

# NATIONAL GATEWAY

## TO SELF-DETERMINATION



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Self-Determination

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## The Impact of College on Self-Determination

Meg Grigal, Cate Weir, Debra Hart, & Chris Opsal

To borrow a phrase from the poet Laura Hershey, “you get proud by practicing.” Pride and belief in oneself are cultivated when young people have the opportunity to be in places and with people who support and promote that growth—safe places for them to “practice.” College and university campuses are designed to be

such places. These learning and living environments provide opportunities for growth in self-efficacy and self-determination which, in turn, foster increased confidence in the young people that attend. Ultimately, the personal growth students experience while they are in college can serve as the bedrock for their future life decisions. This growth is possible for all college students, including those with intellectual and developmental disabilities.

Since the passage of the Higher Education Opportunity Act of 2008, there has been considerable increase in opportunities for higher education for students with intellectual disabilities (Grigal, Hart, & Weir, 2012). Currently, over 210 college and universities in the U. S. are serving students with intellectual disabilities and many more are currently being developed throughout the United States. Though varying in focus and structure, one commonality of these higher education options is

that they require students to actively engage in the learning process.

College is a time that is filled with the opportunity to make choices, some good and some not so good, and a time to learn from those choices and their consequences. College is also a time that fosters maturation and acquisition of the desire for lifelong learning and lifelong friendships. Students who have an intellectual disability now have the opportunity to go to college and benefit from these rich experiences and foster some of the same self-determination skills

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Ben on campus.



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*The Impact of College...  
continued from cover*

expected from college students. Practicing self-determination skills in the context of higher education can be challenging, as it requires considerable self- knowledge, self-advocacy, and, in many cases, perseverance to achieve desired goals.

This edition of Research to Practice in Self Determination is a joint product of the Think College Consortium for Postsecondary Education for Individuals with Intellectual and Developmental Disabilities and the National Gateway to Self Determination. The issue explores the interdependency between self-determination and postsecondary education and reflects the many impacts each may have on a students' path in life. In keeping with the series purpose to support and extend the knowledge about and practices that promote self determination for people with developmental disabilities, the articles included here are about, and in many cases written by, college students with who have an intellectual disability. They touch on universal themes of personal growth and illustrate how postsecondary education facilitates and supports self- determination. The professionals who contributed to this edition share how the structures and practices on their college campuses are supporting the development of self- determination skills in the students with whom they work. Additionally, family members, including parents and siblings, speak from their own experiences about the impact college has had on their sons and daughters, brothers and sisters.

The student contributors share their personal journeys to and through college. In reading their perspectives it becomes evident that being in college has impacted their self-concept—how they describe themselves and what they hope for in the future. These college students share with us their hopes and dreams and discuss the classes they have taken to help them achieve both. As you

will see, college has provided these students the chance to learn more than just the content of their classes. These college students are overcoming fear and self-doubt and doing things that they had previously felt were impossible. These college students are learning to see themselves differently, and redefine who they want to be. These college students are becoming proud. By practicing.

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**Changing Expectations. Increasing Opportunities.**

**Think College is a national organization dedicated to developing, expanding, and improving research and practice in inclusive higher education for people with intellectual disability.**

**www.ThinkCollege.net**  
The Think College website is a trusted source for information, training, and resources related to inclusive higher education for students with intellectual disability. The website includes:

- A searchable program directory to learn more about available college options
- A resource library that includes published research as well as field-created tools and resources
- Online learning modules on a variety of topics
- Research to practice briefs, e-newsletters, and journal articles
- Topical information on the critical issues
- A policy and legislation clearinghouse

**College Options for Students with Intellectual Disability**



# Voices of Self-Determined Students with Intellectual and Developmental Disabilities in Postsecondary Settings

Evette A. Simmons-Reed, Jennifer M. Cullen, Kristall J. Day, Margo V. Izzo, Laura B. Colebaugh

Historically, colleges and universities have been places where diversity and inclusion is supported and where youth with and without disabilities learn the skills required for adulthood; however, until recently this was not a reality for youth with intellectual and developmental disabilities (I/DD). In 2008, Congress signed into law the Higher Education Opportunity Act (P.L. 110-315) to amend and extend the Higher Education Act of 1965. HEOA authorized Model Demonstration Grants for the development of Comprehensive Transition and Postsecondary Programs (CTPs) for students with I/DD that include academic experiences, employment, independent living, and social engagement through participation in traditional courses, internships, student organizations, and residential living. The law requires students with I/DD to be socially and academically integrated with non-disabled students to the maximum extent possible. In sum, HEOA (2008) established that youth with disabilities, especially those with significant disabilities, could learn and had a right to pursue advanced learning opportunities at the postsecondary level, thus providing unprecedented opportunities for individuals with disabilities to become valuable, contributing, self-determined members of our society.

Self-determination has been defined as a complex set of skills and organizational practices that provide opportunities for one to become volitional—that is, to exhibit actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life (Morningstar et al., 2010; Shogren et al., 2008). Wehmeyer (2005) described ten skills and characteristics reflective

of self-determination: choice making, decision making, problem solving, goal setting and attainment, self-monitoring, internal locus of control, self-advocacy, perception of self-efficacy and outcome expectancy, self-awareness, and self-knowledge. Over the past two decades, special educators and researchers have empirically validated, operationalized, and developed instructional content and activities aimed at improving the self-determination of youth with disabilities.

Youth with disabilities, especially those with I/DD, often leave high school without the self-determination knowledge and skills needed to access supports at the postsecondary level (Finn et al., 2008; Thoma & Getzel, 2005). Findings from studies conducted with college youth with a variety of disabilities, including I/DD, have identified five component skills of Wehmeyer's self-determination construct associated with improved postsecondary success: self-awareness, goal setting, self-advocacy, internal locus of control, and decision-making (Finn, Getzel, & McManus, 2008; Getzel & Thoma, 2008; Morningstar et al., 2010; Thoma & Getzel, 2005). This article describes how instructors and facilitators supported these five components of self-determination consistently throughout four summer courses to help incoming postsecondary students with I/DD prepare for their transition into college and provides examples based upon these students' experiences.

## Self-Determination in PSE Settings

The authors of this article developed and implemented a four-week residential college immersion program to

improve the self-determination of nine youth with I/DD to prepare for their participation in The Ohio State University postsecondary program. Universal and assistive technology was used to help maximize student independence across the curriculum. Self-determination instruction was integrated into the curriculum and students were given numerous opportunities to practice their developing self-determination skills.

The first week of the program included the use of various transition assessments to provide information to program staff regarding present levels of performance, baseline data for pre/post measures, and additional information about student interests and personalities (a list of the assessments administered is included at the end of this article). The results of these assessments were summarized in a comprehensive assessment report, which was used to guide future programming and instruction.

The summer program consisted of focused learning community workshops and four classes: College Readiness (Academics), Career Awareness (Employment), Gateway to the Future (Technology), and College Life (Independent Living). Students lived in a dorm on campus for the duration of the program, used meal cards to purchase their meals, and accessed various campus facilities including the recreation center. They were encouraged to explore various campus and community opportunities that would help them prepare for their transition to college.

University students were recruited to act as natural supports, facilitate activities, and provide daily support to the students in the form of mentoring. The mentors assisted in navigation to



and from campus using the campus bus service and the community transit system. They also helped students learn to wash their clothes in the dorms, use their meal cards in dining services, and select activities that matched their interests.

Joe, an incoming student to both the summer and postsecondary program, was interested in getting healthy and prepared for the upcoming soccer season, thus he wanted to begin working out. During the summer program, Joe toured the Recreation and Physical Activity Center (RPAC). He continued to talk about improving his exercise and nutrition and so program staff recruited a university student to work out with Joe and act as a mentor. Initially, Joe's mentor had to provide a lot of direction on healthy eating habits, how to use the equipment at the RPAC, and setting fitness goals. As a result of his experiences with his mentor, Joe began showing other students in the program how to use the equipment at the recreation center during his free time. He continues to work out and says it's his favorite part of the day. He checks in with his mentor via text once or twice a week to ask if a certain food or drink is a healthy choice. He even independently found an app to track his caloric intake using his new iPhone. Natural supports allowed Joe to set goals and establish an exercise routine and better eating habits.

## Setting the Stage for Self-Determination

College courses are not only ideal, natural settings to facilitate the development of self-determination for youth with I/DD, they provide youth with multiple opportunities to practice setting goals to complete assignments; make decisions about what, when, and how to study based on their learning styles; and advocate for and negotiate with faculty for needed supports. For example, the College Readiness course focused on helping students become aware of their needs in a postsecondary setting. Students were asked to assess their learning styles and interests. This resulted in students identifying

strategies that could be used to acquire or communicate information based on their individual needs and preferences.

One student, Jane, identified that her primary mode of learning was through a visual modality, according to her VARK results. With the support of her mentor, Jane identified several visual strategies for studying for college classes and used them throughout the program. For example, she created diagrams and pictorial representations to learn and memorize course content.

Students created long-term and short-term educational goals to help them plan their program of study. For example,

Larry is interested in working with exotic animals and his long-term goal is to work in a zoo. His short-term goal was to identify courses and internships that would help him learn more about exotic animals. As a result, he met with an academic advisor from animal sciences to develop a four-year program of study that would contain core courses in animal sciences and practical experiences that would help him prepare for his chosen career. Larry is also learning how to seek out experiences independently to enhance his academic program. It had been a lifelong dream of his to meet Jack Hanna. Through an Internet search of campus events, he found an event featuring Jack Hanna at the Ohio Union and made plans to attend the event with his mentor.



Larry working at the Columbus zoo.

We found that technology was critical in helping students with I/DD prepare to be self-determined in college. In the technology course, students learned how to use technology to maximize their independence in all outcome areas. Students created digital stories to identify: a) their interest, b) people important to their support network, and c) goals for the future. They included content created in other classes in their digital stories, using music, images, and text to describe their lifelong journey and self-determination plan. These digital stories provided a multi-modal illustration of their future academic, employment, and independent living goals.

When Michael first came to campus, he did not like talking about or hearing about disabilities, especially when they were similar to his disability. His mom indicated that he refused to use any words related to disability or say he had any type of disability. When Michael created his digital story at the end of the summer program, he discussed how he was learning to accept his disability and that he needed to advocate for himself by telling people his needs. Michael said in class this summer, "We are learning more about ourselves and its okay to say we need help and why." Michael has continued to show that he is using these skills since coming to the postsecondary program by asking for access to additional resources and supports like guided notes, to have classes later in the morning so he has time to take the bus to campus, and to have time between meetings so that he does not get overwhelmed.

College settings provide natural opportunities for youth with I/DD to learn the self-determination skills needed to become active contributing members of society. Just as youth without disabilities use the college environment to develop, practice, and refine a multitude of skills associated with self-determination, so do youth with I/DD. This four-week college prep program fostered the development of strong relationships among facilitators, staff, and students. These relationships also provided emotional support many of the incoming students needed to get through the days and weeks of the program.



Larry meets “Jungle Jack” Hanna.

Cameron, an out-of-state student, indicated at the beginning of the summer program that he had some fears about coming to OSU and living independently. He was concerned because the college was far from his home, and he would have to manage his own money and food. Cameron thought the inclusive nature of the program at OSU was much better than other more segregated programs he had visited and decided that tackling his fears of living independently was necessary to accomplishing his long-term goals. However, he did not have family in the area or know anyone in the area that he could live with, so he and three other students decided to share an apartment. These friends from the summer program began to look at apartments in Columbus. Cameron looked up the safety statistics of the apartment buildings they were considering. He also established the need for a “roommate agreement.” Cameron is still apprehensive about living independently, but he knows this is the best decision he could make. He is determined to achieve his goals and continues to express self-determination by advocating for his needs.

## List of Assessments

- AIR Self-Determination Scale, student version and parent version
- Bristol Activities of Daily Living Scale (BADLS)
- Life Skills Inventory: Independent Living Skills Assessment Tool (Washington State Department of Social and Health Services)

[http://www.dshs.wa.gov/pdf/ms/forms/10\\_267.pdf](http://www.dshs.wa.gov/pdf/ms/forms/10_267.pdf)

- Myers Briggs Type Indicator
- Nowicki-Strickland Locus of Control Scale
- Pre-Assessment Profile, University of Kentucky Assistive Technology Project  
[http://edsrc.uky.edu/www/ukatij/toolkit/PreAssess\\_Profile.pdf](http://edsrc.uky.edu/www/ukatij/toolkit/PreAssess_Profile.pdf)
- VARK Questionnaire
- <http://www.vark-learn.com/english/page.asp?p=questionnaire>
- Occupational Therapy Assessment created by OSU OT Faculty
- Transition Planning Interview created by OSU program staff

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# Self-Determination Stories from IUPUI SITE in Indianapolis

## Gwen Chesterfield, Steve Savage, Apple Quick



Keeping a clear schedule can help a college student stay organized.

### Brent

Brent was a student with an intellectual disability in a self-contained special education class in a downtown Indianapolis high school. As he approached his 18th birthday, his routine consisted of coming to school, eating school breakfast and lunch, and wandering around the school campus the rest of the day. He was hard to track down outside of school, staying at either his mom's house or his dad's house, and neither parent was responsive to the school's efforts to communicate. Brent's teachers described him as unmotivated, often

truant, disruptive in class, and possibly depressed. Comments made at the time included:

- "Needs emotional support; will follow directions if prompted to do so, but mostly wants to do his own thing. Assigned a work training site at (a local grocery store) and has only been there one day because of behavior."
- "Brent has had assigned work experience sites but due to refusals, attendance, and numerous suspensions, job sites have not been successful. Brent has been referred to a community mental health center for an evaluation."


A high school job coach brought Brent to the attention of a program at Indiana University – Purdue University Indianapolis (IUPUI) called SITE (Skills for Independence, Transition, and Employment), a 2-year college campus and community-based transition program for students

with intellectual disabilities ages 18-21 following their high school education. When SITE staff first met Brent, he was shut down, non-communicative, and in the process of being expelled from high school due to non-compliance and truancy. He could not or did not articulate much of anything, including his frustrations and concerns. Vocational Rehabilitation (VR) required mental health treatment as a prerequisite for serving him. Program staff found him at his dad's house and met with him to offer him the opportunity to participate in SITE, encouraging him to join up before he got expelled from school. He agreed. He was told that he could only miss 2 days of school at IUPUI—he turned the tide and never missed a day.

