Equity, Opportunity and Inclusion for People with Disabilities since 1975

Volume 42 ◆ Issue 2 ◆ Summer 2017

# Post-Secondary Education and Self-Advocacy





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# Portland, OR November 28 - 30

# Sille The Dive

Each year, the TASH Conference brings together a diverse community of stake-holders who gain information, learn about resources, and connect with others across the country to strengthen the disability field. This year's conference theme, "Be Creative - Innovative Solutions for an Inclusive Life," reminds us to think outside the box during times of uncertainty. Creativity, innovation, and determination can pave the way for meaningful and inclusive lives for people with disabilities.

Call for Proposals Deadline: Tuesday, June 5, 2018
Early-Bird Registration Deadline: Tuesday, September 4, 2018



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### **Letter from the President of the Board of Directors**

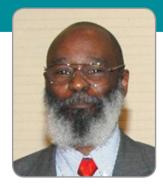
The hullabaloo of contemporary political discussions and the debilitating, too frequent tragedies we share can overshadow the "wonder" and "fullness" of being alive now, right now. We have access to information and individuals that Aristotle, Descartes, and Dubois would envy. Our present technologies are akin to mastering fire. Their potentials are far beyond our imagination.

Our appreciation and valuing of human beings, though challenged, is at an apex in human development. We are developing education strategies and technologies to reveal and maximize the talents and abilities of each person, and across the life span. Many are coming to accept that we are wiser and enriched when everyone's input is included.

Inclusion is not a TASH invention. However, TASH has been a pioneer in modeling, researching and advocating inclusion as an ethical standard and effective policy. In this issue of Connections, self-advocates describe their experiences and the challenges of participating in post-secondary education. While contributing to the enrichment of their lives, inclusion in college classes and activities enables other students to develop the rapport, cultural and social skills, and understanding of constructive interactions with diverse communities. And, our society benefits from the potential intellectual, cultural and technical contributions of advocates.

As you can imagine, this level of inclusion is frequently challenged, derided, and denigrated. TASH "inspired"

and supported research is essential to provide "a breadth of qualitative data demonstrating the power of post-secondary education for students with disabilities" and other community members. Our vigilance, advocacy and research



Ralph Edwards, President

can educate policy-makers and funders. Education of state and national legislators may limit the reduction of federal funding by individuals with low expectations and imperceptive viewpoints.

We must always be at the forefront of education and advocacy! Read these articles and be inspired to provide these opportunities for all. Support TASH with financial and intellectual contribution. Enroll a new member; share TASH! Join (or start) a chapter! Collaborate with local groups to promote and sustain TASH valued change!

Next month in Atlanta!

Ralph W. Edwards, President TASH Board of Directors

| Lalph W. Edwards

### **Letter from the Executive Director**

Equity, Opportunity and Inclusion for People with Disabilities--this issue on postsecondary education for students with disabilities highlights all the values expressed in TASH's tag line! This issue focuses on self-advocacy in higher education. As such, it captures the voices of students who have been part of a burgeoning movement that has expanded the transition of young adults beyond at best, challenging efforts to find employment or more frequently, sitting at home with little to do.

The opportunity to attend college is a growing movement toward the full inclusion of students with intellectual and developmental disabilities. And, as Jessica Bacon, Danielle Cowley, and Beth Myers, the guest editors of this edition note, it is a growing movement worldwide. In the United States alone, 48 campuses are currently receiving or working with Transition and Postsecondary Programs for Students with Intellectual Disability (TPSID) grantees. These programs are leading the way for students with I/DD to be fully included in all aspects of college life.

This issue highlights those experiences and provides us first hand with a rich diversity of students'

expressions of how postsecondary opportunities are informing their own life experiences as well as those of their fellow students and faculty. The thoughtful editing and presentation of their voices gives all of us a unique glimpse of



Ruthie-Marie Beckwith, Ph.D., Executive Director

what these opportunities offer today and the promise these programs have in cultivating future leaders with disabilities around the world. With opportunity and inclusion comes equity.

