A historic school year will soon begin for the student residents and staff of Beckwith Hall, for they will be the last to live, learn and work in the program’s present location on John Street. In the Fall of 2010, the programs and services of Beckwith Hall will be integrated into Ikenberry Commons, a new residence hall and dining facility with state-of-the-art design elements that will substantially enhance the Division’s ability to help students achieve independence in the self-management of their disability-related needs. And, I should add, it is no small task to enhance the performance of a program that has been so extraordinarily successful. Indeed, since 1981, 84 percent of the 181 residents of Beckwith Hall have graduated and 90 percent have either obtained employment or entered graduate or professional school within a year of graduation. Additionally, four of the 21 residents who lived at least one year at Beckwith successfully transferred to alternative housing in the campus area where they will independently manage their personal assistance service needs, and six new students aspiring to achieve a similar outcome are moving in.

As evidenced by the program’s record of performance and the reflections of current residents and their families contained in this newsletter, the programs and services of Beckwith Hall continue to play an invaluable role in fostering self-determination and personal empowerment. We look forward with excitement to the successes that our students will experience in the approaching year, and to opportunities that we will be afforded in the coming years to build upon that legacy of success by exploiting the unique opportunities for innovative programs and services that will be available in the Ikenberry Commons complex.

Brad Hedrick, Director
Disability Resources and Educational Services

Beckwith Hall
“Making important choices...Leading empowered lives.”

Navigating Uncharted Waters

By Patricia B. Malik, Ph.D., Director

André Gide once said that, “One does not discover new lands without consenting to lose sight of the shore for a very long time.” Of course, when one loses sight of the shore, it means that risks are involved — navigating on unchartered waters. During the past year the residents and staff took risks, established new relationships and experienced life to its fullest. Katherine, Paige and I are impressed as we reflect back on the many accomplishments of residents and in how our program continues to grow and improve. This year has been no different. Through the pages you will meet some of those who have contributed and benefited from the “Beckwith experience.”

• K.L. Cleeton received the Matthew Odelius Award due to his entrepreneurial spirit and belief that he can change the world (there is no doubt that he hasn’t already done so).
• Four Beckwith residents — K.L. Cleeton, Alex Gentile, Bryan Jinks, and Katelyn Nelson — will move into other residential environments on campus. It is because of their transition that we have room for six new residents for the 09-10 academic year. Unfortunately, two people remain on our wait list. Within the last two years eight residents have transitioned out before graduation. They truly embody the spirit and mission of our program.
• Two first year residents are taking summer classes and living in Daniels Hall. David Kirby and Philip Edgerley are “discovering new lands” as they live on their own and manage their personal care needs.
• Ten first year residents moved in August 2008, resulting in 21 residents with disabilities.
• Amber Buckley-Shaklee was selected for the Mobility International USA (MIUSA) 2008 US/Costa Rica: Cross-Cultural Perspectives on Disability Rights Leadership Exchange Program last summer. She presented on this two week experience which inspired three others to apply for this international travel opportunity.
• Katy Hoyer received the first Caregiver Eternal Flame Award sponsored by the 2009 University of Illinois Relay For Life. The award is a glass luminary and an eternal flame candle that is engraved with Katy and her mom’s (Cheryl) name. It will be lit annually at each Relay for Life on campus as a memorial to Katy’s mother.
• Beckwith administrative staff worked in partnership with University Housing in a number of areas including: interior design/furniture selection, and co-facilitating a three session Staff Learning Series on disability awareness, Beckwith programs, and University Housing’s culture/philosophy. The partnership with housing personnel has been an exciting new area for us, one that is truly “unchartered waters.” Additionally, the benefits and potential from building a residential model of support for persons with severe physical disabilities in a manner that is far beyond any other university is exhilarating.
• Piloted high school mentoring program with two local students. Paige Lewis coordinated this effort with Shannon O’Brien. The intent is to expand this mentoring program to students across the country.
• A new personal assistant program was piloted by Katherine Johnson using a combination of CD self-study and hands-on classroom training. Twenty personal assistants were hired and trained this year, totaling over 75 PAs on staff.
• The loss of a recent University of Illinois and Beckwith resident, Annie Hopkins, was felt by many within and outside our community. Annie embraced disability advocacy and was willing to take risks and "lose sight of shore" if it meant that she was making a difference in the lives of those with disabilities. She will be missed by many.