"Oh, I don't know about that," was a pretty common remark Brent made in the beginning of his SITE experience. He expressed a lack of confidence, insecurities, and doubts and was seriously averse to anything involving literacy. At IUPUI he experienced a totally different type of relationship with SITE staff and other students—more listening and asking than telling him what to do. The people at SITE acted on what they learned about Brent, and as a result, he began talking more openly. During the initial home visit and Person-Centered Planning process, his strong interest in tools and mechanical aptitude was discovered. He shared that he operated two small businesses, mowing grass and fixing up and selling bicycles. Building on his strengths, Brent got a one-month time job trial at a lawnmower shop. Despite the owner initially saying he would not be able to offer a paid position, Brent was hired part-time as a result of his performance. During his tenure at IUPUI, Brent completed several work experiences consistent



Brent relaxes with friends.



with his interests and talents, and he blossomed. As a result of his successes and hard work in these jobs, VR dropped their requirement for Brent to receive mental health services for depression in order to be eligible for VR support.

Brent responded very positively to the adult atmosphere of the college campus at IUPUI. He realized that people were there because they want to be, moving about to meet their own individual schedules of classes, campus activities, and social life—basically, running their own lives. He experienced people conducting themselves responsibly and being friendly and helpful to one another. Brent was supported by mentors his own age with meaningful opportunities to interact with others and pursue shared interests. He, in turn, assumed a leadership role with the other students. For example, as Brent caught on to successfully budgeting his weekly allotment for lunch, he recognized restaurant logos on coupons in the newspaper and began cutting them out and bringing them in to share with his friends. Though unable to read the coupons, he masterminded pooling their money together, using a coupon, and getting a much better lunch within all their budgets. Brent also became the “go to” person for his friends as they were making plans for social activities off-campus when locations were challenging due to city bus routes. He was respected as a great idea person, someone good at figuring out details and problem-solving unforeseen glitches—he would just tell them not worry, they would figure it out. And with his help, they did. The formerly non-communicative, turned-off young man turned into a friendly, interactive, articulate, self-assured, charming young man.

Brent learned to navigate the urban campus and the city and expanded his knowledge of the city bus system. He took the city bus or rode his bicycle to campus every day. Despite his challenges with literacy, he was provided with instruction and practice using a cell phone and the computer. He learned to text message, email, search the internet effectively, and use Facebook to stay connected with the people important to him. He learned how to budget money effectively. He made some very good friends and developed a strong sense of

self-confidence and a willingness to tackle new experiences. He was given daily practice and support to make decisions, solve problems, work through challenges, and set his own goals and action plans. While on campus, he expressed an interest in seeing a dentist to treat his major dental issues. During his time on campus, Brent independently followed through on more than a dozen major dental procedures at the Indiana University Dental School Clinic, sometimes twice a week, with outstanding results—a winning smile. This contributed greatly to Brent’s increased self-confidence.

Now 21, Brent has moved out of his parents’ homes, lives in his own apartment, and is employed full-time at a local manufacturing plant. He keeps in touch with his many friends via visits, phone calls, texts, and Facebook messages. We often see Brent downtown and he stops by campus twice a year to visit.

## Tyrone

Tyrone received his secondary education in a self-contained special education classroom at an Indianapolis high school. Throughout his high school career, he had a 1:1 classroom assistant who accompanied him everywhere he went in the school and community, including to the school restroom. As part of his high school program, he received instruction in community settings and had unpaid community work experiences to prepare him for employment, all with his classroom assistant. He lacked initiative but was a very good follower. He never took the city bus alone, had very poor pedestrian skills, did not cross streets on his own, did not have or use a cell phone, and did not manage time and schedules without total assistance.

When Tyrone was 19, his parents got serious about looking ahead to what would happen to him when he completed his secondary education at age 22. With the support of the high school transition coordinator, his mother checked out local adult programs and services as a potential fit for Tyrone. Disappointed at what she saw, she inquired about the Indiana University – Purdue University



Tyrone on his way through campus.

Indianapolis (IUPUI) program called SITE, which provides supports for students with intellectual disabilities to attend college. She and Tyrone visited the campus. Both were interested and intrigued by what they saw, but his parents had strong concerns about whether the campus program was a viable option for Tyrone. All SITE students are taught to the ride city bus to the campus and navigate their way around campus and the city. No more yellow school buses or curb pick-up! Discussions took place in team meetings and case conferences to decide whether IUPUI was a fit for Tyrone. His parents were informed that Tyrone could not have a 1:1 classroom assistant at IUPUI, and that if they wanted to apply for the program, the 1:1 assistant would have to be phased out over the next school year. They agreed and Tyrone began to prepare for a transition to college that would not include a 1:1 aide. Over time, his role changed from following his classroom assistant everywhere to directing his own actions and movement, taking the lead in school and in the community.

After Tyrone was accepted to SITE, a dramatic transformation began. It started with instruction on how to ride the city bus to and from campus and walk safely around the campus. Tyrone did not know



how to cross busy streets safely—he spaced out and was inclined to walk in front of traffic. He did not know what to look for when crossing the street, since he was used to following someone else across the street. Staff partnered with his mother to teach him bus and pedestrian skills. Support was faded gradually and soon he rode the bus alone to and from campus, safely crossing the busy campus and city streets.

Tyrone also learned where other bus routes could take him and soon he developed and expressed preferences for certain bus routes. For two of his routine activities, working out at a local recreation facility and taking piano lessons, he learned the bus routes and schedule and began to travel to them on his own. Through daily instruction, practice, and support, Tyrone learned many different city bus routes and planned and navigated successfully to and from destinations all around the city on his own. Now, we frequently see him around the city in various locations at all times of day.

When Tyrone got a cell phone and began to learn how to use it, he would call his instructor, who would ask, “Where are you?” Tyrone would answer, “I’m right here talking to you on the phone.” Instructor: “What do you see?” Tyrone: “Buildings.” Instructor: “Which buildings?” Tyrone: “Big ones.” By the end of the year, Tyrone’s answer was specific and correct. Instructor: “Where are you?”

Tyrone: “I’m at the City Market.” He learned to use his cell phone to schedule lunch dates with friends and to follow through with those plans. By the end of his time at IUPUI, Tyrone was assuming responsibility for scheduling his time, choosing what activities he was going to do, and with some assistance working them around his job schedule to create an interesting daily schedule for himself.

Today at 23, Tyrone is setting the world on fire. He is confident, self-assured, at peace with the world, and very happy with himself. Working two part-time jobs downtown, Tyrone manages his daily schedule very effectively to include maintaining an exercise regimen, tutoring sessions, lunch and dinner dates, and other activities of interest to him, sometimes utilizing support from waiver services. Though he continues to live with his parents, he is rarely at home. He uses his cell phone to call friends and family, communicate concerns or needs, and sometimes takes the initiative to make plans with others. Tyrone likes to plan ahead so that he is always ready for work and he makes sure his weekly calendar includes his favorite activities.

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*practice consultant, Gwen’s focus has been person-centered practices and service and program development consistent with best practice. Gwen was on the team that created the IUPUI SITE Program.*

*Steve Savage, MS, is an IUPUI SITE Program Coordinator. As a teacher, trainer, and consultant, Steve has worked with people with disabilities, their families, schools, businesses and agencies for more than 30 years. His areas of interest are employment, self-employment, person centered planning, school to work transition, community inclusion, organizational development and systems change.*

*Apple Quick is an IUPUI SITE Teacher. Apple is the first and only IUPUI SITE teacher, working for Indianapolis Public Schools in that role for the past 7 years. Prior to that, he taught at Bloomington North High School in Bloomington, Indiana.*



Tyrone takes the campus bus to and from class.

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# A Journey in Learning

## Nicole Villemaire with Kiersten Hallquist

*This story started in my English 001, or Written Expression class, an English class at University of Vermont. The paper was originally called “Project 5,” one of twelve long papers I submitted during the Spring 2012 semester; I also wrote many prompts, and read a book with different stories. This might appear normal for a college student to take this class and do this work, but I took this class having learning challenges. It was my first “real college class,” and I was returning from a tough past and recovery. I had to work extra hard to get the papers completed.*

Many students apply and get accepted to colleges all across the country. Students with intellectual disabilities want the same opportunities; right now, they just have to go about getting a college education in different ways. I am attending the University of Vermont with supports from Think College Vermont (TCVT). TCVT helps students work on social skills, iPad and technology skills, academic skills, and allows them to spend time in the college community. Mentors spend time with the students on campus and support students in the classroom.

### Lesson 1: Postsecondary Education is Possible

Throughout my life, school has been difficult for me. I went away to Riverview<sup>1</sup> in Cape Cod in 2006 for my last year of high school. At Riverview I learned social, independent-living, and academic skills. After graduating from Riverview’s high school program, I then went on to attend Riverview’s postsecondary school program, called Grow. While at Grow, I took a child-care class at the Community College but I only took the class with other individuals with disabilities, and the classes were not taught by college professors.

<sup>1</sup> Riverview School is a private co-ed boarding school that serves students ages 11-22 with learning disabilities, complex language, and learning and cognitive disabilities.

Living away from home, I learned how much my mom was connected to my life, and I discovered how much I could grow when I had distance from my mom. I participated in so many activities and I grew a lot more in postsecondary education than I did back at my old public high school. In high school, I would stay home with my mom when I wasn’t in school, but at Riverview I was able to do activities with others. Also, in high school, they put everyone with special needs and learning difficulties together, and I was not pushed to succeed or do better.

During these early college experiences, I was with people from different states and around the world; I was part of a new community and I could learn from different people with disabilities. I really began to discover who I was as a person, and what I was capable of. I liked living with people with disabilities because they were like me, and could understand me, but I also saw some people take “regular college classes” with students without disabilities, and I wanted that. I wanted it because my class that had only students with disabilities was paced differently; the class was slowed down to where the teacher thought we needed to be. I knew that a college class would set a different pace, and I would have to grow to meet it, and I wanted that; however, the staff kept telling me I wasn’t ready or able to take a “regular college class.” I wanted to meet people without disabilities because I knew I could learn from them; I believed I would be expected to do more, and I could grow more if I was among others without disabilities.

### Lesson 2: The Disappointment of Failure

I was supposed to have completed Riverview’s postsecondary program in 2009 and graduate, but I wasn’t able to do that. I had to leave the program in my third and last year because of my behavior. My life became very complicated. I had moved a few times

and my boyfriend moved away. I felt like my brain was crashing—I was overstimulated and confused—and I had trouble dealing with these emotions. I had trouble communicating with people and building friendships; I didn’t know how to talk to people when I felt they were leaving me out or being mean to me. I did not have the tools I needed to deal with my problems in an effective way and so I began to take a lot of my problems out on my mom. Things fell apart both at school and at home.

I felt like a failure because I let my mom down and I didn’t graduate. I wanted to go back to school to prove to myself that I could handle the work. I knew that a college education would allow me to get the career I wanted in the future and help me build real friendships. But I knew I had to spend some time on myself before I could go back and try again.

### Lesson 3: Recovery is Possible with the Right Supports

It took three years before I was ready to try again. In those three years, I did a lot of talking and communicating with people, and I worked on myself to get better. I had to believe in myself again, and have faith in myself.

I moved into a shared living place with some other people with disabilities and a person who helped us with our life skills and living needs. This person who supported the household really helped me get better. She helped me get off of a lot of the medications the hospital was giving me; she listened and helped me process my emotions; and she gave me the space I needed to grow and learn again. Most importantly, she and my mom helped connect me with a wonderful service coordinator, Starr (pseudonym), who really helped me grow. Starr never told me what to do, but instead she helped me make responsible choices. She helped me connect with an Autism support group, and let me make choices about the services I wanted to use. In the



Nicole (left, in purple) enjoys lunch with friends on campus at the University of Vermont.

past, I had been forced to take a skills class to help me manage my behavior in an effective way and I resented being told to take it. Starr gave me the choice of whether or not I wanted to take the class; when I was given the choice, I decided that the class was helpful to me. I was able to get more out of it because I decided when I was ready to take it—not someone else telling me that I had to.

After three years of working on myself, I applied to and was accepted into TWO programs that offered support to attend classes at the University of Vermont (UVM)! I wasn't told which program to attend; I was able to consider both, and I was able to really think about what I wanted.


#### Lesson 4: How to Get Back on My Feet

I knew I wanted a support program where I could continue to work with Starr and where I could interact with people who did not have disabilities, so I could learn to interact with all types of people and continue to grow. I wanted to take “real college classes”—classes that are not just for people with disabilities. I wanted mentors my age, instead of just program staff. I also wanted a support program that had a flexible schedule, so that I could continue to go to work and participate in my other activities.

I chose to attend Think College VT, a UVM-based postsecondary education program because it provided the kind of support and schedule structure I wanted. I was especially interested in receiving

support from peers who were students without disabilities and not agency staff; TCVT had college mentors who were full-time UVM students. In this program I was able to attend classes at UVM and receive support from my college peers.

One of my reasons for continuing my learning was I would like to be a professional self-advocate one day. When I started at UVM, I chose to take ENGS 001: Written Expression during my first semester to make my writing better, and I am now taking CALS 001: Foundations in Communication to improve my public speaking skills. The professors in these classes gave me a lot of homework, due dates, and meetings to attend, and I was expected to be able to listen and comprehend the information the professor gave out; these are all



important skills for any well-paying job in my future. I also watched my fellow students without disabilities keep up with the course and was motivated to move at a faster pace. I've learned a lot over the first three months of attending these classes and being on campus.

Going to school for the first time after three years was very intimidating, but I was very excited at the same time to start a new stage in my life. At the beginning of my first semester at UVM my brain was overloaded and stressed. I was apprehensive about what college life would be like at UVM. I didn't know what to expect, and wanted to know how the program worked. In my mind I thought, "What am I getting myself into?" I began to think, "This is going to be too hard; I should just give up." I felt like I was drowning in fear and anxiety. What if I didn't succeed? I didn't know how my classes were going to be or what they would entail. Learning my way around campus was nerve-wracking.

Having to develop a consistent homework schedule and doing the work on my own was difficult at times. The reading and paper assignments were piling up like a stack of dominoes and I was afraid everything would collapse around me. All of these were challenging to handle at first, but as I eased into the work, I felt more comfortable each day and felt less insecure and less anxious.

## Lesson 5: How to Be Successful in College

One of the things that I had to learn how to do was communicate with my professor when I needed more time on a project or reading assignment. When I needed help in these areas, I learned how to communicate with my program manager, mentors, and academic advisor as well. I began to understand how to develop a course of study at UVM that best suited my particular needs and goals for the future. I realized that if I wanted to "make the grade," I had to put in the time and work hard. Throughout this semester, I have learned how to be a better self-advocate and ask for accommodations when I need them. This was an important aspect of me becoming an independent college student.

At UVM, I interacted with my mentors on a daily basis. They helped me with my homework and help me to improve my time management skills. They taught me how to use the public transportation system to get home and around campus. At first, I was nervous because I didn't know the mentors and I didn't know how well we would get along or how they would perceive me. However, as time went on I learned to treat them like peers and I felt they did the same with me. When I started trusting them, I began to learn as well as grow from them. We have learned from each other. I now look up to my mentors; I know they give me guidance and support.