As Justin Dart was known to say, Lead On! Lead on, self-advocates; you have a lot to share and we have a lot to learn from their insightful reflections on their experiences.



# Introduction

# **Engaging with Higher Education: An Introduction to the Post-Secondary Education Issue**

Jessica K. Bacon, Guest Editor, Montclair State University, Montclair, NJ
Danielle M. Cowley, Guest Editor, University of Northern Iowa, Cedar Falls, IA
Beth A. Myers, Guest Editor, Syracuse University, Syracuse, NY

his issue of TASH Connections highlights the voices of self-advocates, sometimes alongside their friends and colleagues, who share their stories of attending college across the world. Over the past several years, post-secondary education has become an increasingly viable option for students labeled with intellectual or developmental disabilities. The opportunities provided by inclusive college programming are numerous and growing. As Causton-Theoharis, Ashby, and DeClouette (2009) note, "intellectual stimulation, emotional growth, academic gains, an expanded social network, increased selfconfidence, and independence are just some of the aspects that many college students enjoy" (p. 88).

With the positive outcomes of post-secondary education in mind, the guest editors invited contributions that document college-going experiences through mediums such as writing, pictures, videos, digital stories, poetry, and artwork. We wanted to highlight the diversity that is post-secondary education while honoring the many ways in which stories are shared. Our principle of honoring the voices of these college students first began to unfold through our review process. We were struck, not only by the varied media formats that each author used (traditional academic writing, essays, poetry, paintings, FaceBook discussion posts, photo essays, journal entries, and interviews), but also by the range



Jessica K. Bacon



Danielle M. Cowley



Beth A. Myers

### Introduction

### Engaging with Higher Education: An Introduction to the Post-Secondary Education Issue

of college experiences shared. For many students, college is a time for autonomy, identity development, advocacy, and freedom. Therefore, when reviewing each piece we paid close attention to the authors' choices regarding formatting, media, language, style, etc. Through the editing process, we worked closely with the authors to ensure that their voice and the intent of their work remained intact. Hence, readers may notice some irregularities in formatting, language, etc. Please note that these are not actually irregularities, but active, intentional choices made by the authors together with the guest editors.

Gísli Björnsson and Ragnar Smárason begin this issue through a photo essay about their college experiences at the University of Iceland, and how those experiences led them down a path toward activism. Through 17 photos of their academic and social worlds, the authors provide a holistic narrative of what college meant to them: time spent in the classroom, campus employment, fundraising, friendship, and activism. Björnsson and Smárason highlight their roles as advocates and activists in the realms of disability studies conferences, "guerilla artists," pride parades, and legislative meetings with staff from the Office of Human Rights, the President of Iceland, and the United Nations. The photo essay represents just one unique trajectory that can be taken through inclusive experiences in higher education.

Next, Theresa Clark, Josh Howard, and Ashley Taylor share with us a collaborative collage between two college students and their professor. Former students of Otesgo Academy at Pathfinder Village (a post-secondary program for individuals labeled with intellectual disability), Clark and Howard enrolled in an 8-week course taught by Taylor at Colgate University, titled "Disability, Difference, and Inclusion." Alongside three other students from Otesgo Academy and eight students from Colgate, Clark and Howard explored the following questions: Who is a citizen? What is the relationship between adulthood and citizenship? How are disability rights citizenship rights? How do we support each other to be citizens? Through in-person interviews, email correspondence, autoethnographic vignettes, and course artifacts, the authors provide us with a glimpse into one inclusive college course and their collaborative, culminating social action project.