The 09-10 academic year will be our last year in Beckwith Residence Hall — I am sure that it will be bittersweet. Yet, I for one am excited about “discovering new lands” and making the transition into a new partnership with University Housing. This collaboration will afford University of Illinois students with severe physical disabilities many more opportunities that they so truly deserve.
A Student’s Perspective

by Michael Roberts

When I first arrived at the University of Illinois and more specifically, Beckwith Hall in August 2008, I didn’t really know what was in store for me. I did not have any Personal Assistants (PAs) set up for my care, since I procrastinated over the summer. Also, I did not know how to train and even hire personal assistants, or where to start. I was very much a greenhorn to the whole process. I’ve always been under the care of my parents since my injury, because they are both nurses. A recipe for disaster seemed imminent due to my inexperience and the fact that I had gotten an indwelling catheter placed a few weeks before moving into Beckwith. Luckily, the disaster was averted.

In my first few months here I probably spent more time in the hospital and various medical facilities than in class or in the dorm. However, by a combination of working with Katherine and Paige on my disability management plan, as well as consulting various sources on how to take care of myself in a more proficient way, I made it through the semester. Without Beckwith Hall, I probably would have had to withdraw from Illinois and gone home to a school closer to me where I would commute. I wouldn’t have had a chance to enjoy the true college atmosphere that I enjoy here.

Attending Illinois has also given me a chance to meet people with similar disabilities. Before I came here, I never really connected with anyone else with a disability, since I was afraid of being stigmatized as a “sped.” In my school district, the disability and special education department were one and the same. I felt better interacting with disabled students here since I knew they were all qualified to get into such a prestigious institution. Over the last year, we have become close, almost like a disabled Brady Bunch, where we all look out for each other if ever something happens with no questions asked.

After my experiences this year, I am convinced that Beckwith Hall is the best environment to help people with more serious disabilities transition from life with dependence to one of independence through its tremendous support services as well as the sense of community that develops.

A Parent’s Perspective

by Joe Roberts

My son suffered a spinal cord injury at the age of 14. We were shocked how we had to fight the school district tooth and nail for everything we thought he was entitled to under laws and state vocational guidelines. Despite the paucity of supposed disability support resources Michael finished 10th in his class.

During the search for disability support at colleges, I found the website for DRES and we thought “Illinois is too damn far!” We live 25 miles north of New York City. So we just disregarded Illinois early in the college search process. We became acutely frustrated by false promises and the lack of insight college disability officials had for Michael’s needs. After a particularly painful visit at Cornell, because of the coarse way the disability officer spoke to us, my wife had a life affirmation moment right there in the parking lot, and yelled out “ILLINOIS!!?”

Michael already was accepted as an early admit so in February 2008, we drove 951 miles to Champaign and our first encounter with Paige Lewis was when she came out during a snowstorm without a coat to greet us!!! We met with Paige and Pat and we were just blown away with all the information and their genuine concern for Beckwith students. Michael and the family decided right there and then, he would be among the Illinois Class of 2012.

We got lots of flak from family and friends about our lack of judgment by wanting to send our paralyzed son alone, out to the middle of the country. We dug our heels in and just had faith in the support we believed Beckwith and DRES would give to Michael.

After spending five days settling Michael in, and already dealing with his first medical emergency, I left him alone in the hands of people I trusted with his life. I cried the hardest in my life until I drove through Indiana, and then questioned our decision for the next ten hours back to New York.

In early September, Michael had to be hospitalized. I flew out the next morning because of fear. I was reassured by the Beckwith staff that Michael will have to deal with any emergency on his own and of course I was very anxious about the whole process. During the fall semester, Michael had been to the emergency room twice, visited the McKinley Health Center many times, and even dealt with the malfunction of his wheelchair on his own. His confidence increased each time though, as he increased his independence.

Finally, Michael used to call every day sometimes just to chat and at times because of anxiety relating to self care issues. This past February he celebrated his 19th birthday and now we have to call him more often than he calls us. Just like a typical college student!!! I like to think of my son like the bird in the Beatles song “…Blackbird take your broken wing and begin to fly; we are just waiting for this moment to arrive.” Soon after Michael’s accident, I wasn’t sure if he would ever get that chance. Thank God for Beckwith!!!
Law school notoriously features the Socratic Method, where, rather than providing the necessary information, professors spend class periods firing questions at their students. It is in this process—that students begin “thinking like lawyers.” Frequently dubbed the most demanding graduate curriculum is, in effect, a commitment to independent thought and independent living.

But what exactly does “independence” mean to me, in this context?