My classmates are also kind and respectful. They helped me learn and grow despite my learning challenges. I have learned how to communicate better with my classmates and my professors. I have also learned how to improve my interactions with people without disabilities. I invited one classmate to lunch, and we ate together and have since become friends. I have gotten the courage to build relationships with other students who are different from me.

Because of the help I received from my mentors and my own hard work, I have become a better self-advocate. I took a course through Green Mountain Self-Advocates, "GMSA's 7 Habits of Highly Effective People." It was helpful because it was group activities where we learned teamwork skills, building confidence, communicating with each other, and how to participate together as a group. This course helped me learn to cooperate within a group, and how to interact with my fellow students.

## Conclusion

I've been in college for three months and I have learned to not let the past define who I can be in the future. I want to take what I have learned and continue to grow to be a better student and a better person. Someday, I hope to become a professional self-advocate; I know that the skills that I have learned and will learn at UVM will help me to reach this goal.

## Acknowledgements

The author would like to thank the Think College Vermont Program Manager, Kiersten Hallquist, for transcribing and

editing her story. She would also like to thank one of her many mentors, Devon Miles, who also helped edit her story. She would especially like to thank National Gateway to Self-Determination for helping her tell her story to the world.

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*Nicole Villemare is a continuing education student at The University of Vermont, and is studying to be a professional self-advocate. Nicole is part of her local advocacy leadership team, serves on the Jean S. Garvin Research Fellowship Committee, and she is a member of the Vermont Autism Task Force.*

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*Kiersten Hallquist is the Think College Vermont @UVM/CDCI Program Manager and serves as the full-time primary contact for the program. She also supervises the program's peer mentors, supports the students day-to-day, and facilitates the iPad Assistive Technology aspect of TCVT. She has truly enjoyed working with Nicole this past year.*

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# “So Maybe We’re Just Like Everyone Else?” Students with Intellectual Disabilities Use Participatory Action Research to Discuss their Concurrent Enrollment Experiences

Maria Paiewonsky

In Massachusetts, students with intellectual disabilities (ID) have been using participatory action research (PAR) methods to document their college experiences. Unlike other research methods, PAR is an inclusive research model that allows participant researchers to co-direct research and share the stories that they want to tell. The PAR results indicate that these students with ID are demonstrating self-determined behaviors at college and persevering in pursuit of their postsecondary goals.

## Background

Massachusetts Inclusive Concurrent Enrollment (ICE) is a statewide initiative that provides transition-age students with ID, ages 18-22, the opportunity to participate in college as part of their transition education. This participation involves learning, socializing, and engaging in college life with typical students, and supports the development of self-determination and self-advocacy skills.

ICE started in 2001 as a small pilot project between one high school and one community college, supporting just three students to include postsecondary education in their transition plans. Over the past 11 years, it has grown to include seven 2- and 4- year state colleges and 100 school districts supporting up to 80 students every year. Students supported by ICE have taken a wide range of college classes, participated in campus activities, and learned to use public transportation and college shuttles to travel between the campus and jobs or home. Evaluating the impact of this initiative has been an integral part of ICE.

## Selecting PAR for Evaluation

To evaluate the impact that college participation has on these Massachusetts students with ID, researchers from Think College and the Consortium for Postsecondary Education for Individuals with Developmental Disabilities sought a research method that would involve students’ active participation. Participatory action research (PAR) was selected due to its flexible format and because it seeks individuals’ stories about their lives.

PAR is designed to be an inclusive form of research that presumes researchers and participants work together to explore an issue or experience. With this model of collaboration, it is also possible to decide on meaningful research strategies. One research strategy that has interested PAR collaborators is storytelling, because it encourages people to share stories that help them make sense of their experiences. Rather than assume researchers will determine survey or focus group questions, co-researchers encourage personal stories because they value what individuals want to share about their lives and, more importantly, appreciate the time someone takes to tell their story (Ferguson, Ferguson, & Taylor, 1992). It is through these stories that presumptions can be challenged. Instead, the storytellers shed light on their actual experiences (Taylor, Bogdan, & Lutfiyya, 1995).

## PAR Tools and Strategies

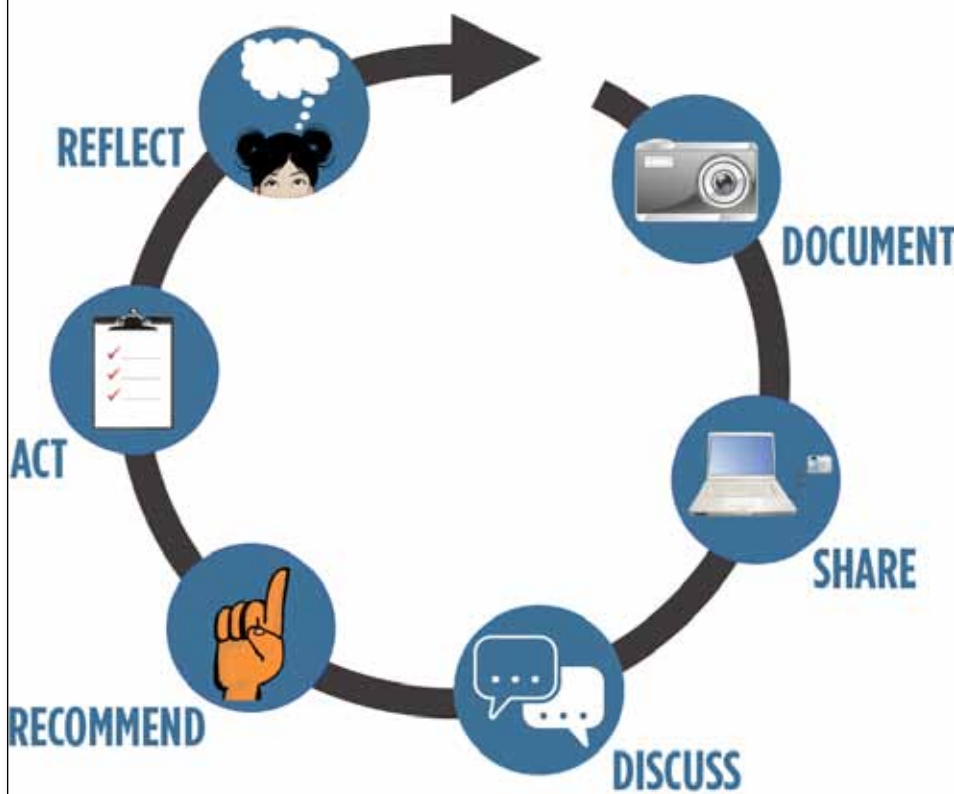
The ICE PAR coordinator suggested two strategies that she hoped would provide students with an easy way to collect and share data about their inclusive college experiences. First, she suggested

digital cameras and pocket video cameras to them to collect data. By using these media tools, the students could develop and share meaningful data (Tarleton, 2005; Tierney, Curtis & O’Brien, 2009; Ward & Townsley, 2005). The ICE PAR coordinator also suggested VoiceThread (2007), a digital storytelling website that where students could share, discuss, and analyze their data. All of the instructions and materials were designed with plain language and other principles of universal design to be sure the research process was clear (PLAIN, 2005; Tarleton, 2005; Tierney, Curtis, & O’Brien, 2009; Ward & Townsley, 2005; Zambo, 2009).

## Student Researchers

Since 2009, 25 students supported by ICE have participated in PAR to document their college experience. To participate in PAR, students must have completed at least one full semester of college so they could comment on the whole experience. Using a typical PAR research cycle, the student researchers were asked to participate in 6 phases of research: 1) documenting their college experience with cameras or flip video cameras, 2) sharing their work on a private VoiceThread digital storytelling site, 3) discussing their data with their co-researchers, 4) recommending actions, based on their findings, 5) acting on their recommendations, and 6) reflecting on their work. The students typically met with the research facilitator to review their research activities in the libraries or study centers at their colleges when they had free time in their schedules. All the student researchers completed the PAR cycle over the course of two semesters. This article addresses findings

# PARTICIPATORY ACTION RESEARCH



from the first three ICE PAR phases – documenting, sharing and discussing.

## Findings

The students' data, including photos, video clips, captions, transcribed notes from VoiceThread, and meeting notes, revealed their **self-determination** and perseverance in ways that traditional research methods may have missed. Evidence of this was discovered in three places:

1. The ways in which students planned and implemented their own research;
2. The ways in which students used self-determined behaviors in everyday college activities; and
3. The ways in which students persevered when underestimated by others.

## Students Planned and Implemented their own Research Methods

In planning meetings, the research facilitator offered students some guidance for conducting research, including

information on the purpose of doing research and how to conduct research responsibly, and provided examples of research that included photographs and video clips. Students had opportunities to practice using consent forms. They also read through prompts that were meant to help them consider what pictures they wanted to take for their 'document' phase. These prompts included questions such as, "What do you do at college?" and, "What's going well at college and what's difficult?" Having two to four weeks to collect their data, the research facilitator expected that, based on the examples she showed them, the students would document a day's activities at college or take pictures that would depict their best or worst day on campus. In fact, several students carried out their research exactly that way, but others took a different path. They developed their own research questions and set out to film interviews with peers about their perceptions of college and, in one case, to learn how classmates and faculty perceived students supported by ICE in college classes.

Crystal, one of the student-researchers, independently wrote four questions that she used for her research, including two for classmates without disabilities:

1. What's it like to have a student from the ICE program in this class?
2. Do you think it would be okay for more students with disabilities to come to college?

and two questions for faculty:

1. What do you think about having a student from the ICE program in your class?
2. Do you find it difficult to teach students with disabilities?

Armed with a pocket video camera, Crystal collected consent forms from four classmates and two faculty members and recorded her interviews with them. A transcript from an interview with a classmate reveals Crystal's ability to probe further to get the answers she was looking for:

*Crystal: What's it like interacting with a student from the ICE program?*

*Classmate: I didn't know. You seem like just another college student.*

*Crystal: So, you wouldn't know that I have a disability?*

*Classmate: Um, no.*

*Crystal: So, maybe we're just like everyone else?*

*Classmate: Yeah. At a community college everyone is just everyone.*

*Crystal: Thanks.*

Unlike traditional research methods, in which researchers must typically follow strict protocols which are created ahead of time, doing PAR with digital tools not only permitted Crystal and her co-researchers to more actively engage in research, but also allowed them to refine the research in ways more meaningful to them. Implementing PAR in this manner allowed the students to act as the "primary causal agents" in research, "free from undue external influence or interference" (Wehmeyer, et al., 2000). With this autonomy, the students had the freedom to turn the research outward as described above or inward, by turning the cameras on themselves and using the opportunity to reflect on how their college experiences were impacting them personally.



## Students Used Self-determined Behaviors in Everyday College Activities

As students moved from the ‘Document’ phase of their research to the ‘Share’ and ‘Discuss’ phases, their images and follow-up discussions with each other on the PAR VoiceThread revealed self-determined behaviors in a variety of everyday college activities. In fact, over 50% of the photos and video clips feature the students themselves on campus, revealing their emerging independence through activities such as walking to class, eating lunch at the student center, working out in the fitness center, studying at the library, and using public transportation. Students used these photos to explain to their fellow PAR participants and the research facilitator how they were looking like, sounding like, and acting like college students. In a specific example, Ariel, a second-year student with ID and vision impairments, arranged to have video taken of her performing with the college’s choral group at a college concert. She explained that taking voice and a piano class helped her to find her voice and believes that voice has helped her in many situations in college, including advocating for the music classes she wanted to take, joining the college choral group, and requesting additional accommodations.

*Ariel: See, these voice classes? Now I’m speaking up for myself and advocating for myself.*

*Research facilitator: Oh, I see. Are you saying that the choral class helped you to find your voice?*

*Ariel: Yes, and for many different situations. See, here I am talking about college. It’s like, Bam! I’ve got everything under control.*

In another example, Tim, a second-semester student with Down syndrome, reflected on his decreasing reliance on an educational coach at college. With support, Tim learned to be more independent on campus, including managing his own college schedule, communicating with his instructor and tutor, and traveling to and from the campus using public transportation (Paiewonsky et al., 2010). As an example of Tim’s emerging independence from

his coach, Tim described what it meant to him to complete a college assignment for the Oral Communications course without help from his educational coach:

*She said she was a tutor for anyone in the class who needed help. At first I didn’t want to go. My coach told me she could help. So I went. She gave me a good tip. Use note cards to practice your speech. I’m glad I went. I got an ‘A’ on my first class speech: “How to make a blueberry smoothie.”*

In many ways, students demonstrated that they were taking pride in every opportunity to advocate for themselves, adjust to college expectations, make decisions, and set goals that would maintain or improve the quality of their college experience.

## Students Persevered When Underestimated by Others

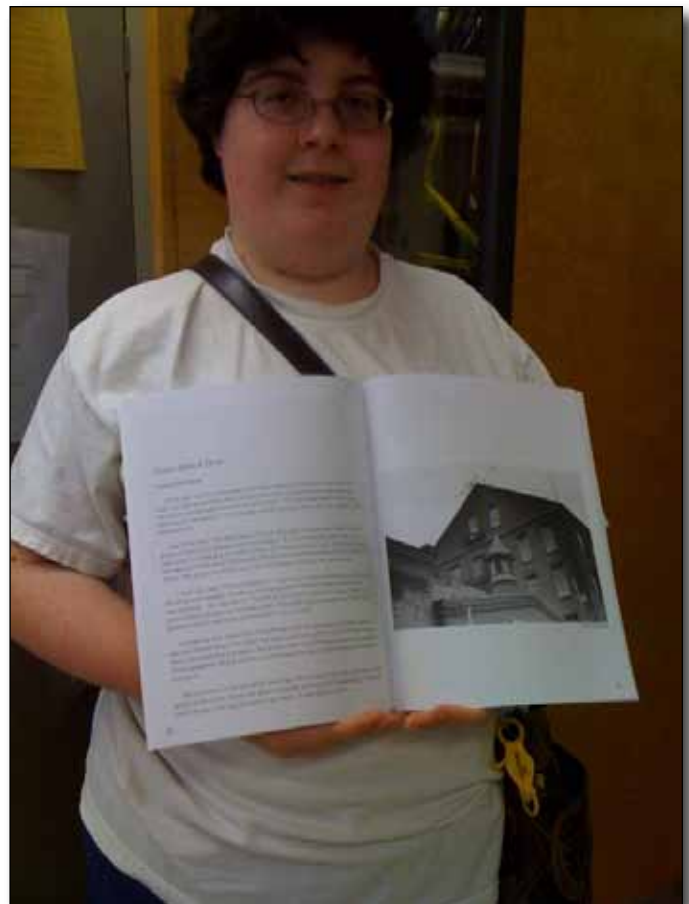
Students involved in the ICE PAR sometimes brought up issues that revealed the perseverance and self-advocacy they drew on when they perceived that others were underestimating them. Rather than ignore or withdraw from the situation, they discussed with each other on the PAR VoiceThread how they addressed these situations. Joe, a second-semester student with ID, arranged to have a photo taken of himself holding a first aid book. His caption read, “My whole family are EMTs. Someday I will become an EMT. I took this First Aid and EMT class at QCC. The reading and tests are hard. I will never ever give up.” Joe explained that his educational coach thought that failing the class quizzes had convinced him not to repeat the class.

