

BECKWITH *News*

A Newsletter of Beckwith Residential Support Services

Fall 2012

Nugent Hall | University Housing
College of Applied Health Sciences



 ILLINOIS

That was Then...This is Now

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



It seems like just yesterday we were celebrating the Beckwith program's 25th anniversary. That was five years ago, when our program was housed on John Street and the majority of our students didn't transition out to other residential environments (there were few options). We were operating our own residence and separate dining hall, and every year one resident was selected to receive an award at the annual DSO/DRES Awards Program. We were the best kept secret on campus. That was then. . .

. . .This is now. Our program is housed in the newest residence hall on campus, and residents have food options from seven food stations at the IKE. Cooperative programs with Campus Recreation include swimming at CRCE, floor hockey, ice skating and the indoor climbing wall at the ARC. And we supported four interns in the spring (two from i-health and two from community health programs), and six Beckwith-supported residents received awards at the DSO/DRES Awards Program. We continue to take advantage of opportunities to educate others on campus through events like the Disability Awareness Program last October with alumnus Kevin Fritz that drew over 200 participants, and the "Lunch and Learn" Program with Student Services that had 77 students in attendance. Five years since our Silver anniversary and I can gladly say, we are no longer the best kept secret on campus! Summer 2012 was an exciting time for Beckwith staff Katherine Johnson and Paige Lewis, who along with eight current and alumni residents: Kathleen Downes, Erik Jenkins, Kushal Parikh, Jill Von Fumetti, Amber Buckley-Shaklee, KL Cleeton, Ji Hae Lee, and Vicky Raymond represented the University of Illinois at the Smithsonian Folklife Festival on the Mall in Washington, DC. After the festival, millions of people from around the country know about the program, students and alums! We are no longer the best kept secret anywhere.

This fall we will once again look different. The final phase of Nugent Hall is completed which enables Beckwith Residential Support Services (BRSS) to accommodate 26 residents — additionally, we will have a new computer lab, work room, instructional kitchen/meeting rooms and staff offices. Once again, the Beckwith staff and residents are excited about what the future has to offer us. While we can reflect on the past and be excited about the future — here are some highlights from this year:

- Three residents, Ryan Domier, Stephen Welty, and Courtney Griffith, are transitioning from BRSS. Two will be living in other residential environments on campus and the third transferred to Loyola University.
- Corey Hyslop and Michael Roberts graduated spring 2012. Corey has a full-time position with Northrop Grumman, where he completed an internship during the summer of 2011.
- We began an Environmental Control Unit pilot study in four rooms – residents have the ability to control the door, lights, shade, TV, etc. through a web-based application.
- Katherine Johnson, with the assistance of live-in PA Katie Foy, established a partnership with the University of Illinois, College of Nursing with the first community health nursing students beginning a rotation at Beckwith in the fall.
- An online timesheet pilot was established with the intent to have the system fully operational this fall.
- The DRES/Beckwith website has been updated and has a totally new look. Check it out: www.disability.illinois.edu.
- Paige Lewis was awarded the Citizen Commendation Award from the Division of Public Safety for her work making the RAD program accessible to those in power wheelchairs.

As always it is a pleasure to share the stories of excitement, learning and new adventures of Beckwith residents and staff. I hope you enjoy this year's edition. While it is important to focus on the present, as Mark Strand stated, "The future is always beginning now." And so we begin on new opportunities and experiences for the next five years.



Reflections and Projections

By Brad Hedrick, Ph.D., Director of DRES

I hope you enjoy the diverse reflections in this 2012 edition of *Beckwith News*. These personal stories vividly reflect the uniquely beneficial and life changing impact of Beckwith Residential Support Services (BRSS) programs and services upon all who live and work there. We're now looking ahead to the 2012-13 academic year with the final phase of Nugent Hall opening. BRSS increases their capacity to accommodate 26 residents who require personal assistant support services. Additionally, they will gain a new multi-purpose room and a training kitchen, as well as a computer room and a dedicated voice activated computer room. Furthermore, the ability of residents to transition out of BRSS will be made even easier with the opening of four additional transitional rooms, one of which includes the SureHands lift system.