A little background is necessary to answer this question. I had not been admitted here for undergraduate studies, but decided I wanted the smaller liberal arts environment that would help me develop my writing, research, and interpersonal skills. I attended Lake Forest College, twenty minutes from my house in Deerfield, and majored in Politics and Communications. For the first three years of my career there, I lived at home and commuted every day. In order to prepare for law school, I lived in a dorm during my senior year. Still, a one-on-one aide helped me throughout the day, as had been the case since kindergarten.

Only marginally aware of the nature and depth of the crucial commitment to independence, I visited the University of Illinois in March, 2008. Beckwith was my first comforting stop. Sure, I had heard that Illinois is at the forefront of accessibility, but it is so that fact does not allow for its comprehension. Beckwith is unique in that independence is embedded in its mission. The Hall is equipped with an elevator activated either by the push of a button or touch of a wheel or foot, maids that make your bed daily and do your laundry once a week, a pager system that connects to a “floating” personal assistant available 24/7, and meal assistants responsible for assisting residents in the dining hall. After satisfaction of prerequisites, students are given a list of personal assistants employed by Beckwith. These individuals, having passed criminal background checks and training, can now be contacted and hired by the student who retains the right to terminate the employee at any time. Thus, the residence hall is designed with people with disabilities in mind; thisibt of services, social opportunities, and more to its students. For example, the DRES buses stop at Beckwith on the half-hour and can transport students anywhere they need to go as long as the destination is on campus.

Transition was still difficult for me. Going to Illinois meant I had to be away from my family for an extended period of time. While my parents visited me often at Lake Forest and were able to help if something went wrong, here, they would be three hours away and only able to provide advice and moral support. There were bumps in the road, including my own self-doubt and some technical and spatial difficulties. In the end, though, it is completely worth the effort and pain of being away from family; not only am I receiving a top-notch legal education, but I am also learning to live independently. Communicating with personal assistants and other staff can be intimidating, especially if, like me, you try to see the good in each person with whom you work. And while it is good to treat each person as you would want to be treated, also remember that you have to maintain a businesslike relationship with your staff and be able and ready to exercise control if necessary. You are the boss. It is your life that is affected here. My experiences at Beckwith are daily reminders of this truth, and opportunities to become more independent. That Illinois has people with disabilities in mind, to recapitulate, does not mean that you will not have problems in this setting. Do not be afraid when problems arise to utilize the resources you have access to, and remain cognizant of them when you leave as they may come in handy as you again enter a world not designed with you in mind; you can stand up and fight for your needs and the needs of others.

So, what does independence mean in this context? Merriam-Webster’s Dictionary does not have an appropriate definition, and so I am forced to turn to yet another tool of my trade. Black’s Law Dictionary says that being independent means that you are “[n]ot subject to the control or influence of another” and that you are “[n]ot dependent or contingent on something else.” In truth, these definitions do not fit the disability community either, because if we use personal assistants, note-takers, buses, and the like to get around, then to the extent we rely on those services in our daily living, we are subject to the control of another or dependent on something else and therefore not independent.

But if you have a disability and live in your own dorm room, apartment or house, without the assistance of family members in completing activities of daily living, then you are deemed to be living independently. And, in that sense, then, there is no set definition of independence. It varies based on your particular abilities and needs.

And that’s what Illinois, DRES, and Beckwith are all about—redefining independence, one person at a time.

**By David A. Kuriniec**
By Annie Hopkins

(Abridged Reprint from 2006 Beckwith Annual Newsletter)

As I prepare to leave the University of Illinois, I can look back on my senior year and be proud of my accomplishments. I entered the University with many insecurities and no idea what I wanted to do with my life after college. I was used to my life back home, where I had 24-hour personal assistance provided by my mom. When I came to college, it was taken away from me and I had to get used to the idea of independent living.

What is independent living? It is not having someone there for you at your beck and call. It is being able to manage your own life - from what time you are going to shower to how you are going to get to your exam in the pouring rain because you forgot to schedule a ride from DRES. It is also needing more than two hands to count the number of people who have seen you naked. These people are personal assistants and my peers, and hiring them was the hardest part of independent living because I had to have my own peers help me with very personal needs. Eventually, I became comfortable with this new life and I was able to set personal and academic goals for myself.

I changed my major three times throughout college, but I was still able to accomplish my goal of graduating in four years. I entered a major that made me happy and excited about my future. I will be graduating with a degree in Community Health, concentrating in Rehabilitation and Disability Studies. At first I was not sure what I wanted to do with this degree, but over this past summer I had an epiphany of what I wanted to do with my life.