The multi-media piece by Cleo Hamilton, with Katherine Vroman and Beth Myers provides a glimpse into the experience of one first-year student at Syracuse University's Inclusive U. Cleo Hamilton's college experiences "speak for themselves" through a series of unedited FaceBook posts from his personal

page. Hamilton's narrative updates, photos, videos, and online interactions show a college life of friendships and extra-curricular activities alongside coursework. Hamilton's cultivated social media representations are reflections of an authentic college student, where posts such as "I'm staying focused on my class at Syracuse University campus #syracuseuniversity #orangenation #chesterphx (Selfie looking serious into the camera)," shape the meaning of a truly inclusive experience.

Miss Kaye<sup>1</sup>, alongside Cara Levine, shares poetry across the span of her writing career – some 20 years old, others written just a few months ago. Like Cleo Hamilton, Miss Kaye is a student at Syracuse University's Inclusive U. She begins with her very first poem, "The Night I caught my Train" written when she was in the 6th grade.

"And while I was staring at this incredible sight, the most terrific sound, in the distance rung..."

The beauty of Miss Kaye's poem cannot be understated, however, she also brings to the reader's attention her intentionality with spelling, grammar, and language. She notes, for example, how she incorrectly spelled "cemetery" with an s, changed it once, and then went back — "semetary" it would be. The body of Miss Kaye's work spans the topics (and poetic devices) of inspirational people in her life, the apropos of spelling and grammar errors, color, empathy in loss, detail, and relationships.

In "Connecting Through Art," Matti Poole, a third-year student of UI REACH at the University of Iowa, shares three paintings that she created during her time with the BIG 10's first inclusive post-secondary education program. Poole explains how, through the arts, she was able to communicate, express herself, connect with others, and find her voice. Painting is her preferred medium, and through pieces such as "I CAN'T HEAR YOU" and "UI REACH" she captures her own identity as a college student with a hearing impairment, as well as the friends and colleagues who have inspired her. We also feature Poole's award winning self-portrait titled, "Myself," which resides in the U.S. Department of Education office in Ohio. As guest editors, we first noticed Poole's paintings in another submission (see Rila and Kaldenberg, below) and inquired if she would like to have additional paintings of hers highlighted in this special issue. We were thrilled, as we know the

<sup>&</sup>lt;sup>1</sup> Pseudonym

### Introduction

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readers will be, that she agreed.

Next, Ashley Rila and Erica Kaldenberg expand upon Poole's experiences at UI REACH. The program is in its ninth year and has officially been recognized as a Comprehensive Transition Program, where students are able to apply for financial, need-based grants. The authors share the stories of personal growth of several students labeled intellectually disabled. Rila and Kaldenberg discuss the various systems and structures of this inclusive post-secondary program while focusing on opportunities for self-advocacy and self-determination experienced by students Matti, Ellie, Justin, and Greg. Like Cleo Hamilton's experiences at Syracuse University, these student narratives demonstrate that higher education is more than coursework. Connectedness to peers is an essential component to an inclusive college experience.

"The Muse of Love" by John Smyth, we offer just one example of the academic work done by students with disabilities in higher education. Smyth shares with us a story of exclusion and segregation during his P-12 school years, "languishing" in a life skills classroom, but follows with the true power of "presuming competence." Once Smyth was provided with an inclusive and truly educational opportunity — at Marian University — he excelled. Smyth's touching essay on love is a visceral piece of writing where both senses and emotions are "felt" running across the page.

Closing out this special issue with their photo essay, Patricia Walsh and Antonio Reyes also describe an example of an inclusive transition experience set on a college campus: The Increasing Access to College (IAC) Project housed at Montclair State University. High school student Reyes works with undergraduate student Walsh to provide readers with a multi-faceted look into this inclusive college program. They begin by discussing one challenging (for them both) course they took together emphasizing visual storytelling. The students explored new apps and technologies and with the support of each other and their peers, honed their media and journalism skills. Through photos and vignettes, Reyes and Walsh highlight the coursework, recreational activities, sporting events, and other campus amenities used by IAC students. Both students name positive peer support, relationships, and a welcoming community as keys to a memorable college experience.