The year ahead will also see a number of exciting applied research projects designed to enhance independence and social integration, ranging from our ongoing evaluation of an environmental control system and a wireless personal elevator control device, to our collaboration with faculty in Speech and Hearing Science and Engineering to develop a multimodal tablet PC whose function blends the strengths of a human translator and of an augmentative and alternative communication system. All the while, BRSS continues to do what it does best, help students with severe physical disabilities pursue their educational and career aspirations. It's remarkable how far the program has advanced since its humble beginnings at Greenbrier and Tanbrier in the late 50's and early 60's.



The Gift

By Kathleen Downes
2012 Matthew A. Odelius Award Recipient

Going to the University of Illinois last fall began as a somewhat crazy idea, when I, a native New Yorker, decided that college should be an adventure. So, here I am, fourteen hours away from home and having the adventure I asked for. This year has been a whirlwind of paper writing, getting lost on campus, and filling one giant white binder.

But fortunately, it hasn't all been school work. I have been blessed with many opportunities around campus, including the chance to work on a leadership certificate. I have participated in Best Buddies and enjoyed the Down Syndrome Walk, as well as the "Spread the Word to End the Word" campaign on campus. I also volunteered at the Annual DSO Holiday Party and served on the Beckwith Residential Support Services Director's Student Advisory Council. In January, I began a weekly shift at the Crisis Nursery with children who brightened up my day every Sunday. In the midst of all this activity, I realized how profoundly grateful I was that this community has been welcoming and provided such great services. I still have to pinch myself when I see the beautiful accessible mass transit system.

It is a true honor to receive this year's Matthew A. Odelius Award which celebrates the accomplishments of a former Beckwith resident, presented annually to a student with a physical disability residing at Beckwith that has demonstrated leadership in student organizations while balancing academics and other commitments. It warms my heart to know that I am seen as a leader. It has been a gift to open my heart to the wonderful people here who never hesitate to open their hearts to me.

2012 Smithsonian Folklife Festival

The impact of public service, teaching, and research at Illinois on accessibility issues, assistive technology development, and public policy and perception in the past, present, and future was highlighted through an exhibit installed on the National Mall in Washington D.C. from June 27 through July 8, 2012. The exhibit, entitled *Empowerment and Access*, included interactive technology stations, video, a series of posters and images, and an empathic modeling area where patrons were able to experience various disabilities, assistive technologies, and learn about wheelchair sports. Students, faculty, staff, and alumni from the Division of Disability Resources and Educational Services interacted with patrons, sharing first-hand the impact of Illinois as a leader in accessibility.

“It was a great experience in a beautiful city! I’m glad we were able to share Beckwith and DRES with so many new people!” — Kathleen Downes



President Easter trying on “the open socket” prosthetic arm.



Alumni and friends enjoying the reception hosted by the UIAA in the U.S. Department of Agriculture, Whitten Building patio.



Festival visitors experiencing wheelchair basketball.



Beckwith alum KL Cleeton highlighting the Beckwith program with visitors.



Jon Gunderson demonstrating IT and web accessibility programs developed at Illinois.



A Sweet Slice in Time

By Katie Foy
Live-In Personal Assistant

During my very first shift as a Personal Assistant (PA), I transferred a student from his bed to his wheelchair. Upon doing so, his head dropped to his shoulder and he began to scream, “Ow, it hurts!” My heart sunk and I lifted his head as quickly as I could, supporting it in my trembling hands. Thoughts began to race through my head... “Is he okay? Am I cut-out to work for students with disabilities? Is he going to fire me?” As I stood pale as a ghost, the student began to chuckle and said, “I love doing that to new PAs.” A wave of relief came over me. After the blood came back to my face, I found the humor in his somewhat cruel joke. I had never had a friend who used a wheelchair, but I wanted him to be my first. That was me three years ago.

As a nursing student, I wanted to learn everything I could about various types of disabilities. And who are better experts than the students at Beckwith? So I applied to be a Live-In PA. I gained a wealth of knowledge about the abilities of each student. However, I gained far more than knowledge...I also gained a family. The people I have met over these past years are some of the most uplifting and inspirational people I may ever meet. There’s always someone there to put a positive spin on life when things just don’t seem to be going your way. Since living here, I complain much less and smile a whole lot more.