Crystal also related a story about a professor she believed

doubted her ability to understand his class. On a VoiceThread discussion she wrote:

*I took a reading class, a writing class, and a mythology class. The mythology class was very interesting plus I knew some information already. The professor who taught my mythology class was skeptical about taking a student in special ed. But when I started spouting off info on the myths, he changed his mind. The reason the professor changed his mind is I did a lot of reading and I sort of have an older version of the textbook at home. So, I had already read it. If you have a professor who is skeptical about having you in their class, give them an example of your work. Show them your skills.*

Students in these PAR activities demonstrated that could draw on their own knowledge of themselves and their self-awareness when others did not believe in them, and persevere when given the opportunity to speak up for themselves. In a college climate that requires students to speak to faculty and staff directly,



Crystal proudly displays her published story.

these students demonstrated that they could live up to those expectations.

## Recommendations for Research Facilitators

For individuals interested in facilitating PAR with college students with ID, here are some considerations:

- PAR isn't easy. It takes lots of time on the part of both the research facilitator and the student researchers. It requires flexibility and patience. But the process of participatory action research can provide insights into students' experiences that might be difficult or impossible to gather from other research methods.
- Be as inclusive as possible in your collaboration with student researchers. Talk with each student (and staff they know well) to determine the best way to communicate and work together.
- Be patient. Remember that students with ID are rarely, if ever, given the chance to have equal footing in research. If they are missing deadlines, review how important it is for them to share their opinions about college and explore different ways to help them follow the research timeline.
- Use more than one strategy to help students participate in all phases of PAR. There are a wide variety of tasks involved in PAR that may need some adaptation in order for students to fully

engage in each phase. Be prepared to make these adaptations, and also be aware that some adaptations will need to be made on the spot.

## Conclusion

PAR with digital tools holds promise as an engaging and empowering research method for individuals with ID. Given the participatory and flexible nature of this research method, it is possible to allow young people to determine for themselves what is important for others to know about their postsecondary experiences. By using these inclusive research methods with college students with ID, stakeholders are learning how postsecondary experiences influence students' self-determination and getting a glimpse into the perseverance these students exhibit as they pursue their goals.

Maria Paiewonsky, EdD, is a transition specialist at the Institute for Community Inclusion. She has coordinated numerous transition related projects. Maria also facilitates participatory action research. This inclusive research work involves teaching youth to use photovoice, digital stories and story mapping to communicate their own transition knowledge and expertise.

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# Choosing Opportunity: An Internship Miles from Home

Jo Hendrickson, Janis Mendenhall, Sue Heath

After graduating from high school, Ali Heath worked at a grocery store, earning her own money and being supported by friendly co-workers. Yet she yearned for more—she lived in a college town and wanted to go to college. Her college dream was realized when she learned about The University of Iowa (UI) REACH (Realizing Educational and Career Hopes) Program. (See [www.education.uiowa.edu/reach](http://www.education.uiowa.edu/reach) for more information about UI REACH.)

While attending UI REACH, Ali lived in the residence hall with other college students, made new friends, and actively participated in community and university activities. In her classes she learned the ins and outs of applying for a job and meeting workplace expectations. She worked in the same daycare center she had attended as a young child. Ali thoroughly adored her work and the children in her charge and believed that she had found her calling. But after completing the UI REACH program, she did not find a position in childcare. She was bored and her life was in the doldrums. She continued to pursue avenues for working with young children, hoping for an entry-level job.

## An Opportunity Unfolds

In fall 2011, Wellmark Blue Cross Blue Shield, a national health insurance company, started a 12-week paid summer internship program for a graduate of the UI REACH Program. Six alumni were encouraged to apply, and Ali was awarded the internship. She used the interviewing skills she had learned in college and impressed the interviewers with her attitude and knowledge about Wellmark. Beyond the interview and online research skills she had developed in college, her postsecondary experience had set the stage for this next phase of her life, giving her confidence that she could live away from home and learn a new job. Although she was nervous and

a little scared, she believed that she could take the next step toward independence.

## Moving Past Feeling Alone, Overwhelmed, and Frustrated

Ali's anxiety grew as she moved into her new apartment. Her roommates had not moved in and it would be two weeks before the first one arrived. All too soon her belongings were stowed, basic food supplies were in the refrigerator, and it was time for family good-byes. She had never felt so alone, so desperate. How would she survive? Did she really want to do this?


Ali recalls, "I remember... my first day up in the office... I was so nervous... in a new place, in a new town... Part of me felt like I wanted to go back to Iowa City. I even called my mom saying I did not want to be here, but she told me that everybody in and outside of Wellmark was there to help me."

When a UI REACH advisor made a visit just after Ali began her internship, she noted that internship orientation included

long periods of group presentations about various topics (e.g., benefits, paperwork to be completed). Instead of finding Ali going through an assigned training module, the advisor found her "slumped at a computer, looking dejected." During that morning visit, Ali complained about the heat, had great difficulty focusing, interrupted conversations inappropriately, and displayed negative body language. Ali's Wellmark supervisor, an individual with limited experience with individuals with cognitive challenges, concluded, "Ali was becoming more and more frustrated... things are not going that well." Ali's mom recalled, "Orientation scared the heck out of her—besides being a very long day, she received a lot of information that didn't make sense to her." UI REACH staff remembered the challenges that Ali overcame during her transition to college life. When overwhelmed, she might cry, "shut down," or be rude to others, but with time, the establishment of routines, and advising



Ali and her best friend make their way to work.



support, she learned to advocate for herself to meet the challenges of each day.

## Coming into Her Own and Then Some

Major transitions are difficult for everyone. To help Ali deal with the stress of this new job and new city, she was reminded by UI REACH staff that her Wellmark supervisor and Wellmark mentor were now two key people in her “circle of support.” With encouragement from UI REACH staff, an end-of-the-day check-in with her Wellmark supervisor, virtual pats on the back from her family, and self-talk “pep talks,” Ali became calmer and more confident in her ability to succeed. UI REACH recommended that Ali be given a new task only after she had mastered a previously introduced task. Wellmark and Ali agreed with this supervisory approach.

By the end of the second week, Wellmark Human Resources reported that Ali was up-beat and excited about all of the new things she was learning. HR reported that she was scheduled to begin bar-coding, scanning, and mail preparation tasks with her mentor. In week 3, Ali’s new roommate from Florida moved in and they started taking the bus together to work. Her struggles with the transition to work seemed like a distant memory.

By mid-June, Ali was utilizing the Wellmark wellness center and thrilled her mother with a call while she was running on the treadmill. Later in June, Ali’s supervisor noted, “Ali has been very engaged at work and is effectively managing her work schedule. Ali goes to mail prep on her own each day and when she is done...she is back... completing her bar-coding/scanning efficiently. Overall, Ali is managing and prioritizing the work tasks well on her own. We are planning to move forward next week with an eight-hour work day.”

By the end of the month when UI REACH staff visited, Ali was able to proudly and expertly provide a tour of the entire building and introduce them to colleagues at different work stations. Each Wellmark colleague spontaneously shared a positive story or praised Ali. Ali also told UI REACH staff about the fun things she did on weekends with her roommate and about socializing with other interns. At

UI REACH, students are encouraged to socialize, develop new interests, and adapt stress management strategies to work for them. Ali now smilingly described how “just getting up and walking around and going to anyone in the claims department when something is bothering me” was a strategy she had developed for herself at Wellmark. Ali’s mentor noted Ali’s good attendance and punctuality, two of the “soft skills” emphasized across the curriculum at UI REACH.

Ali’s final day at Wellmark was in mid-August, and her housing contract was over at the end of July. What to do? Finish the internship early or find someplace to stay? Ali’s mom sent an email to UI REACH, saying, “The girls [Ali and her roommate] have decided to live together. They have a 6 month lease.” Ali’s mom was overjoyed that the bus schedule would allow Ali to continue in the downtown volleyball group that she had joined or to work out at the end of the day.

## In Their Own Words

Ali’s mother said, “She has accomplished so very much and yes, it took a village surrounding her. We are blessed to have so many people involved with her... I don’t think Ali has ever felt so very productive and contributing to the working world. This has changed her forever.”

Ali recalls, “To be honest when I first heard about the internship, I did not even know there was a place called Wellmark... I certainly did not know much about health insurance. (Since arriving at Wellmark) I worked ... in Claims Financial and some of my responsibilities included sorting mail, preparing data, attending group meetings, and typing up X004’s...I have met a lot of great people but the two I think who have helped the most would be my boss and my coworker (mentor)...My boss told me to never be afraid to ask for help if I needed it... [my mentor] is very fun to be around, she always has jokes to tell and loves to laugh. These two people have been wonderful and I cannot tell them enough how grateful I am to them.

*“...for 3 months I lived (in university housing in Des Moines)... while I was in Des Moines I made some new friends and even made a best friend.*

*She and I now live together in our own apartment complete with a pool!”*

*“...part of me does not want to leave Wellmark because I have made so many good friends...and I feel safe here. A lot of things have changed since I moved here, I have become more independent and less dependent on my parents...I do know that I want to stay in Des Moines for a while... I am going to be looking for a job. ... (This) doesn’t mean I will turn into a Cyclone fan! I will always be a loyal Hawkeye fan!”*

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*Jo Hendrickson directs The University of Iowa REACH Program (Realizing Educational and Career Hopes), a campus-based program for 18-25 year-old students with multiple learning and intellectual disabilities. She has over 100 publications related to serving individuals with cognitive, learning, social, and behavioral challenges.*

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*Janis Mendenhall is the Coordinator of Career Development and Transition for the REACH Program (Realizing Educational and Career Hopes). She has over 25 years of experience in assisting individuals with disabilities in the public non-profit sector and owned and operated a private company providing supported employment services.*

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*Sue Heath is the oldest of 11 siblings, married 33 years, proud mother of 4 children, and grandma to 2 wonderful boys. Sue has a passion for faith, family, gardening, antiques, and most importantly, advocating for Ali to help her attain her desires and dreams in becoming an independent adult.*



Students relax in the sun between classes.



# College as a Path to a Career: Jose’s Story

Christian Haas



Jose on campus.

Jose grew up surrounded by women, living with his mom and four sisters. School had always been tough but not because of the curriculum. He never felt terribly challenged by the assigned material but he could not stand the ridicule that came with being in special education classes. Jose remembers being called “Special Ed” by other students or just “Ed” for short. He would make his way through high school, day by day, wishing he were in a place where he was treated as an equal.

Upon graduation from high school, Jose tried his hand at auto mechanics at a local technical institution. Between the intensity of the labor and the greasy work environment, he decided there had to be something better. He heard about a new program at University of South Florida St. Petersburg that gave students an opportunity for continuing education on a regular college campus. He enrolled in “Project Stingray” and began a college experience that focused on self-determination, employment

readiness, communication, and independent living skills. The program matches students with peer mentors, an academic mentor, and a community mentor. It also places students in on- and off-campus internships.

Jose’s first peer mentor, Jon Ellington, was the newly-elected student body president who recognized the quality of Jose’s character and took him under his wing. Jon would always make time for the two of them to eat lunch, meet with other students, talk with administrators, and even hang out on the weekends. Jon knew of Jose’s passion for cooking and often invited Jose to his house to prepare meals together. This relationship was special to Jose as it was the first time he felt like he belonged on a college campus.

During his time on campus, Jose did two internships: one at an animal shelter and another at a local restaurant. Both experiences boosted his confidence and showed him that he had skills and talents.

Jose audited one class each semester. His first class was Environmental Science where he learned about ecosystems and the importance of keeping them in balance. The structure of the class was new to Jose as there was a lot of group work and collaboration. The inclusive nature of the class made this course his favorite. He and his classmates made a field visit to Fort Desoto, where he and his academic mentor took samples of seawater.

It wasn’t until Jose took a course called Career Development did he realize that he could have a career, not just a job. After months of in-class evaluations and company research, Jose narrowed his top two career interests to chef and firefighter. Jose and his academic mentor toured an upscale restaurant, where Jose was allowed to cook up some mussels using his own recipe. He also rode along with a St. Petersburg firefighter to explore the

details and responsibilities of firefighting. He toured the training facility, sprayed the hose, and climbed four stories to the top of a lookout tower. After realizing his life-long struggle with asthma could get in the way of becoming a firefighter, Jose decided to become a chef.

College is not just about classes, it’s also a time when many people create lifelong personal relationships. Jose was never shy and when he saw a young woman reading a book in the student lounge he asked if she wanted some company. The young woman, Erica, was a sophomore majoring in criminology and appreciated Jose’s confidence. She became his girlfriend and almost 2 years later, they are still going strong.

After his college program ended, Jose landed a full-time job at the Don Cesar Hotel Resort working in the kitchen with full benefits. The decision to work full-time was not as clear and simple as most would think. Jose received some pressure from his mother to continue working part-time so that he would continue to receive Social Security benefits. His family’s struggle with finances made the decision more complicated. After carefully weighing his options, and discussing the issue with people he trusted, Jose made his decision. Jose has been competitively employed for more than 7 months. He is now the primary source of income for his mother and sister.

*“I just don’t get it. Why should I keep getting Social Security if I am able and willing to work? I’d rather work for my money then get it for free.” –Jose Cruz*

*Christian Haas, 24, graduated from the University of South Florida St. Petersburg with a degree in political science and leadership. Christian was born and raised in Daytona Beach moving to St. Petersburg in 2008. Since graduation, Christian has worked with students with disabilities in a post-secondary transition program, recruiting and training mentors, setting up internships, and facilitating the transition from high school to college.*



# An Alternate View: The Process of Self-Reflection on Life, College, and Disability

Kristen Love and Richard Baker

## Introduction

Self-determination has become an increasingly popular theme within education initiatives and self-directed service reforms (Burke, 2012; Wehmeyer, Field, Doren, Jones, & Mason, 2004). The term “self-determination” involves a combination of skills, knowledge, and beliefs including an understanding of personal strengths and challenges and the belief that one is capable of making decisions (Field, Martin, Miller, Ward, & Wehmeyer, 1998; Wehmeyer & Smith, 2012). One element of self-determination is the process of self-awareness, in which a person reflects on and explores their identity as a person of varying abilities. The process of self-awareness is especially evident during the college years as young adults are in the midst of discovering a career path, exploring intimate relationships, and obtaining a sense of stability and independence away from their families (Arnett, 2000). Recently, a number of postsecondary education initiatives have been established to increase access to higher education for students labeled with intellectual disabilities. As a result, self-awareness on the college campus plays a more significant role for students with intellectual disabilities who must advocate for their needs; in the process become exposed to experiences that empower them while making choices.