Collectively, this issue leaves readers with a breadth of qualitative data demonstrating the power of post-secondary education for students with disabilities. There is no denying the academic skill and competence brought forth by each of the student-authors and participants in these pieces. Higher education was and is a diverse, memorable, and meaningful time for each of them. Their voices and perspectives remind us that post-secondary education must be discussed as a viable option for any interested student. Keeping in mind the mission of TASH, to promote the full inclusion and participation of children and adults with significant disabilities in every aspect of their community, we must remember that full inclusion includes higher education and the college campus is an aspect of their community.

### References

Causton-Theoharis, J., Ashby, C., & DeClouette, N. (2009). Relentless optimism: Inclusive postsecondary opportunities for students with significant disabilities. Journal of Postsecondary Education and Disability, 47(2), 88-105.

### A Journey from College to Activism

By Gísli Björnsson and Ragnar Smárason

Diploma Program for People with Intellectual Disabilities at the University of Iceland in spring 2013. The vocational diploma is a part-time inclusive, but non-credit bearing two-year program with the aim to prepare students for specific jobs within the field of education, in preprimary schools, after-school clubs, and within the field of disability and self-advocacy (occupations in which the School of Education provides training). Our job training included working in an after-school club, library, and setting up our own coffee shop in downtown Reykjavík.

Our essay includes 17 pictures from our academic and social participation during our studies at the university. In January 2016, we were hired by the University of Iceland to work on the research project *Equality for All*! The aim of the project is to explore the ideas of men labeled as having intellectual disabilities regarding equality, with a special focus on gender equality. We will provide pictures from our participation in national and international academic conferences and our workplace.

In the summer of 2016 we took on the role of guerilla artists, i.e. designed posters and artwork on the issue of equality and displayed them in public places in Reykjavík. Our essay includes photos of our guerilla art and our participation in advocacy, e.g. from a meeting with the president of Iceland, Guðni Th. Jóhannesson, our participation in Reykjavík Pride 2016 where we distributed postcards with statements on equal rights, and meetings with politicians before last year's elections .

The photo essay is narrative, i.e. a collection of photographs that tell a story of our journey from college students to advocates and researchers, and includes 17 photographs.

### A Journey from College to Activism



# 2017: Ragnar and Gísli in front of the University of Iceland, main building.

We graduated from an inclusive diploma program for people with intellectual disabilities at the University of Iceland in spring 2013. Three years later we were hired as project managers for the research project Equality for All!



### 2011-2013: Ragnar and Gísli in class.

During their studies, Ragnar and Gísli completed various courses which were inclusive, i.e. the courses were also offered to other undergraduates at the University of Iceland.



### 2012: Ragnar conducting bingo for fundraising.

Ragnar and Gísli actively participated in various social activities as students at the University of Iceland. Participation in social events is important for the sense of belonging to the college community.



# 2013: Gísli working at Café GÆS (acronym for "I can, I will, I shall").

During their studies at the university, Gísli and Ragnar were required to complete a work placement. Ragnar worked at a library and Gísli worked at an after school club and was one of the founders of a café in downtown Reykjavík, organized and operated by students from the diploma program.

### A Journey from College to Activism



# 2013: The class of 2013 on a graduation trip to Manchester, England.

During their trip, the class of 2013 visited colleges and self advocacy organizations in Manchester, England.



### 2016: Ambassadors for the UN's CRPD.

Gísli is part of a group advocating for the CRPD and regularly gives presentations regarding human rights and disability issues in upper secondary schools, for college students, and municipalities.

### **COURAGE**

### **EQUALITY**



### 2016: Guerilla project downtown Reykjavík, Iceland.

In the summer of 2016 we took on the role of guerilla artists, i.e. designed posters and artwork on the issue of equality and displayed them in public places in Reykjavík. The aim was to disturb the existing social order by asking pedestrians to stop and reflect on their society. Who are welcome, who have access, and what is equality?