My time here has come to an end as I graduated in May. I’m filled with a bitter-sweet feeling. What will I do when I can’t just walk downstairs for a shoulder to cry on, or to share some laughs? I will miss being surrounded by such a compassionate group. Living-in has given me an eye-opening opportunity that most others will never get to experience. I have established friendships that will last forever. These people left an imprint on my life that words cannot describe. I have watched the upperclassmen take the freshmen under their wings. Soon, these students will graduate and begin to make their imprints on the world. Nugent Hall will become the home to a new Beckwith-ian Family who would be lucky to have half the warmth and spirit it does now. Before we embark on the future, let’s cherish the memories from this past year. For one day we will look back in time, and remember now, a sweet slice in time.



Beckwith residents and PAs enjoying a game of Broomball while taking a break from studying for finals. This event was hosted by Camps Recreation.

The Importance of Family: A Mother and Son Share Thoughts on Beckwith

By Erik and Jacqueline Jenkins

Overcoming Obstacles and Climbing Walls

by Erik Jenkins

I've climbed a lot of walls in my life. Most of them were figurative, but as you'll soon find out, some were actual walls. My most recent wall was high school. My high school experience was amazing and I regard those years as the best of my life so far. I was highly regarded by my teachers due to my academic prowess and was recognized for being the Radio Speaking Conference Champion for two years on the Speech Team. However, I knew it would soon be time to move on.

When it came time to think about college, the University of Illinois was my first choice and when I got accepted I couldn't have been happier. Still, the idea of living away from home frightened me because, for all of my academic accomplishments, I didn't have that much life experience. The rest of my senior year went by fast and I arrived at my last week of high school sooner than expected. During that last week, I attended a "Meet the Deans" function at school and it was there that I had my first real taste of life experience. The Army was there with a giant rock wall to climb. Although I was hesitant, I decided to ask the representative if I could try it, thinking he would tell me "no"

because, who in their right mind would let a guy in a walker climb a rock wall? However, all he said was "We're the Army; we don't know 'can't.'" The next thing I knew, I was harnessed up and climbing. After climbing about a quarter of the way up the wall, the craziest thing happened; the whole school gathered around the wall and started chanting for me. Although I didn't make it all the way up the wall that day, I realized at that moment that I could do anything.

I knew then that overcoming the challenges of living at Illinois were going to be just like climbing the rock wall. Scary, but also fun with all the support you could need. The help of my PAs, Pat, Paige and Katherine, and the community at Nugent have been indispensable during my first two semesters here. As I look to my years ahead, I see hard work coupled with great success. I see myself overcoming the metaphorical walls that I will face, as well as the actual rock wall at the ARC. I have certainly had my challenges during my first two semesters of college, but when things get tough, I remember the rock wall and the wise words of Randy Pausch's Last Lecture: "The brick walls aren't there to keep us out; they're there to give us a way to show how much we want it."



Erik eager to talk to visitors at the Smithsonian Folklife Festival.

19 Years for Peace

by Jacqueline Jenkins

I have a confession to make. I didn't cry when I hugged and kissed my son goodbye and left him at college this past August. As he drove his power chair down the ramp to his new life, I looked at his receding figure dry-eyed remembering how we got here. Before judging me you have to understand that this event is something that I worked toward for the last nineteen years. That may sound odd to some parents, but when you have a child with special needs you understand quickly there will be countless decisions that you will make that will affect your child's health, independence, education, confidence and future.

I always kept Erik's future in the back of my mind when deciding which surgeries to have, his educational track, and what activities would challenge him giving him opportunities to succeed and develop skills he could use in the future. This was easy when he was young and I could make those choices for him, but as he got older he became part of the process and was committed to succeed. Erik always knew he would go on to college, but was content with the idea of attending a junior college so he could stay home with all the support he enjoyed and depended on. When I told Erik that I expected him to go away to school and I believed he would be ready when the time came, both he and his father looked at me like I was crazy.

We visited the University of Illinois in the summer before Erik's senior year primarily because of their reputation for excellence in academics. We later discovered they were rated #1 in the country for accessibility. We met with Pat Malik, Director of Beckwith Residential Support Services, and Susann Sears, Disability Specialist, and had a tour of Nugent Hall and the support facilities. We were impressed to hear about the programs and amazing personnel that were in place to assist students in becoming successful regardless of their abilities. When the meeting ended and we were alone, Erik looked me in the eye and said "I will do anything to be accepted here." My dream for him now became his goal and I could feel a shift in our responsibilities.

I know Erik had his own fears and insecurities about going away to college; it was a huge step for him. But I felt nothing but pride and happiness for him, because he would be receiving the best support from DRES, the best education from the University, and the best opportunities for his future.