I have always enjoyed educating people about individuals with disabilities and I think that this kind of education is very important at the college level. My interactions with peers have led me to want to provide this kind of experience for other students. I believe I can do this on a larger scale if I pursue my doctorate degree and become a Disability Studies Instructor. I have taken many disability-related classes taught by people without disabilities, but through my interaction with peers I have concluded that information provided by people with disabilities about disability-related issues is much more valuable to them because the information is more credible. Knowledge gained from disability studies courses will help reduce discrimination and benefit both people with and without disabilities through meaningful interactions with one another.

Although my last semester has been busy and packed with many activities, it has been my happiest and best semester. I have prepared for grad school by applying and figuring out independent living outside of the University of Illinois. I do not know where I am going, but I now know exactly what I want to do.

The Anne Hopkins Foundation

The main goal of the Anne Hopkins Foundation is to grant scholarships to college students who demonstrate a similar life’s passion to Annie’s to improve the lives of people with disabilities. We cannot bring Annie back to life or do her work alone, so the best way to continue her battle is to empower others who share similar passions. Annie was a champion of education and its ability to shape someone’s life and position them for success. Hopefully through scholarships, we can assist others in achieving Annie’s dreams.

www.annehopkinsfoundation.org

“Embrace diversity. Educate your community. Empower each other. Love life.”
— Annie Hopkins
By Steve Hopkins

I am a 2006 graduate of the University of Illinois at Urbana-Champaign and a former resident of Beckwith Hall. I graduated with two degrees from the College of Business and have worked for my family’s financial services company since leaving. The story that I’d like to share is less about me and what I’ve been doing and more about my little sister Annie’s story and what I’ve learned from her life and recent passing in January 2009.

Annie and I were born 15 months apart with the same neuromuscular condition, Spinal Muscular Atrophy (SMA) type 2. We lived our whole lives much like we were twins and best friends, even up through college living in the dorm together. The two of us remained very different, though, in several ways. I always believed that there was no place in my life for disability advocacy, but that by being a successful person in my field of choice and a good role model for others, that was enough. While I believe that my position on the matter holds some merit, I think that Annie had a much better approach. She challenged all obstacles, social, physical, and legal — all the time. Sometimes winning and sometimes losing battles, Annie would go out of her way to live her life to the extreme, putting her disability aside. In college, if there was an apartment party we knew about, I’d stay home out of ease and Annie would find someone to carry her up three flights of stairs and find a comfortable couch to sit on.

All in all, she was not happy living life to the restrictions her disability placed on her, so she didn’t and she even took that a step further to pursue a career in disability advocacy and a higher education, hoping to spread her message and approach to other people with disabilities, people like me.

So, while I moved back in with my parents, and still do remain with them, Annie moved into an apartment on her own in Chicago, to follow her dream of independent living and contribute to the disability rights movement and social model of disability. She achieved many things while living on her own for almost three years, including master’s degree coursework and getting accepted into the Ph.D. program. Annie won “Advocate of the Year” from an independent living center for her work on sexuality education, the company she founded, 3E Love, and also the potential they believed she had.

I cannot pretend that Annie’s journey was easy. Living independently with a severe mobility-impairment will never be a cake walk, and Annie fought the expected battles with hiring quality personal assistants, safe transportation, accessible housing, and the bureaucracy of government support programs like Home Services and Vocational Rehabilitation. All of these struggles took a major toll on her mental and physical state, and when she went in for a simple medical procedure to help her consume food more easily, she died from medical complications and errors 14 days later. Even in the last days of her life, she was advocating for better quality healthcare than what she was receiving. She was always a fighter!

So yes, I lost my sister and best friend at the age of 24. She died fighting the good fight, though — a fight that more of us need to engage in if things are ever going to change for the better. She accomplished more and was happier in her three years of struggle than I have been in my entire 25 years. This probably is true for many others with a disability who take it the easy way like I have. Getting a good education, a good job, and living a healthy life aren’t the only measures of success. It’s important to take that next step and challenge yourself and challenge society’s expectations of you.