### A Journey from College to Activism



# 2016: Ragnar, Harpa (PA), and Gísli getting ready for Reykjavík Pride.

Gísli and Ragnar handed out postcards with equality messages at Reykjavík Pride 2016. The parade is a safe space for different voices, where everybody is different and everybody is the same.



# 2016: Gísli, Katrín (PA), and Ragnar giving a presentation at a national disability studies conference.

Gísli and Ragnar have participated in numerous international and national conferences on the issues of disability and human rights. Conferences are often inaccessible for people with intellectual disabilities. Buildings are inaccessible, language is inaccessible, conference fees are expensive, etc.



**2016: Disability Studies Conference in Lancaster, England.** 

After giving our presentation at the conference we had some spare time to explore the historical city of Lancaster. International conferences are important to us, not only to meet other activists, but also as an opportunity to travel and enjoy life.



**2016: The University of Icleand's Faculty and Staff Annual Ball.** 

Ragnar and Gísli know how to party and find socializing with coworkers an important part of being employed.

### A Journey from College to Activism



# 2017: Disturbing Existence Conference, Reykjavík Iceland. Gísli, Lydia X. Z. Brown, and Ragnar.

Gísli and Ragnar took part in a conference/grassroots festival. The keynote speaker was Lydia X. Z. Brown, a gender/queer and transracially/transnationally adopted east asian autistic activist, writer, and speaker whose work has largely focused on violence against multiply-marginalized disabled people, especially institutionalization, incarceration, and policing.



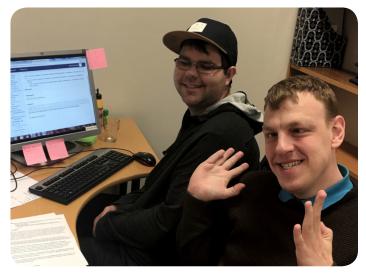
2017: Guðni Th. Jóhannesson, the President of Iceland and Ragnar.

The newly inaugurated President of Iceland invited a group of self advocates for a short meeting and a discussion on disability rights.



2017: Kristín (coworker), Silja (PA), Gísli, and Ragnar lecturing at the University of Iceland.

Part of Gísli and Ragnar's job description is giving lectures at undergraduate and graduate levels. The lecture topics include research findings from the Equality for All project, disability rights, human rights, guerilla art, and activism.



2017: Ragnar and Gísli at the office.

Ragnar and Gísli share an office on campus and some days are spent sitting by the desk working on more mundane tasks.

### A Journey from College to Activism



# 2017: Steinunn Ása Þorvaldsdóttir, Office of Human Rights at the City of Reykjavík, being interviewd by Ragnar and Gísli.

Gísli and Ragnar have been working on photo essays on the topic of equal opportunities for paid work. They interviewed disabled people working in the open labor market. The photo essay was presented on their Facebook page https://www.facebook.com/jafnrettifyriralla/.



### 2017: Gísli working at the University of Iceland.

At the start of 2017, Gísli received additional work duties at the University of Iceland. In addition to working on the Equality for All research project, he now also delivers mail inside the university building, prepares coffee and snacks for board meetings, and is in charge of purchasing groceries. Ragnar is hoping to get a job at the University Library.

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# Citizens of Higher Education: An Inclusive College Course on Disability Rights, Self-Advocacy, and Citizenship

By Theresa Clark, Josh Howard, and Ashley Taylor

ho is a citizen? What is the relationship between adulthood and citizenship? How are disability rights citizenship rights? How do we support each other to be citizens? These are some of the questions explored during an 8-week long collaborative course at Colgate University, first offered during fall 2015. Disability, Difference and Inclusion brought together Colgate University undergraduates with students from Otsego Academy at Pathfinder Village, a postsecondary program for individuals labeled with intellectual disabilities. Five students from Otsego Academy joined eight students from Colgate University, all of them majors or minors in the Department of Educational Studies, meeting twice weekly on Colgate's campus.