This article captures a recent conversation with a student participating in a postsecondary education option that provides supports and services to students with intellectual disabilities. Richard attends Roberts Wesleyan College, located in Western New York, through a support program entitled the Bridge to Earning, Learning, and Living (BELL) Program. This program is funded through a federal initiative, Transition Postsecondary Programs for Students with Intellectual Disabilities (TPSID). The program is a collaboration between

Roberts Wesleyan College, Monroe #2-Orleans school district, and CP Rochester, an agency providing services to adults with disabilities. Richard was the first student supported by the BELL program to participate in college classes and become a member of various campus clubs. Richard struggled in his first year with navigating the academic and social milieu of college just as many college students do. With support from program staff and faculty on the campus, Richard learned what resources were available to him and how to communicate his needs. Over the years in college, his salient understanding of his strengths and current limitations as a student within the postsecondary education program allowed him to advocate for additional access to art classes and organizations on campus. Awareness of one’s abilities, strengths, limitations, and preferences enhances the ability to advocate for changes in many aspects of life. Richard demonstrated this through requesting – and learning how to request – more access to courses and supports at college. He described his current limitations as an evolving process of personal growth, one that includes possibilities in the future. His ability to reflect on his needs and personal growth allowed him to demonstrate self-determination by explaining what is achievable for him at college and how to make that happen.

## An Achievable Outcome at College

When talking with Richard about his college experiences, the conversation began very broadly by asking him to reminisce about his impressions of college. Richard made careful observations during the conversation by asking for clarification – more specifically, was I referring to a person who was accepted to the university through the typical matriculation process or a person who

is participating in a postsecondary education program using an alternate pathway provided for students labeled with intellectual disabilities? This distinction played a key role in much of our conversation, as we decided to parse out instances when he was referring to himself as a traditional college student and moments when he was reflecting on his experiences as part of the alternative pathway (BELL) program. It became apparent throughout the conversation that by distinguishing between ‘college student’ and a ‘person enrolled in a postsecondary education program’, Richard was able to reflect, adjust, and create college goals that were meaningful and attainable to him. In reference to himself as a college student, Richard responded to the general question of “what is important about going to college” by saying that it “improves your mind.” More specifically, after he discussed that people have varying abilities, he explained that even though he had not matriculated into the Art program, he could potentially achieve this goal because the college provided him with the opportunity to audit courses. However, he noted that his pathway to possibly pursue a degree would be different than others because of his intellectual disability, which he does not see as a barrier to his future. He explained:

*“I am what I am. There are people that are somewhat intelligent, some that are really intelligent, and some that aren’t. There are many moderations in life. I am happy the way I am. It would have been nice to get an acceptance letter through the college, but I can work up to it. It’s not like I am stuck in cement or anything. I can get to that goal.”*

In his response, Richard addressed his current situation but affirmed that he has the opportunity to continue his learning in the higher education system. His ability to self-reflect allowed for options such as continuing to pursue a college



degree. Through an understanding of his ability, Richard demonstrated that self-awareness leads to the ability to practice self-determination in a college class.

## Identifying Supports and Services in Courses

An important aspect of Richard's experience on the college campus is auditing art classes each semester – five classes altogether in two years. Because Richard was the first student in the program to audit courses, staff learned, alongside Richard, what kind of supports he needed in his classes. At times, program staff guided Richard to understand technologies and resources available to him, such as peer mentor supports or Livescribe smart pen. They discussed with him how to request additional supports from the program, as well as what to do when he needed assistance in his classes. Richard shared his preferred method of requesting support:

*“I don't think I need help with much, but there have been some instances where I have forgotten a few things about when an assignment is due. There were a few instances where that happened in my classes. But, I've caught on [to what I need]. When I do need help, I usually talk to my instructor or my classmates. I look to the people in my class.”*

For Richard, the opportunity to independently practice seeking supports and observing his classmates' method for requesting support was the best way for him to experience identifying and requesting assistance. This is an essential aspect to his experience, as he is practicing self-determination skills by observing how others sought support and then enacting those observations in his own life. When provided with the opportunity to request support, Richard exerted agency over his college learning, making it more likely for him to be successful in his next class. These were values that he learned through opportunities to independently practice self-determination skills and participate in conversations about his understanding of course content, with the support of program staff in a college environment that promoted his independence on the campus.

## Practical Strategies for Enhancing Self-Awareness on the College Campus

Fostering self-determination has become a best practice for school systems, particularly for transition-aged students labeled with intellectual or developmental disabilities (Wehmeyer, Argan & Hughes, 2000). Encouraging self-awareness on a college campus is an aspect of self-determination and a natural step to preparing a student for adulthood, thereby increasing social acceptability of people labeled with significant disabilities who will be working and living in their communities. As the literature suggests, self-directed learning and opportunities to use the skills where it naturally occurs are key components to increasing self-determination skills (Rusch, Hughes, Agran, Martin, & Johnson, 2009; Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000). These same elements provide opportunities for establishing self-awareness on a college campus. With this in mind, a few practical strategies for enhancing self-determination are:

1. Engage students with intellectual disabilities in conversations about campus membership and access. As demonstrated by the conversation with Richard, opportunities to reflect and share personal feelings about participating in college classes or requesting supports is an ideal way to understand how a student perceives their abilities in comparison with other college students. This is a powerful conversation for students to have with others as they prepare for living and working in their communities.
2. Take a step back and provide opportunities for the student to be independent or on their own on the college campus, even if it means they will struggle. It was not a simple task for Richard to identify and advocate for supports and accommodations in his college class, but it was an important experience for him, as he will use that skill as he continues his higher education. The experience of arriving late to class or losing an assignment are experiences that any college student

would face, experiences that come with important lessons to learn.

3. Require students to request academic accommodations through the Disability Services Office. A valuable skill for students to learn is the awareness of what they need in order to be successful, and how to communicate those needs. Even without direct contact with the Disability Services Office, students should practice completing accommodation forms and requesting the appropriate support. This can only be learned through practice and experience, which is most beneficial when staff are available to support students as needed. As Richard prepares to take classes in the future, he will need a good understanding of how to formally request accommodations at college and what his responsibilities are for ensuring he receives those accommodations.

## Conclusion

The process of self-reflection and awareness is a critical endeavor that each person must be willing to pursue in order to live a self-determined life. As illustrated, by understanding his abilities, strengths, and current limitations, Richard was able to advocate for changes in his college experience. When students are not fully immersed on a college campus, there may be moments when they have an internal conflict between being a member of the campus and participating in a program for students with intellectual disabilities. Institutions and program staff can take positive action toward providing experiences and opportunities for self-awareness and ultimately, instances of self-determination. The conversation with Richard illustrates an overall need to establish empowering environments for students with intellectual disabilities who are pursuing higher education. An overall consideration for emerging or established postsecondary education initiatives is to structure authentic academic access and campus membership so students view themselves, and are validated, as college students on their campuses.

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Richard Baker is a recent graduate of the BELL program at Roberts Wesleyan College in Rochester, NY. He continues to audit Art classes at the college and work at a local library. Richard hopes to illustrate children's books as a career.

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Kristen Love, PhD, is a Project Coordinator for the TPSID grant in New York State. She provides technical assistance to four TPSID sites and talks with students about increasing their independence on campus and utilizing technology and social media.

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# Hidden Treasures Behind Closed Doors

## Janice Fialka and Richard Feldman

When our son Micah was a toddler and being evaluated for his many developmental delays, a psychologist asked us, "Does Micah ever become frustrated when he can't do something or can't get something he wants?" Picturing our happy, mild-mannered child, my husband and I looked at each other and answered in unison, "Rarely." Micah was pretty low-key most of the time, content to sit and observe the world around him. He didn't seem interested in stacking blocks, or emptying drawers or pulling himself up on the furniture, activities that fascinated – and sometimes frustrated – his playgroup peers. "He's such a good boy," the other parents would say as they pulled their howling toddlers away from the allure of electric sockets or swinging doors, and we had to agree. Micah's contentedness was endearing and easy for us as harried new parents.

But later, as we reflected on the psychologist's question, a new idea began

to stir in us. Perhaps a certain sense of frustration was essential to Micah's growth and development. We began to recognize that satisfaction would not spur Micah to try new things, to achieve more – to reach for the wooden block on the shelf or to coax his chubby fingers to grasp the ball. As long as Micah was content to sit, when would he walk? If we continued to anticipate his every need, when would he learn to talk? And so we began that lifelong awkward dance of parenthood, dancing between honoring who he was as a person and nudging him to try new things, to want more, to be dissatisfied with what he could do. Although it was often uncomfortable, we learned that we had to challenge Micah and encourage others to have great expectations for him too. We learned to embrace frustration as a precursor to progress.

As he grew and entered school, it was apparent that Micah liked to keep things easy-going. He didn't like being frustrated

or seeing others upset and often tried to be the peacemaker. He liked being liked by people and won many friends with his contagious smile and concern for others. In third grade, Micah's insightful teacher told us about Howard Gardner's work on multiple intelligences and described Micah as being "people-smart," as evidenced by his attunement and responsiveness to his classmates. The teacher's description was empowering and reassuring to us. Children with labels such as cognitive impairment are rarely referred to as smart. But this wise teacher knew better.

Throughout his teenage years we had a few flickerings that Micah had opinions and desires for "something more," but in the midst of sleepless nights we worried that he might not push to reach his full potential, especially if it might create hassles or dissonance for others. Micah's oft-repeated mantra was, "I'm fine. Everything's fine." Little did we know that tucked inside his sweet soul,

hidden behind that magnetic smile, there was an emerging sense of righteousness and dignity that would ignite in due time, *when it was really important to him*. At age 23, he would demonstrate to us and to the larger world how profoundly motivated he could be when frustrated – in this case, by injustice.

## Opening the College Door

In 2003, when he was 19, Micah joined the first major wave of students with intellectual disabilities (ID) across the country who were attending college. He enrolled in the Options program at Oakland University, a fully inclusive program for students with ID. He got a student identification card, attended three classes most semesters, participated in student organizations, went on a student bus trip to Chicago to cheer on the basketball team at the NCAA Playoffs, attended the Presidential Inauguration in Washington, DC with his classmates, participated in the student leadership retreat and, in his own words, became “a college guy.”

After a few years of taking two buses each day to campus, and shortly after helping to move his sister into her dorm, Micah decided that he wanted the full college experience –including dorm living. In October 2007, he arranged for a tour of the dorm with a friend, and later with his dad and the director of housing. He learned about the cost of living in the dorm and the various meal choices available. He selected a meal plan that would provide three meals a day (including unlimited French fries!) at numerous sites on campus. He completed the housing application form with his father and with eager anticipation submitted it to the housing office.

At first, there was no frustration, just feelings of excitement as Micah anticipated no more buses, sleeping in late, and having 24-hour access to cable TV. Within a few weeks he received confirmation that his housing application was accepted and he was given an official move-in date of January 8, 2008. To secure his placement, he submitted the \$100 deposit and marked his calendar with the big letter “D” which meant “moving into the dorm” (and “getting away from my parents, finally!”).

But a few weeks later, my husband and I received an early morning email

from a college administrator informing us that Micah could not move into the dorm due to “administrative issues.” We sat at the computer stunned, reading and re-reading the four short sentences that would catapult Micah and the university into a two-year tangle of truth-testing and life-changing conversations.

Up to this point, the university had been remarkably supportive, committed, and innovative in its full inclusion of Micah and other students with ID into campus life. The school was, in all respects, an exemplary leader in postsecondary education for students with ID.

In our efforts to understand this unexpected reversal of an agreement, we learned that an administrator opposed allowing Micah to move into the dorm because of groundless concerns that he might not be able to respond to a fire alarm, that other dorm students might be cruel to him, and that his move into the dorm might set a precedent that anyone taking even one class could live in the dorm. Each of these issues was unfounded. In particular, Micah’s ability to live in the dorm was predicated on his official enrollment as a student in a university-sponsored program. Later we learned that the university revised the housing form shortly *after* they admitted Micah into the dorm. The revision stipulated a new requirement that a student be matriculated in order to apply for dorm living. Although Micah was an official university student via the Options program, he was not considered a matriculated student.

Micah was faced with a conflict. He loved his university, his classmates, his




Micah's family and legal team outside the Courthouse after the ruling that the university must provide campus housing for Micah, a university student.

professors, and the administrators. Due to his friendly nature, he knew more of the campus community than most students. He also fiercely wanted to live in the dorm. How would he handle his intense desire – his right – to live in the dorm and still remain on a friendly basis with his college community? Micah had a history of opening doors, beginning in early elementary school when he declared that he wanted to go in the same door as his friends and be in general education classes. What would he do about this door – the dorm door – being shut in his face?

## Opening the Dorm Door

The following two years were a crash course in real-world advocacy and self-determination for Micah and his community. Micah had become frustrated and felt compelled to “do something.” He had grown up in the era of the Individuals with Disabilities Education Act (IDEA) and had been fully included throughout his school career. He also had been mentored by strong young activists with disabilities who had helped him understand disability not as a deficiency or misfortune but as a difference and a unique experience. All of these experiences



came into play when Micah realized he was being discriminated against.

Soon after hearing the unwelcome news, Micah, on his own, scheduled a meeting with a key administrator to explain his desire and right to live in the dorm. To prepare for this important meeting, Micah worked with a professor to talk through what he wanted to say to the administrator. He practiced delivering his major points with determination and respect. When the administrator did not reverse the decision, Micah met with other students for support and ideas. With their help, he created a petition-and-letter-writing campaign resulting in 300 letters and 1,000 student signatures supporting Micah and protesting the discriminatory housing policy.

Next, Micah took a bold step and spoke at the public meeting of the University Board of Trustees. With dignity and poise he stood at the podium, thanking the university for opening its doors to him and other students with similar disabilities. He explained that he was officially a student as evidenced by his enrollment in the Options program. He paid full tuition, participated in classes and student organizations, volunteered on campus, and had his housing application accepted and his enrollment check deposited by the university. He explained why he wanted to live in the dorm and why it was his right to do so. There was a hushed silence as he spoke, and our eyes brimmed, since there had been a time when had we questioned if he would ever be able to talk.

He returned to his seat and intently listened to the next testimony. It was given by a long-time member of the Michigan State Board of Education who joined Micah in praising the pioneering spirit of the university. She articulated the reasons why Micah had a right to live in the dorm and reminded the Board of Trustees and administration of the recently reauthorized Higher Education Opportunity Act (HEOA), which provides federal funding for model demonstration programs at institutions of higher education, initiates groundbreaking policies supporting students with ID to attend college, and makes students with ID eligible for Pell Grants. She was followed by a passionate presentation by a disability law attorney.

