/2003/education.htm>
- Newbart, D. (2007, May 28). A chronic problem on campus: Illnesses such as chronic fatigue syndrome and MS make it tough for college kids to make it through. *Chicago Sun-Times*, p. 12.
- Newbart, D. (2007, May 28). DePaul may be first school with program that can help. Students can take courses online, miss tests and not worry. *Chicago Sun-Times*, p. 13.
- Perrin, J. M., Bloom, S. R., & Gortmaker, S. L. (2007). The increase of childhood conditions in the United States. *Journal of the American Medical Association*, 297, 2755-2759.
- Redden, E. (2007, Nov. 8). Reaching students with Chronic Illness. *Inside Higher Ed*.
- Shieu, S. (2001). Issues in the education of students with chronic illness. *International Journal of Disability, Development and Education*, 48(3), 269-281.
- 30 Smart Business Ideas: successful business processes and practices to consider. *University Business*, (2007, December).

Endnotes

1 According to the U.S. Department of Health and Human Services, Center for Disease Control and Prevention, “chronic diseases such as heart disease, cancer, and diabetes are leading causes of disability and death in the United States. Every year, chronic diseases claim the lives of more than 1.7 million Americans. These diseases are responsible for 7 of every 10 deaths in the United States. Chronic diseases cause major limitations in daily living for more than 1 of every 10 Americans, or 25 million people. These diseases account for more than 70% of the \$1 trillion spent on health care each year in the United States.” <http://www.cdc.gov/nccdphp/publications/index.htm#2> accessed on September 10, 2007.

2 Founded in 1898, DePaul University was named for and inspired by the life of St. Vincent de Paul, who dedicated his life to giving voice to the poor and disenfranchised. The university’s historic mission is to offer special assistance to students of high potential who have been handicapped by educational, personal or societal obstacles beyond their control. DePaul has always been committed to educating children of immigrants and first-generation college students, especially those from Chicago’s many diverse cultural and ethnic groups: nearly 30% of DePaul freshmen students are from minority groups and about 30% are first in their families to attend college. With 23,000 students, DePaul is the 10th largest private not-for-profit university.

About the Authors

Lynn Royster, J.D., Ph.D., is founder and Director of the Chronic Illness Initiative at the School for New Learning, DePaul University where she also teaches in the on-line program. She is Vice Chair of the Chronic Fatigue and Immune Dysfunction Syndrome Association of America and the parent of a young man with chronic illness. She can be reached by email at lroyster@depaul.edu.

Olena M. Marshall is a senior proposal writer for DePaul University. She has contributed to articles on information systems in the health care industry, issues concerning post-secondary education in computer science, and fundraising. Presently she is researching the occupational identity of elite restaurant chefs. She has an MA in Sociology from DePaul University and a BA in the English Language and Literature from the V.N. Karazin Kharkiv National University (Ukraine). She can be reached by email at omarshall@depaul.edu.