The course focused on disability rights and citizenship, looking closely at subjects such as the meaning of adulthood, independence and interdependence, supported decision-making, civic friendship, ally-ship, and the social meaning of ability differences more broadly. The intention of the course was to create an opportunity for labeled and non-labeled students to learn together about disabled people's social movements and the philosophies of inclusion that come out of that movement. Through a variety of activities and assignments, students were encouraged to collaboratively construct their own meanings and interpretations of citizenship in light of ability differences.

This article will provide a glimpse of this college project of aspirational inclusion. It is written as a collaborative collage among Theresa Clark (shared in person), Josh Howard (shared by email), and Ashley Taylor (shared in person and by email). Theresa and Josh are former Otsego Academy students who graduated in Spring 2016 and who participated in Disability, Difference, and Inclusion. Ashley is a faculty member in the Department of Educational Studies at Colgate University and primary instructor for the course. We hope to offer some insight into the experiences and products generated through our class meetings and beyond.

### **Inclusive Higher Education**

Ashley: Universities and colleges across the United States offer few opportunities for individuals labeled with intellectual disabilities to participate in meaningful ways in the academic and social life of higher education. While what constitutes meaningful engagement will differ according to the desires, needs, and abilities of individual students, disability advocates and scholars of disability studies in education emphasize the importance of creating opportunities for labeled individuals to participate as respected peers in the regular activities of a community. Like many of my colleagues, I interpret this to mean, among other things, that students with intellectual disability labels should have opportunities to learn and participate in college-level academic coursework and have access to informal social opportunities on and off campus. Colgate University, where I work, offers no institutionalized program, project or pathway for students with intellectual disability labels to pursue coursework across campus or to complete regular or alternative degrees. However, because of the community connections that faculty and staff at Colgate have worked hard to build and sustain, many opportunities do exist to generate meaningful academic engagement among Colgate university undergraduates and students at partner organizations

Citizens of Higher Education: An Inclusive College Course on Disability Rights, Self-Advocacy, and Citizenship

like Otsego Academy at Pathfinder Village. As a new faculty member at Colgate, I took full advantage of these connections and the support of colleagues to build a course designed to offer one opportunity for meaningful inclusive academic learning and engagement.

My partner organization, Otsego Academy, is a two-year post-secondary program, "where students with intellectual disabilities can embrace love of learning on their path to independence, adulthood, and meaningful employment" (www.otsegoacademy. org). The program is aimed at job readiness training and fostering independent living skills. Students who attend Otsego Academy live in residence at Pathfinder Village, a village community offering educational, employment, and residential living opportunities for individuals with Down syndrome and other developmental disabilities. With the help and support of partners at Otsego Academy, I was able to design a course that provided Otsego students opportunities to pursue academic coursework at Colgate, while offering Colgate students the opportunity to learn more about Pathfinder and its programs.

Josh: Those are the only 2 things I really enjoy doing while being at Pathfinder Village's Otsego Academy, to be in at Colgate learning new experiences, [taught] by Ashley and also to work at the Pathfinder Village's Produce Market. The reasons are very hard to explain but I guess I can say is getting out of the house of Otsego Academy was very easy to do. My Otsego Academy Staff helped me out, a lot they are very nice people to be with. I apologize for not saying any names because of there are too many RA friends that were and still are part of that program.

# **EDUC 332: Disability, Difference, and Inclusion**

Josh: Oh yes I sure do remember being at Colgate University and I sure do remember going there for the first time with my friends walking into class with me. I differently have to say that the self-advocacy is my favorite class because I speak highly on that term, all the stuff that I had to learn mostly comes from the heart and my brain picks up the message then I just type it down either on my laptop or iPad. I have to admit I didn't like my second year at Otsego Academy very much, yes we did some fun stuff like going to Colgate University and learning on self-advocacy from Prof. Ashley Taylor, also working at the produce market was really fun working and learning on the job. That was pretty much it right there. At Colgate I learned on being a better teammate and working with very good friends, they also learned speaking up is

Very good for the soul and I completely agree on that.