Within a few days, Micah was informed via a letter that the dorm

door remained shut to him and other students with ID. He was sad and mad (and frustrated) but undeterred. He met with friends and several student organizations to explain his situation. With the involvement of many students, a forum was held to discuss the issues. The Sociology Club held a rally and marched through the student union holding signs and chanting, "Micah is a student." As news of the issue spread, formal and informal conversations continued, not only on campus but also across the country, discussing what it meant to be a college student. The university student council extended support, and Micah again addressed the Board of Trustees. This time many students – as well as faculty, alumni, and others – spoke on behalf of Micah's right to live in the dorm.

This particular university is not known for campus activism, but the issue of Micah's studenthood sparked the moral ire of many students, many of whom had attended public schools where full inclusion of individuals with disabilities was the norm. For those who had grown up living and learning alongside students with disabilities, having Micah and his Options classmates on campus and in the dorm made sense. For others, it just seemed right. Many students felt compelled to support Micah and speak out on the broader issue of discrimination and the university's discriminatory actions.

After repeated efforts to negotiate with the university, Micah met with Michigan Protection and Advocacy Service, Inc. and decided to file a lawsuit against the university for discrimination against him. This was not an easy decision for Micah, and yet he possessed a clarity that took our breath away. As he emailed one friend, using his voice-to-text technology, "If I give up, most things won't change."

The next year-and-a-half included many meetings, a deposition, two hearings in federal court, and many conversations with family and friends. One of the most demanding experiences for Micah was the deposition, in which he was interrogated for five hours. The unexpected use of a video camera and the seating of the university administrator directly in front of him the entire time didn't deter Micah from answering the questions and staying engaged. Micah's lawyer said that Micah handled the

undue pressure magnificently, answering each question with respect and poise.

On December 23, 2009, two long years after we received that early morning email blocking Micah's right to move into the dorm, U.S. District Court Judge Patrick Duggan ruled that the university must provide campus housing for Micah. As Micah put it, "The judge understood that I was a student." The victory for Micah and for the larger community was covered by newspapers and radio shows across the country, including NPR. He became CNN's Intriguing Person of the Day.

On January 4, 2010, Micah moved into the dorm. As we carried boxes of his belongings toward his long-desired new home, we were deeply touched by the many students and their parents who greeted Micah with handshakes and words of congratulations and welcome. Micah simply nodded, smiled his infectious smile and said to each person, "Thank you. I'm happy to live in the dorm." (To watch Micah move into the dorm, go to [www.throughthesamedoor.com](http://www.throughthesamedoor.com).)

## What Unexpected Treasures did Micah Find Behind the Door?

Since December 2007, when we received the e-mail indicating that the dorm door was (temporarily) shut on Micah, we have heard Micah express the following thoughts. His words best reveal the unexpected treasures Micah gained through this experience.

- I got more confident.
- I learned I could do really hard things.
- I learned how to be a strong advocate.
- I learned I could speak out and tell my story in my words.
- I learned I could understand most of what my lawyer said, and when I didn't understand him, I learned I could ask him to repeat it in a different way.
- I learned that sometimes life is hard and doesn't make sense.
- I thought it was going to be easy. I didn't know it was going to take two years.
- I learned "I can do it, but not alone."
- I learned what discrimination feels like and it isn't good. I learned I can fight it.





- I learned that a lot of people understood that I was a student, but not everyone understood that.
- I learned that I can talk to administrators by myself.
- I learned that people change their stories.
- I learned that professors can help me.
- My parents learned . . . a lot. They learned I can do hard things.
- I learned that when I feel upset I can talk with someone or listen to music.
- I learned why my parents and teachers taught me about Rosa Parks and Harriet Tubman.
- I learned that sometimes life is hard, and I am not always happy but I can get through it.
- I learned why it is important to talk with other people with disabilities.
- I learned that going through this fight helped me know that I wanted big things to happen for me and that gave me the confidence to move to New York and work at Syracuse University. (See page 24 of this publication to hear Micah's story of moving to Syracuse.)

In the course of this two-year ordeal, Micah earned a Ph.D. in self-advocacy, so to speak. No PowerPoint or self-determination class could adequately teach what Micah learned. He lived it.

There was nothing glamorous about these lessons. Micah often came home troubled and confused about why he could not live in the dorm. It seemed so unfair; he was a student in every other sense of the word. He was forced to struggle with what might be called the existential questions of life: how to question authority, what it means to be a student, what it means to be human.

Living in this frustrating ambiguity, Micah learned the power of persistence, community, asking for help, and getting through tough times. He learned that when faced with adversity, it is important to connect, to converse, and to continue – not to hide. In reaching out to others, he heard stories about people who faced adversity and how they handled it. That inspired him to go on. Suddenly all the stories read to him at home and in school about Harriet Tubman, Martin Luther King, Jr., and Rosa Parks had real meaning to him and gave him direction. He began to see his story as part of a bigger story.

He learned that sometimes there weren't clear answers, and that friendly people, people who smiled and said 'hello' to you in the university hallways, could also discriminate against you. He learned that social smooth sailing didn't necessarily mean the absence of conflict. He learned that everyone has "life is hard" experiences, and that simply knowing that you're not alone can get you through the tough times.

As parents, we learned that we could not protect Micah from all the hard stuff. We had to "let go" (not give up!) and support him, often from afar. As much as we wanted to find that magic wand to keep him out of harm's way, we knew that he had the right to make his own choices, even if it meant "failing" or feeling troubled, sad, or mad. We can't say it was easy, but we began to deepen our trust that Micah could grow in his confidence and skills. We realized that if we tried to shield him from the frustrations of life, he'd never reach his full potential.

We are profoundly aware that Micah could never have pursued this fight without the support of others. We witnessed the powerful impact this experience had on students and professors, both on campus and across the country, who rallied in support of Micah. We are indebted to Micah's attorney, Chris Davis of Michigan Protection and Advocacy, Inc., who always respected Micah and believed in his abilities. Chris never wavered in his professional obligation to "communicate with the client and to let the client set the direction at all times." He made sure Micah understood what was happening and what his choices were. He honored Micah's often-asked question, "But why?" and he appreciated Micah's need to have things explained in basic terms. Chris later told us how Micah's questions sometimes challenged him to think more clearly about what he said and how to articulate complicated matters in concise ways.

Two years is a long time to struggle with an issue. Honestly, we were uncertain if Micah would be steadfast in pursuing his desire to live in the dorm. We had assured him that he could change his mind and stop at any time; he had our full support and respect regardless of the path he chose. When he got discouraged, we reminded him that what he had

done so far in pursuing his dream was more than most people ever do.

Throughout those two years, there was no guarantee that Micah would grow, thrive, and build his self-determination. But all those things happened when he faced up to his frustration and didn't back down. On the night before his federal court hearing, Micah sat somberly, still bewildered by the university's persistent fight to keep him from living in the dorm. He shook his head in disbelief at the thought that tomorrow he would be sitting in a courtroom. As Micah shared his thoughts and feelings, we sat perfectly still, longing to say something that would make it all better. We had no words, only the certainty that he needed us to listen to him. After a long minute of silence and, as if he was scanning the past 20-plus years of his life, Micah said, "Since I was a little kid, I've had speech therapists, OTs, PTs, social workers, lots of teachers, counselors – all kinds of people in my life." He paused, grinned, and then continued, "I never thought I would have a lawyer too!" We burst out laughing as a family, the kind of laughter that heals, helps, and binds us together in hope and love. We agreed, "You are so right, Micah. We never knew that you'd have a lawyer or be headed to federal court."

Raising children with or without disabilities is a journey into the unknown. In our efforts to do our best to support Micah to be confident and self-determined, we stumbled head first into the great lessons of life. We – and Micah – learned that frustrations and closed doors are part of the journey and that they must be treated as detours, not dead ends.

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*Both Janice and Rich are authors, national speakers, and the proud parents of Micah and Emma. To read more about their publications and work, visit: [www.danceofpartnership.com](http://www.danceofpartnership.com).*

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# I Felt at Home

Micah Fialka-Feldman

with Barbara Schloss, Onondaga  
Community Living, Onondaga, NY

Even when I lived in Michigan, I had heard about Syracuse University (SU). I knew they had a long and rich history of disability culture and that they trained their K through 12 teachers to work respectfully with ALL children. Then I got to go to Syracuse myself to speak at two big conferences in August 2011 that were sponsored by the School of Education. I just loved being at a place that really “got” inclusion and disability. I really felt at home. I wanted to figure out a way that I could move to Syracuse.

So while I was still at SU last August, I approached Julie Causton-Theoharis, one of the conference organizers and a professor in the school of education, to set up a meeting with her and George Theoharis (another professor). They told me to write a letter to Dean of Education, Doug Biklen, indicating my interest in working here. That was the beginning of many long conversations about how both Syracuse University and I could benefit by my coming here. After the close of the two conferences, I returned to Michigan where I have been living for my entire life.

I was determined to make Syracuse my new home and I wanted it to happen by January. Many people wondered if I could make that dream happen in just six months. I couldn't think about IF I could make it happen, I could only think about HOW I could make that happen.

Over the next six months, we had several conference calls and Skype calls to discuss how we could work together. I knew I had to build my circle of support in Syracuse right away. In November 2011, I saw Wendy Harbour, another education professor, at a conference and she told me that she had two job opportunities for me at Syracuse University. During that same month I returned to SU to speak in Julie Causton-Theoharis' education class. I was making more and more connections. It seemed definite that I would be moving here. I was excited.

## Planning to Move

Once I had a job lined up and knew it was definite that I was moving to Syracuse, I posted a housing flyer on Facebook and sent it to my Syracuse email list--which was getting bigger every week! I found a place to live within walking distance of the university. I found someone whose roommate was moving out, and I contacted her. I was able to see the room and the house in November. Next, I had to find an agency to partner with. Jessica Bacon, PhD student at Syracuse, who is on the Onondaga Community Living (OCL) board, recommended OCL. I liked OCL because they believe in giving people choices and understand how to treat people with disabilities. They clearly believed in me as a person.

## Arrival Time

I arrived in Syracuse on January 13, 2012 and have been working at S.U. as a graduate assistant. I help teach a class in the school of education with my friend Michelle Damiani, a doctoral student. I also work with a program called Peer-to-Peer, which links college students with other college students with disabilities. I am also helping with a campaign called “I Am Norm” at Liverpool High School and am part of a disability rights group, Beyond Compliance Coordinating Committee, and a sign language club, both at S.U.

## Taking Care of Myself

So lots of things went great for me! I spoke up about wanting to move to Syracuse, and I made it happen, with help from family and friends. I got a job and a place to live. But sometimes I have to deal with things that are scary or unfamiliar, and I can get nervous about it. One thing that happened is when my housemate was moving back in with her parents, I had to



get a new housemate. I heard that the new housemate was moving in in the middle of the night, and I did not even really know him! I was nervous and scared about that. So I called my parents, and we came up with some things I could do, like go spend the night at another friend's house the day he moved in. I felt better once I had a plan. He did move in - not in the middle of the night - and it went fine. But I was glad that I had talked to someone about how I felt.

Living and working on my own, away from the place I lived my whole life, means I have to speak up for myself and do what I think is right for me. I take classes at Syracuse, as well as work there, and I had thought about taking a class in Disability Studies that sounded good. But then I found out there were over 100 students in the class! I knew that I did much better in smaller classes, so I chose a different one. I learned what works for me and that helps me make choices.

Over the years, I have opened many doors with the help of many people. It all started when I told my parents that I wanted to go in the same door at school as my friends in second grade. Opening this newest door in Syracuse happened in just six months. Not only do I feel at home, but now I am at home, in my new home in Syracuse.

*Micah Fialka-Feldman is a teaching assistant at Syracuse University, student, national speaker, and pioneer who fights for disability-pride, justice, and inclusion. He is part of the first wave of adults with intellectual disabilities attending college and has been fully included in school and community.*



# My Brother's Journey: A Sibling's Perspective About College and What Comes Next

Emma Feldman

I love telling people that my parents, who reside in Michigan, live at least a day's car ride away from me (in Boston, MA) and my brother (in Syracuse, NY). This is a BIG deal. My brother and I visit each other in our different east-coast states without our parents. This is a BIG deal. My parents talk to my brother and me, at most, a few times a week. This is a BIG deal. Never could I have imagined that this would have happened. Instead, sometimes, having a brother with an intellectual disability, I grew up wondering things like: Who are Micah's real friends? Will he ever live on his own? How will he live a dignified life when most of society doesn't value him (and his label)?

In many ways, Micah had a picture-perfect inclusive K-12 education experience (this doesn't mean it was easy to create or actually perfect in execution) – he had a circle of friends, he ran on the Cross Country team, he was elected to homecoming court, he played on the local soccer team, he won the social studies department award. Inclusion has always been a foundational belief and practice in our family. It was an essential part of Micah's education experience and unlike some special education students, his inclusive journey continues well beyond grade school.



Siblings Emma and Micah.

However, it wasn't until he and I both went to college that something finally clicked for me as his sister. Inclusion became real and practical. Up until this point, inclusion made me feel good. In grade school, I felt safe knowing that Micah had things to do on the weekends, like his peers. It felt good knowing that Micah's peers cared about him. In the back of my mind, I had always wondered if people really wanted to be his friend (or did it just make them feel good)?

As we moved into college, inclusion felt more complex. I saw Micah being valued and I actually saw others grow in genuine ways as a result of having a relationship with him. I began to see people develop relationships with Micah because they saw the worth in who he was—not just because being his friend made them feel good. I saw Micah make decisions about *who* he wanted to be friends with. Suddenly everyone didn't have to be his friend; he and they could choose to become friends.

I saw Micah grow academically from the rigor of college. There were times when we were both taking similar courses and we'd talk about what we were both learning. He didn't "get" everything in the textbook (neither did I) – and that was okay. Not understanding everything is part of his disability. This does not mean that we lower our expectations; it means that we don't all have to understand everything.

College meant that Micah had to negotiate what his paid support-staff peers would do with him and unpack the tensions around "paying" a peer to support him. Inclusion in college meant that it wasn't always easy for him; the path was not paved for him – he had agency and self-determination in creating his future. He faced institutionalized discrimination; the college would not allow him to live in the dorms. He sued, eventually won, and spent his last semester living in the dorms. Micah's learning did not just happen in the courses he took. Like most college

students, he also grew leaps and bounds from the social interactions and genuine experiences outside the classroom. For example, as a result of his legal battle, Micah now knows lots of legal jargon. Inclusion meant he grew as a result of his (real) life experiences, not the simulated life experiences in a classroom.

Like me, Micah got to test the waters of "independence" (or at the very least, had the opportunity to see if he could make it without our parents) and develop the courage to continue to take risks. When he returned from a conference and told my parents that he wanted to move to Syracuse, this short statement seemed to reflect his entire history of being immersed in all aspects of life. As a result of his college journey, Micah had learned to create networks of support and advocate for his needs. Today, he wants to live away from our parents, create new communities, and be immersed in a community that he believes just "gets it" (disability, inclusion). He knew (and I knew) moving to a different state in an apartment with roommates without disabilities was not going to be easy. But he had the tools to make it successful.