When he turned the corner that day I was overcome by one emotion, peace. The peace in knowing I made the right decisions that got "us" here. A sense that he belonged here, this is where he should be and anything else would have been very wrong. When I talked to Erik a couple weeks later and asked how he was doing, he said to me "Mom, I am happy here; this is where I belong." That's when the tears came, and they were of pure joy.



Erik and his parents at his high school graduation ceremony.

Kathleen's Big Adventure

By Kathleen Downes



Sometimes it's still hard for me to believe that I'm in college. It doesn't seem that long ago that I took my first bus ride to junior high. But that was then, this is now, and here I am at the University of Illinois. When I was a little girl, my grandmother used to say "We're going on an adventure!" everywhere we went. I think she knew then that I would someday be ready for the big adventure that is living at college. So, I buckled up (literally) and went on my way.

I have learned a lot from being here, both in and out of the classroom. I've gotten lost more times than "Where's Waldo," but I like to think I took the scenic route. I've sharpened my scheduling skills and I can say with pride, "Yes, I know when I'm taking a shower three Tuesdays from now; do you?" So if you ever need your day packed into a spreadsheet, I'm your girl. Not every day has been easy, but I am so lucky to have the Beckwith community here for support.



Kathleen enjoying the creation of a new piece of artwork.

When I sat down to write this piece, I thought a lot about what it really means to be part of a community, and my friends here have illustrated just that with warmth, compassion, and humor. Having a community here in Beckwith means that everything doesn't have to go perfectly, and when it doesn't, someone will be there to listen or simply to share a laugh. Having a community means getting your questions answered, and for those without easy answers, like "What exactly is breakfast pizza?" someone will be there to say, "I don't know, but it's probably good." Sometimes having the support of a community means having someone to tell about your day, or having someone who will still love you even if you accidentally paged about twenty times in the middle of the night. It's having the best cupcakes ever on a Saturday night with a friend who will tell you if you have frosting on your nose. It's having someone to finish your deep dish pizza when you order a few too many pies. It's all the little things that make the day a little brighter, a little easier and a little funnier. Those things are the most important kind, and so far I've found them within my Beckwith and Illinois communities. Ask me to describe this experience in a word, and I'll definitely say "adventure." Ask me what's next on the journey and I'll say "I don't know, but it's probably good."



An Everlasting Impact

by Vytautas Kunickas
i-Health Intern

My involvement with Beckwith stems from being an interdisciplinary health major. A part of the curriculum is for students to complete an internship from a provided list of sites in the Champaign/Urbana area. Prior to interning at Beckwith, I had some general knowledge and exposure in regard to people with disabilities. For example, I completed a couple of courses in disability studies, observed a physical therapist whose specialty was working with patients that had impaired mobility, and also a member of my family has a severe disability. Without hesitation, I decided to intern at Beckwith knowing that it would be a great facility that would fuel my passion for disability studies.

As part of my internship, I worked with Paige on revamping the Transitional Disability Management Program, better known as the DMP. This program encompasses a variety of facets ranging from improving social integration to acquiring knowledge and skills that are necessary for independent personal assistant management. The DMP is intended to help students transition into college, and at the same time assist them in obtaining valuable skills that would facilitate their transition into the real world. As a result of interviewing the students, looking at disability programs at other colleges and working on a survey for incoming students, I have been able to learn firsthand about a variety of topics that I otherwise wouldn't have learned in a classroom setting. I am better aware of the number of programs that Beckwith offers, and at the same time the challenges that residents encounter on a daily basis. Aside from the DMP, I also volunteered with the aquatics therapy program through DRES at the CRCE pool. As an individual who is pursuing physical therapy in the future, I have found the experience of aquatics therapy very relevant and extremely valuable. It has been very hands-on and has taught me many intricacies of working with students that have disabilities, and also resulted in my gaining an extensive amount of new knowledge on exercise programs that I can certainly use in the future.

Even though my time spent at Beckwith was relatively short, it was a great experience. It was a blast working with the supervisors and other interns and mingling with the residents. Looking back, I wish that I would have gotten involved with Beckwith earlier in my college career simply because it has taught me more about learning styles, and the elaborateness of Beckwith/DRES than I ever anticipated on learning. I was sad to end my internship with this program. Nevertheless, I hope that through improving the DMP and making it more individualized, that it will be able to help the current and future residents more and thus leave an everlasting impact of my time and presence spent at Beckwith.