That’s what I’ve learned from Annie. So even though I will continue to live and work with my parents in the short term, I’m taking more steps to live like my little sis did. This summer, I am going on a road trip for an entire month with a current Beckwith resident, Hugo Trevino, who has SMA type 2 as well and I have known for many years. Hugo and I, with the help of some able-bodied friends are jumping in my van with one backpack of clothes and some supplies, and will travel the country. Is it reckless and maybe a little impulsive? Yes. But it’s how Annie lived and exposed herself to thousands of new people and experiences. She just put herself out there, no hesitation.

Coming back from my trip, I hope to return with not only great stories and an appreciation for our country, but hopefully also with film, pictures, and a message to others. Hopefully I can find the energy and will to then continue some of the work she started and be an advocate for myself and others.
Leadership can show itself in many different forms. However, what inspires and motivates people the most is leadership that is shown through example. It is common to find those who are capable of handing out orders while sitting on the sidelines. But the measure of a true leader is whether they are ready, willing and able to perform tasks they ask others to complete. Reflecting on these truths, I have come to consider myself a leader.

While I am not the type of person that shines particularly bright in a group setting, I believe because of my singular actions I have grown to be seen as a leader. My high involvement in film production, political activism, education reform and more have shown that anyone can truly live a life with no barriers; even those with disabilities.

The achievement that has meant the most to me is the production and widespread viewing of 2FAST4U, a documentary about me. With this documentary I have been able to educate audiences from Effingham, Illinois to New York City to Barcelona, Spain. Those who otherwise knew nothing about the disabled community have been able to witness a slice of disabled life with this film.

I hope that in my time here as a resident advisor, I have helped some of you in facing your own challenges, whether personal or academic. However, more importantly, I want to thank each of you for helping me face mine. I have never met such selfless, compassionate, and genuine people than those that both reside and work at Beckwith Hall. Your simple acts of kindness continue to amaze and inspire me on a daily basis. This year, you showed me life; you opened my eyes to many new things and taught me how to be a new person, and for that I am forever grateful.
After reflecting back on this past semester I am really glad I was able to be a part of the high school mentoring transition program. I really enjoyed helping others in the transition process from high school to college, because there is a big difference between the two. One of the main points I stressed throughout the entire semester are the two simple words, you and your. Although at first it may seem odd, but these two words characterize a main part of the transition from high school to college: You are now the one making decisions about your life; whereas before your parents have always had a say about what you do because you are living under their roof. In college you, and you alone, are now in charge of determining how your valuable time is spent. This can be a difficult idea to grasp at first, as you haven’t been in this position before, so prepare yourself ahead of time. No longer are your teachers and your parents going to be actively involved in making sure all your work is done on time and you get where you need to go. I believe that if you realize ahead of time the differences between high school and college, it is possible to have a smoother transition, as you can prepare yourself for these changes and you can be aware of them before they begin to occur.

As a part of the mentoring program, I presented on the importance of embracing self advocacy, time management and stress management strategies when you are in college. When it comes to self advocacy in college, you have to advocate for your rights, whereas in high school they are provided by law. Although it is not hard to request accommodations in college, it is important to recognize that you are responsible for initiating them. Nobody will track you down to establish your accommodations unless you initiate the process. Understanding your learning style can help you decide whether or not it would be beneficial to tape record your lectures or if printing the PowerPoint slides is sufficient, as well as the best ways to train your PA staff. All in all though, I think this semester’s mentoring program was a success and I am looking forward to seeing Peter and Ryan transition in the upcoming semester! I hope their parents have felt more confident also through their participation in the mentoring program.
Beckwith Mission

Beckwith Hall opened in 1981 to accommodate the residential needs of students with disabilities who require the help of personal assistants to perform basic activities of daily living. While aiding students in the management of their activities of daily living (transferring in and out of wheelchairs, dressing, grooming, bathing, etc.), Beckwith also offers individualized training designed to help students learn to independently manage their disability-related needs and, whenever possible, transition to mainstream community housing. The ultimate goal of Beckwith Hall programming is to make it possible for graduates to go anywhere their lives and career aspirations take them, confident that they can manage their own needs.

Beckwith is much like any other university residence hall in that it has a dining hall, student government, laundry room and a campus location along the Division's bus route. In addition, Beckwith offers the unique convenience of private sleep-study rooms with adjacent semi-private bathrooms. A computer lab with four workstations, voice activation systems, and a wide range of peripheral assistive input devices are also available.

For additional information about Beckwith Residence Hall, or for an alternative format of this document, please visit our website at www.disability.uiuc.edu/services/beckwith. You may also contact the DRES Student Services Office by phone at (217) 333-4603 (v/TTY), or send email to disability@illinois.edu.