I was excited when Micah moved to Syracuse in January 2012, but I was also worried. And as he continues on this exciting journey there are a few things I continue to worry about. Micah has lots to share with the world and especially educators. I hope that Syracuse finds a way for him to share his stories--what he has learned, not just about inclusive education but also about disability culture and disability pride. I think what makes his story unique is that inclusive education for him has been tied to learning more about his disability and becoming part of the disability justice movement. I know he can do more than be a go-to person at Syracuse--I think he can show his PowerPoint and teach segments of disability studies and education courses. This is going to take work on so many levels so



I'm excited that he's surrounded by people who care about him and totally "get" him.

My worry is that his just being in Syracuse will be enough for Micah, that he will be so happy to be around people who respect him that he (and his community) will forget that genuine respect comes from being challenged to continue to grow. I am afraid that we will get complacent. That's my fear, my nightmare. I hope that he is able to find ways to connect, grow, and learn from the Syracuse community.

That he is able to develop, to be challenged on his PowerPoint and speaking skills. That he is able to learn more about social justice issues. That he is surrounded by people who challenge him--who tell him when he's talked too much about himself and when he hasn't asked enough questions about others--when his ego is gotten a bit too big (I say this with the most love in my heart). I hope people can continue to be real with him.

While supportive, nurturing communities that help people grow as people and as professionals is something many hope for, it is particularly important for people with disabilities. I think because the struggle to create inclusive communities is challenging, it is easier to be satisfied when we think we've finally done it (create the community); in reality, though, creating inclusive spaces and communities is always ongoing. Efforts to include Micah didn't stop once he was attending the neighborhood school, they didn't stop once he was playing on the local soccer team, and they didn't stop after he moved in the dorms at college. Micah continues to find more ways to make the world more inclusive for people with disabilities. It is process that forces him, our family, and our communities to grow and constantly strive to do better.

We're still figuring out this new chapter in his inclusive journey through life. I can tell Micah that it's not always perfect, that he shouldn't get complacent when it feels safe, and that he should continue to dream. And that he's got a community around him to help make the unimaginable imaginable and tangible for him.

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# Building Self-determination by Designing PSE Programs as Empowering Settings

Seb Prohn

Self-determination is dynamic. It can grow or diminish depending on the environment (Abery, 1994; Wehmeyer & Garner, 2003). Environments that provide people with the opportunity to develop and demonstrate individual capacity, self-efficacy, and influence also foster self-determined attitudes and behaviors. When self-determined individuals emerge and flourish in empowering environments (Sprague & Hayes, 2001), they often improve their communities in the process. Beyond improving individual wellbeing, enhanced self-determination skills contribute, at least indirectly, to stronger communities. It is essential, therefore, to improve our understanding of what makes settings empowering and to provide people with intellectual disability (ID) access to environments that allow for empowerment.

## Empowering Settings

Empowering settings are ones that contribute to individual and community development. Various settings, congregations, or community organizations—including colleges—can possess or cultivate the necessary qualities of an empowering setting. Maton (2008) provides a blueprint for empowering settings built upon six primary characteristics: group-based belief system, core activities, relational environment, opportunity role structure, staff, and setting maintenance (see Table 1). The empowering processes and outcomes associated with such environments for disadvantaged youth, recovering alcoholics, Afghani women, and other traditionally marginalized populations have been documented (Maton, 2008). Similar processes and outcomes are also evident in many postsecondary education programs (PSEs) for students with intellectual

disability (ID), but these programs have yet to be examined as 'empowering settings' using Maton's framework. This article will describe how college settings can exhibit Maton's key characteristics, highlighting features of a PSE program at Western Carolina University. If used with intention, Maton's characteristics can facilitate self-determination and help students with ID exercise control over their lives and strengthen their communities (Zimmerman, 1990).

## The UP Program as an Empowering Setting

Western Carolina University's University Participant (UP) program ([wcu.edu](http://wcu.edu)) is an on-campus living and learning experience for 18-25-year-old students with ID. UP participants and staff strive for all university experiences to intentionally attain two outcomes: independent living and employment. Many factors, such as parental support or strong social skills, contribute to achieving these outcomes. However, for all participants, increased self-determination is essential for achieving independent living and employment. Therefore, the UP program implements the organizational characteristics and procedures essential for fostering the "combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior" (Field, Martin, Miller, Ward, & Wehmeyer, 1998). Exemplifying Maton's six characteristics, the UP program operates as an empowering setting to encourage self-determination as both a process and an outcome (see Table 1). Below, I describe how the UP program implements each of Maton's characteristics.



## Belief system

The UP Program's long-term vision and daily procedures are guided by its system of beliefs: inclusion, self-determination, high expectations, and evolving support. These beliefs never function in isolation. For the sake of self-determination and for the UP Program to function as intended, the presence of each and all of the beliefs in concert must be considered in each decision and activity. Therefore, participants are encouraged to choose the activities, classes, and employment options in which they will participate. Problem solving is also emphasized, from searching for lost objects to rescheduling activities when plans shift unexpectedly. This balance guides university experiences and a PSE program created for and by participants.

## Core activities

Foundational beliefs held by the UP Program are manifested through its core activities. For example, the UP Program fosters academic inclusion by ensuring that participants access, with non-UP students, a variety of college courses. To date, participants have enrolled in 60 diverse courses at WCU ranging from political science and geography to education and first aid.

And, just as participants' development hinges on classroom participation, their inclusion in evaluation is emphasized. Each week, participants provide suggestions to schedulers about fading support and which alternative activities should be integrated into the following week's schedule. UP participants also

maintain wiki sites where they document, describe, and critique their college experiences, especially regarding class and work. Because all members of the WCU campus community are permitted to view wikis, some UP participants, for instance, use this medium as a platform to elicit peer suggestions or to express gratitude towards faculty that make class interactive. On one occasion, in an effort to educate their campus community on perceived facilitators of and barriers to their college participation, UP participants displayed evaluative photography in the university center gallery. Each of these activities acknowledge that UP participants are the best arbiters of what is working and not working for them, UP program included, in the college setting. Valuing participant voices drives UP program improvement. The value of inclusion dictates that participants co-construct, through participation in evaluation, the knowledge that defines successful PSE experiences. Their feedback, sometimes direct, sometimes indirect, has been clear: expand the program's reach. Participants push UP staff to expand experiential opportunities. By challenging UP program boundaries, participants have created opportunities with the college football team, campus police, and for international experiences in the summer of 2013. In each case, the act of providing feedback reinforces self-determination while contributing to UP program growth.

## Relationships

UP participants work, volunteer, and attend social activities and classes where new relationships are formed. At first, friendships develop with a diverse group of nearly 250 WCU students who naturally support UP participants. These so-called 'natural supports' are paid and unpaid WCU students. They are approximately the same age as UP participants and intervene as necessary to facilitate UP students' inclusive participation in residential living, coursework, and social and recreational activities. Because these natural supports are familiar with the university's social landscape, they facilitate participants' membership and involvement in many aspects of the college experience, including religious organizations, Greek life, and the

community. As UP participants become valued members of these varying social circles and connect emotionally to other students, their sense of belonging grows.

Also, where similarities are acknowledged and mutual benefit is perceived, relationships grow. Participants and natural supports get a glimpse into one another's lives through their interactions. These are opportunities for each to recognize the other as living similar college experiences including attending classes, completing assignments, living in residence halls, and making new friends. These commonalities establish that all students are members of the same group in name and in action.

## Roles structure


Relationships with other students help build the comfort necessary for participants to exhibit self-determined behaviors. A supportive environment encourages participants to access new classes, social arenas, and activities. Multiple environments and novel activities allow students to refine multiple roles, each requiring unique capacities. Taking classes requires a certain set of skills; yet other skill sets are required for work. Students become more aware of contextual cues while applying skills in appropriate times and places. For each role, in each environment, feedback encourages decisions that often steer closer to the goals participants set for themselves. Learning a multitude of roles better prepares students to make decisions in the dynamic environments they are sure to encounter.

In student roles, participants practice self-regulation and organization. Schoolwork takes priority over social commitments and recreation. As for any student, balance between what one wants to do and what one needs to do is difficult to achieve but necessary to strive for.

Likewise, on the job, participants make decisions necessary to complete tasks and fulfill the role of 'good employee'. This might include actively engaging children at the child development center rather than waiting for children to initiate contact, or limiting socialization with students who are exercising in order to assure the safety and cleanliness of the weight training center. Participants also rate their own on-the-job performance to practice



Seb Prohn with David at graduation.



self-awareness and keep an inventory of their strengths and limitations.

As fans, friends, and group members, participants have the opportunity for 'in situ' learning experiences. Friends encourage 'appropriate' social engagement while unsuccessful behaviors are replaced or eliminated from participants' social repertoires. After all, peers are excellent at noting strengths and limitations that we may be unaware we have.

### Leadership/staff, program maintenance

The UP staff, from the director and coordinator to undergraduate paid natural supports, takes responsibility for facilitating participant success. In order to do this and also reinforce self-determination, responsibility for the program is dispersed among all involved, including the participants. Engagement and honesty among all UP stakeholders allows for consistent, formative feedback. The same way UP participants use feedback and reflection to meet individualized goals for college participation, the UP Program also uses evaluations--from natural supports, instructors, employers, and outside evaluators--to grow. A steady commitment to continuous improvement combined with an atmosphere of shared responsibility reflect a leadership style that helps the UP Program project its values and accomplish its goals. When the school year winds down and participants are away from campus, the UP staff reflects on successes and challenges in preparation for the next year. Each semester, by improving policies, staffing and training, the program is revamped to make participants' college experiences as impactful and powerful as possible.

### Community Betterment & Radiating Effects of Self-Determination

Self-determined individuals excel at proactively managing fortuity- they create 'chance' encounters that when capitalized on can radically alter one's life for the better (Bandura, 2001). Bolstered self-belief and openness to new experiences position students not just to capitalize on community opportunities but also to create opportunities where they do not

exist. Exposure to novel opportunities and ideas are more likely as students' physical and social environments expand. College provides this exposure as UP participants work, recreate, attend classes, and interact with WCU students, faculty, and staff.

But, to be clear, students with disabilities are not just beneficiaries of opportunity, they are benefactors, too. UP participants serve, educate, and engage the community creating a more accessible campus culture (Flora & Flora, 2008).

One component of the campus community, WCU students, surveyed in 2011, showed a strong belief that college students can benefit from having PSE programs on their campus (Westling, Kelley, Cain, & Prohn, in press). Campaigning against the 'R-word' and volunteering provided opportunities for students of all abilities to work toward common goals, efforts likely to build respectful and egalitarian views (Barber, 1991). Fittingly, WCU students noted that the UP Program provided active learning opportunities and a chance to practice understanding and acceptance of diverse populations (Westling et al., in press). One student studying education stated, "As a future teacher, I feel like interacting with these students that are the same as me but just have a few difficulties learning is extremely beneficial." In partial fulfillment of education practicum requirements, some prospective teachers--serving as study partners, tutors, and academic supports--reflect weekly about developing improved abilities to differentiate, accommodate, and provide strengths-based approaches to instruction. Many students have similar stories. Some speak of personal growth--of becoming more patient and adaptable. Others describe becoming better able to communicate with diverse populations. The campus itself becomes more capable as undergraduate natural supports develop skills. Supports and their peers are becoming high-quality future educators, nurses, psychologists, recreational therapists, civic leaders and, above all else, more aware citizens who will work to make their communities more socially just and empowering.

Like their peers, UP Participants have demonstrated the capacity to apply their skills and self-determination to issues that transcend the boundaries of the college community. A first-year participant whose

uncle was diagnosed with cancer decided to participate in the Relay For Life®. By the end of the week, the UP participant had raised more money for cancer research (over \$1500) than any other student at WCU. And, as self-value and political efficacy grow, UP Participants are likely to engage in social movements dedicated to sharing subjective experiences and meeting the needs of others with disabilities. (Maton, 2008). This was evident when a UP participant applied to and was accepted to North Carolina Partners in Policymaking™. In this role, he served as an advocate who communicated with state policymakers, legislators, and public officials. This self-determined participant not only contributed to his increased wellbeing but also expanded education and opportunity for many, with disabilities and without, across North Carolina.

Overall, we should feel confident that postsecondary education programs (PSE) can facilitate self-determination. However, these behaviors and attitudes do not develop on their own. Rather, when PSE programs intentionally develop characteristics known to enhance empowerment, students will be more likely not only to believe that they *can* make choices that dramatically affect their lives and others' lives, but that *they have* the responsibility to make such choices.

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**Table 1. Empowerment setting characteristics, descriptions, and examples**

<b>Empowering Setting Characteristic</b>	<b>Characteristic Description (Maton, 2008)</b>	<b>University Participant Program Example/ Application</b>
<i>Belief system</i>	Ideologies or values, often motivational and strengths-oriented, that define a setting's culture.	UP program values include: <ul style="list-style-type: none"> <li>• Inclusion</li> <li>• Self-determination</li> <li>• High expectations</li> <li>• Evolving support</li> </ul>
<i>Core activities</i>	Engaging, participatory, and high-quality endeavors, both planned and natural, that exemplify core beliefs.	UP activities/endeavors include: <ul style="list-style-type: none"> <li>• Program evaluation</li> <li>• Community art exhibit</li> <li>• Work</li> <li>• Volunteering</li> <li>• Sporting and cultural events</li> <li>• Auditing college classes</li> </ul>
<i>Relationships</i>	Interpersonal resources--including support, caring relationships, and sense of community--essential for increasing "control over one's life and environment."	UP participants access interpersonal resources through: <ul style="list-style-type: none"> <li>• WCU students, who serve as natural supports</li> <li>• Clubs and organizations</li> <li>• Recreational therapy</li> <li>• Meals</li> </ul>
<i>Roles structure</i>	Access to and availability of pervasive, multifunctional roles that provide opportunities to develop capacities and implement self-determined behaviors.	UP participants assume the following roles: <ul style="list-style-type: none"> <li>• Student</li> <li>• Employee</li> <li>• Evaluator</li> <li>• Fan</li> <li>• Volunteer</li> <li>• Advocate</li> </ul>
<i>Leadership/staff</i>	Inspirational and talented individuals who have and share responsibility for the setting.	UP leadership/staff includes: <ul style="list-style-type: none"> <li>• UP Staff</li> <li>• 3 graduate assistants</li> <li>• ~18 undergraduate paid supports</li> <li>• UP leadership/staff:               <ul style="list-style-type: none"> <li>• Model respect, support, and dedication to UP students</li> <li>• Challenge and motivate natural supports</li> <li>• Disseminate UP values through outreach, publications, presentations, and workshops</li> </ul> </li> </ul>
<i>Program maintenance</i>	Ability to be responsive and adaptive to internal and external challenges.	UP program maintenance efforts include: <ul style="list-style-type: none"> <li>• Formative evaluations</li> <li>• Reflections</li> <li>• Strategies for sustainability</li> <li>• Procedural and structural modifications – primarily during summer</li> </ul>

*Seb Prohn is the faculty liaison/ outreach coordinator for Western Carolina University's University Participant (UP) Program. He is completing his doctorate from North Carolina State University's Psychology in the Public Interest Program. Seb's research interests include social inclusion, psychological sense of community, participatory methods, and accessible evaluation.*



# Paige's Journey to End Discrimination

## Paige Wintler

Paige has always been interested in sign language and enjoyed being around young children. When she came to Highline Community College (HCC), through her school district as a dually enrolled student, Paige knew she wanted to work with children who are deaf or hard of hearing. The only career she had previously been exposed to that used sign language was that of an American Sign Language (ASL) interpreter. Through her first year at HCC, Paige explored a number of different careers that used sign language while identifying and growing her skills. She enrolled in the Early Childhood Education program and earned her Initial Certificate in School-age Care. Through the program's internship requirement she completed a six-month internship at a local elementary school with children who are deaf and hard of hearing.