Beckwith residents and PAs enjoying a pool party hosted by Campus Recreation.

An Unbelievable Journey!

By Alicia Santerelli
Disability Advocate



It's easy to pinpoint defining moments over the years. Be it throughout my time as a personal assistant, my time as a disability advocate (DA), or my time as a student at the University of Illinois, there are countless memories that immediately come to mind. The first failed microbiology exam, when my mom had to convince me that one "F" didn't mean I couldn't make it at a big university. The first personal assistant shift, when I knocked on the door of a complete stranger's room, and helped her use the bathroom and get dressed all within the first 15 minutes of meeting her. My first emergency situation as a DA, when I realized I had a huge responsibility to every resident here.

Looking back, those seemingly life changing moments now make me laugh, cry, and cherish the amazing times I've had throughout the years. The transition from where things start to where they end is always filled with surprises, unknowns, and bumps in the road. When I decided to apply for the position as a DA, I never could have predicted the direction it would take my life. It opened doors for me that wouldn't otherwise have been possible. No matter what the period or transition in life, it often takes a good support network, a sense of humor, and a lot of patience to get through it. Defining moments don't always present themselves that way, rather it is through the process of looking back that things become clearer.

The important part for me, as my time as a student at the University of Illinois and a DA at Beckwith is coming to a close, is to focus on what the future holds. I mean this not only for myself, but also for the Beckwith program, and each resident as an individual. We will all have many more "firsts," and without a doubt some will be exciting whereas some will be scary. But if there's one thing I know for sure, it's that the people that live and work at Beckwith have taught me an unbelievable amount over the last three years. Whether it's how to deal with conflict, who the people are that I can go to when I'm upset, or where people will be at midnight when I can't study anymore, I have found it here. When someone builds you up, laughs with you, and relates to you, friendships are formed that will stay with you for life. I am better for having known the Beckwith residents and staff, and wish each of them nothing but the best in the future!



Mark, Alicia, Gina, and Hugo happy with the outcome of the Disability Awareness Program.



Valuable Lessons

by Krystal McSweeney
Disability Advocate

As a new student to the University of Illinois, I was unsure of how well I would deal with this new college community and I was even more concerned about how well I would be able to do the job I had agreed to undertake in the Beckwith program as a DA. However, that was then; this is now. I have learned a lot from the entire Beckwith community. I have developed new skills and I now have a healthy appreciation for the multiple blessings that life has brought me.

In the beginning of my journey at Beckwith, I was tempted to be intimidated by the mere idea that people were dependent on me and that my actions were crucial to their safety. I had not worked directly with students with disabilities and had never been a personal assistant. It seemed impossible to be a truly effective DA since I had not had the opportunity to experience the limitations of this population directly or even as a concerned bystander. I was simply a resident assistant from an inner city, private university seeking to obtain her graduate degree in social work, in a setting where I would get a chance to work with and for students. The Beckwith program addressed my desire to work closely with students and quickly began to shatter my insecurities and inhibitions with regard to what needed to be done and how easily my actions could determine the course of someone's day – and my own. Working with both the residents and administrative staff, I have learned valuable lessons that I will take with me for the rest of my life. Although some of those lessons were hard ones, a positive approach and an attitude that required me to accept failures and to choose to learn from them, has given success a new meaning. I now view success as being nurtured by the failures and challenges life presents and is measured by the degree to which I am able to change and learn from them. This I could never do alone. It has only been possible because of the support and encouragement I have received from the Beckwith community.

When I think of the residents and community the Beckwith Program has built, I feel inspired. Even though they might not know it, each of the residents has encouraged me to be a better person, to not be defeated by my obstacles, and to overcome obstacles by facing them head on and in the most positive manner. This program has truly been a blessing to me and it has provided a very fertile ground in which I could grow and develop as a professional. I have heard it said that “when you know better you do better.” Today, because of the Beckwith program I know better; as a result of the Beckwith program, I do better. And, for those lessons I've learned, I am grateful.

Support from the people in your environment has much to do with your success. The Beckwith Program continues to provide support and encouragement for me and its residents. I am no longer where I was when I first arrived here. I can truly say, “That was then; this is now.” I can also add that THIS is much improved.



Krystal, Mary and Alicia celebrating a great year for our DAs.

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