As part of her education certificate Paige took a class that examined People, Politics, and Planet. This was a 10-credit coordinated studies course combining Education and Sociology. Paige became interested in ableism and the disability rights movement through this course. The course allowed her to examine how people with disabilities had to fight for the rights that she benefits from today. She learned how people with disabilities fought for civil rights and equal opportunity. Paige became excited about being a pioneer herself as a college student with an intellectual disability. She learned it was important to speak up about injustice and misunderstanding and to use her voice to stop them when she saw them. This inspired her to share her story through a "Letter to the Editor" which was published in the college's newspaper, the ThunderWord. The following is Paige's letter:

### My Letter to the Editor

Hi my name is Paige; I am a young woman with Down syndrome. Down syndrome is also known as trisomy 21. It is part of an extra 21st chromosome. It was named after John Langdon Down,

the physician who described the disorder known as "Down syndrome." My mom and dad did not know I was identified with it until after birth. It was quiet in the surgery room when the doctor said, "Did you see the TV show with the boy on TV? She is like him." The doctor was talking about the show *Life Goes On* with actor Chris Burke. My mom did not have prenatal screening and had no idea she was having a baby with Down syndrome. Before they had me, my parents had never even thought about people with Down syndrome or intellectual disabilities.

I have a mental delay. My Down syndrome did not affect my physical growth. I was not delayed in that way. My mom did not want to give me an IQ test. I had to have one for SSI (Social Security). My IQ test showed a score low enough to get services. A person with an IQ of 70 or below can get services because they qualify under the category of mental retardation. My mom decided to never give me an IQ test again because I am more than a number.

My family is giving me support with school and at home. I am a full-time college student. I am working really hard to show people I can do this! Before 1975 people like me didn't go to school. The Individuals with Disabilities Education Act (IDEA) gave us the right to go to school with other kids.

Even though we can go to school now, people still believe I cannot do college or that I can't learn. They are wrong! That's why I don't want to be called retarded. I'd like to spread the word to end the word – the R-word. Calling people the R-word makes people believe that we aren't as smart as other people and that we don't count as much.

The R word has become a bad word since many people use the word as a derogative. People can say retardation as a way to be mean to someone or to tell them they think you are ugly or not smart. My sister calls me retard because she doesn't like how I fold laundry. She thinks she



Paige Wintler

knows how to do it better than me. I feel angry and frustrated when she calls me this. My ex-boyfriend calls me retard too. He also calls me baby. He calls me these names to say that I'm not good enough. I was really mad at him. My mom helped me break up with him. People should not say retard. Calling people retarded hurts everybody's feelings, like mine.

I first heard about the "Spread the word campaign" during practice on a Special Olympics basketball team. Sharon Boyle was the coach of the basketball team and it was her that handed out shirts with the name and logo of the "Spread the word campaign." The Spread the Word Campaign is dedicated to ending discrimination of people with disabilities by ending the derogative use of the word "Retarded" altogether. Their shirt logo is a cross-out symbol of "The R word" and listed below is "End the R word." I got the shirts from basketball practice and I have worn them with pride ever since.

People use the R word and call people that name to say that they are bad, stupid and/or worthless. People who are classified as having intellectual disabilities are not all the same, they are different from other people, however; that does not make them bad or stupid people as many people perceive them to be. It is because of this stereotype that people like me are regarded as targets and that is exactly why I want the R word to no longer be used. People with intellectual disabilities can learn, speak for themselves, live independently and fall in love. People with intellectual disabilities should be treated equally and don't want to be labeled.

*Paige Wintler is a student at Highline Community College in Des Moines, Washington, where she studies sign language.*





# One Student's Journey to Self Discovery

Erica Schelly

Josh has always dreamed of accomplishing two goals in his life: to become a history professor, and to one day get married and start a family. Josh, diagnosed with Asperger's Syndrome as a child, has come to understand how his disability impacts his life. He knows that he has limitations and challenges, but also that he has unique strengths, such as an affinity for remembering historical facts and dates, the ability to talk in a variety of different accents and a talent for video games.

After graduating from high school, Josh decided to attend the community college in his hometown, where he could pursue his passion for the study of history and hopefully meet some new and interesting people and make friends. Josh registered with the Disability Services office on campus and requested academic accommodations. Unfortunately, in spite of the receiving those accommodations, Josh's first two semesters in college did not go as planned. He did not complete any courses, either dropping or failing all that he attempted. Why did things fall apart if by most accounts Josh had done everything right?

At the beginning of each semester Josh felt prepared and confident that he could complete the coursework required for his classes. But as the semester unfolded, Josh's anxiety became debilitating. He stopped showing up to class, started missing appointments with his tutors and Disability Support Counselor, and stopped turning in his assignments. Josh was terrified by the idea of failing and decided that it was better to stop trying altogether rather than to try and not succeed. He hated the idea of disappointing people, so he avoided calls from his support team on campus and began hiding his poor performance and class attendance from his parents.

At the end of his second failed semester in college, Josh and his parents knew they needed to do something to help Josh make a change. They feared that Josh would continue down a spiral of depression and anxiety that would prevent him from getting through school or obtaining employment. Josh's parents

envisioned Josh living in their basement for the remainder of their lives.

Josh went to the doctor and was diagnosed with generalized anxiety disorder and depression. Getting these diagnoses gave Josh a better understanding of himself and the challenges he had been facing. It also helped him realize that he needed some additional support to overcome these challenges and be successful in college. Josh's parents offered to support him financially for one more attempt at college, but warned that if he continued the pattern of disappearing when the semester got tough that they would no longer help him with tuition.

It was at this time that Josh decided to join the "Opportunities for Postsecondary Success" program, or OPS – a program designed to provide individualized support services for students with intellectual disabilities, including those on the autism spectrum. Finding a program that helped Josh focus on developing his self-advocacy and self-determination skills allowed him to feel like he would be able to achieve his goals.

At the start of Josh's third semester at the community college, he sat down with his parents, Disability Support Counselor and his OPS Transition Coordinator to determine how this semester would be different from the last two. One difference was that Josh would be connected to a student mentor who would provide him with guidance and encouragement. The other difference was that Josh committed to working towards two very specific goals that were designed to keep him in close contact with his support team on campus, particularly when the semester became overwhelming.

The change in Josh is extraordinary. Josh did more than just make it through the semester; he achieved the goals that kept him connected to his support group, and when the semester got tough he used the resources on campus to keep him going. Josh has now completed two successful semesters where he earned A's and B's, and he has started his third semester.

Josh also started working on other skills that allowed him to become more independent. He began managing his own personal budget and started answering his cell phone and responding to email regularly – things he had never done in the past. At the end of the summer Josh moved out of his parents' basement and into an apartment with two of his friends – an accomplishment that his parents originally feared might not have been possible for him. He continues to attend classes, turn in his assignments and earn A's and B's. He is making progress towards completing his Associate Degree and plans to transfer from the community college to a university upon completion of this program. Josh has also started training for a job where he will be selling Cutco knives.

If you talk to Josh about the change he has seen in his own life over the last year, he will tell you that the biggest difference is that he now believes he can accomplish anything. Josh knows that he will continue to face challenges in life, but he is better equipped to handle these challenges now that he has become a strong self-advocate. Josh's success in school has helped to transform his life, giving him the confidence and self-determination to work towards and achieve his dreams and aspirations. One day when Josh achieves his goal of becoming a history professor, he hopes to help other students gain the confidence needed to achieve their own goals.

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*Erica Schelly is a Transition Coordinator at the Center for Community Partnerships at Colorado State University. She works on a project called Opportunities for Postsecondary Success which supports Community College and University students on the Autism Spectrum and students with Traumatic Brain Injury as they transition into higher education. The project provides individualized support that goes above and beyond academic accommodations in order to help students reach their educational and life goals.*



# Social Skills Support Self-Determination: My Story

Will Farris, with Cindi May and Gail Farris

My name is Will Farris and I am a junior at the College of Charleston in the Realizing Educational and Career Hopes (REACH) Program. Going to college is something I have wanted to do for a very long time. Some people ask me why I wanted to go to college, and for me that answer was easy—I want to have a job, have a life, and have friends. At the College of Charleston, I have lots of friends—some of them have disabilities and some don't. I have taken more than 10 different classes, have had the chance to experience lots of jobs, and have tried to figure out what I want to do. I have also learned about my disability, how to explain it to others, and how to rely on my strengths.

It was not always easy for me. I have Asperger's and I learn differently. In the past I had trouble making friends. I used to talk too much or too long and I didn't know how to take turns or listen to other people. Now, I want to share how I have changed in college, how I was able to reach my goals, and how I think college can help other people with disabilities. I want to be the one encouraging others and helping them understand what they can do.

What helps me at the College of Charleston? The main thing is taking regular college classes. These have included Intro to Business, Public Speaking, Psychology, Digital Media, Graphic Novel, and Intro to Education. I study hard in each of my classes. I really like the projects, as they give me a chance to get out and use what I know, and to work with other students. But the class that made the biggest difference for me was an Interpersonal Communication class with Dr. Deb McGee. Dr. McGee explained and broke down the various parts of communication, so that I could better understand body language and facial expressions. I learned how to stay on one topic when I speak with other people. Dr. Deb also helped me understand people from different backgrounds so that I could do well in lots of different situations. For



Will Farris on campus at the College of Charleston.

example, I have one friend who likes me to get to the point right away; he does not like long-winded conversations or much detail. When I talk with him, I try to keep it simple and straightforward.

Before college, I had learned some communication strategies, like counting to 10 before speaking and letting others take turns leading the conversation. But in college I could put all of those skills into practice and use them in real social situations. When I am in class, I know when to let other people talk. I don't hog the conversation or take over the whole class. Now I try to listen to others and absorb the information they are sharing, and then decide when it's my turn to speak. Communication is like music. The bottom line is that you are the producer, and no matter what you are producing—a paper, a presentation, a test—it is your work of art. It must represent what you want to communicate but it also must make sense to those who receive it. If a professor is receiving it,

then it must also be of excellent quality. Our professors challenge us to make great art in our communication.

With more confidence in my communication skills, I decided to pledge a fraternity—Alpha Kappa Psi, a business fraternity. While I was pledging I had to learn information about the founder of the fraternity. I also learned how to “sell myself in an elevator”—that is, to describe myself succinctly and clearly like you would if you were introducing yourself to someone and only had a few moments to do so. I learned how to explain my strengths and goals in a very short period of time and to let other people know who I am and what I want to do. I also learned to cut to the chase, not ramble on. I now know how to listen to people and take feedback from others without being so hard on myself.

Another thing I have learned that it is very important is to understand the person you are talking to. For example, I have one friend who really likes to joke around. I am more serious and direct most of the



time. I had to learn that I shouldn't always take everything he says so seriously. He often uses sarcasm and at first it was hard to know when he was being sarcastic. I have also learned how to let him know when the joking and sarcasm have gone too far without hurting his feelings.

Before college, my friends were mostly my family. The other students at school didn't seem to "get" me and sometimes were mean to me. I had more trouble with my emotions and making friends. I didn't know how to rely on my strengths. I didn't want a label. I didn't want to be pinned down by my disability. Now I have learned to talk about my disability and to use my strengths to express myself. I am very comfortable with myself. The students here seem to recognize my differences but are accepting of them.

My new communication skills have also helped me professionally. At work, I try to stay on point and keep conversations relevant. I have had several paid internships at the College

of Charleston. I have worked in the Admissions Office and in the "Charleston 40," a group of students who get to give tours to students who might want to come to the college. I recently got the position of Clyde the Cougar (our mascot) and I get to be the Cougar at lots of sporting events. I also worked at the YWCA and helped coordinate an event for Martin Luther King Day. Last semester I worked in the public relations department of a hospital, and this semester I will work for a non-profit.

When I came to college I thought I wanted to be a teacher, but as I explored that option I realized I was not going to earn all the credentials needed to teach in the public schools. I talked with different people on campus to explore career options that fit with my personal interests and abilities. I considered a variety of careers including business, but now that I am in the final stretch of my college education, I have decided on Communications as my major. It helps me

with interpersonal stuff, understanding myself, and growing professionally. I really want to help other people who have Asperger's and I know I can. I definitely want to assist others who want to go on to college. And someday I want to be able to help my own children understand the world and do their best.

*Cindi May is a Professor of Psychology at the College of Charleston, and is Project Director for the TPSID Grant awarded to the REACH Program.*

*One goal of her research is to develop strategies and interventions that will optimize functioning for older adults and individuals with intellectual disabilities.*

*Will Farrow is a junior at the College of Charleston. His overall goal at the College is to help others view all types of students with disabilities as equals. By doing that, he is helping his peers break out of their shells and succeed.*

*Gail Farrow is Will Farrow's mother, and a strong advocate for people with disabilities.*

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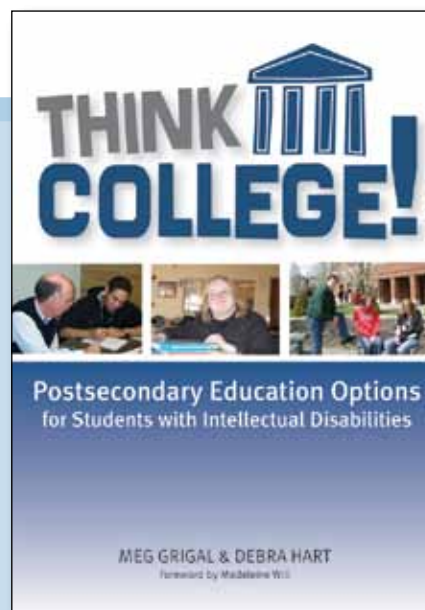
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