Ashley: Most of our class meetings took place on Colgate University's campus, with one mid-semester visit to Pathfinder Village to hold class on their campus. The course was broken into four topical areas, followed by a student-driven social action group project. Topics and readings were all related to broader themes of citizenship and inclusion, including Supportive learning, Civic friendship, Self-Determination, and Self-Advocacy. Readings were selected to highlight the work of labeled individuals, and included Daniel Docherty and co-authors' "This is What We Think" (2005), Mike Kennedy's "Self-Determination and Trust" (1996), excerpts from the Jenny Hatch Justice Project's online resources in supported decision-making, and Simone Aspis' "Self-Advocacy: Vested Interests and Misunderstandings" (2002). These readings were complimented by work from the fields of Disability Studies and Disability Studies in Education, including Amy Petersen's "Shana's Story: The struggles, quandaries and pitfalls surrounding self-determination" (2009), Scot Danforth's "Friendship in the Classroom" from Becoming a Great Inclusive Educator (2014), David W. Leake's "Self-Determination Requires Social Capital, Not Just Skills and Knowledge" (2014), and excerpts from Fred Pelka's What We Have Done: An Oral History of the Disability Rights Movement (2012). We had film viewings of Rachel Is (2009) and Monica and David (2009) and followed these up with discussions, focusing on some of the questions these films raised about contemporary citizenship and social rights of persons labeled with intellectual disabilities.

Most class periods were semi-structured and activities-based. Typically, I offered students a brief overview of the topic, employing principles of inclusive practice to maximize student comprehension and engagement and offer multiple means of access, engagement, and expression (Baglieri & Shapiro 2012; Valle & Connor 2011). These mini lectures were followed by discussions focused informally on the readings for that day. Students then participated in a number of small or full group activities, paired discussions, or individual artistic or written reflection. In preparation for this collaborative course, Colgateenrolled students completed coursework in foundational ideas in disability studies and inclusive education. The principle of "presuming competence" (Biklen & Burke 2006) was a driving force behind the course design and practice, and was apparent in students' engagement with one another.

Ashley: What did you like about class?

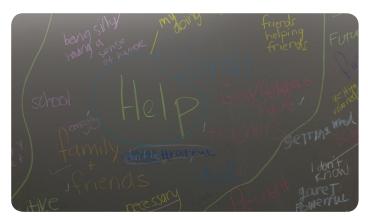
**Theresa:** I liked the circle. We could talk together as adults.

Citizens of Higher Education: An Inclusive College Course on Disability Rights, Self-Advocacy, and Citizenship

### **Critical Perspectives on Self-Determination**

Wednesday October 28: What is Self-Determination?

Activity: Help. Support. Guardianship. Independence. What words do you associate with these?









# Wednesday November 4: Practicing Self-Determination (or What it is, What it's Not) Reflection Activity: What does self-determination look like for you?

Do you think Jenny is being supported to be self-determined? What part of her story do you find important/interesting? Why?

How do we make sure that a person's rights are not taken away like my rights were? Who will make sure that no one has to go through what I went through? Who will make sure that the CSB [Community Services Board] and JFR will do the right thing? Just because a person has a disability does not mean they need a guardian. Many times they just need support and need help.

— Jenny Hatch, Jenny Hatch Justice Project, "Introduction to Supported Decision-Making" (2014)

Do you think Shana is being supported to be a citizen? Why or why not?

Yet as I listened to Shana share her story, I realized that while

she had received a "life skills" curriculum centered on teaching the perceived skills needed to live and work independently, her experiences did not entirely resemble self determination as a democratic ethos. Although the legal requirements had been met, I was less certain that Shana had been afforded and supported in opportunities to exert authority, autonomy or responsibility over her life. There appeared to be a disjuncture between the skills Shana learned and the opportunities she had to use the skills in a manner that would support self determination as a democratic outcome. The most striking example of this disjunction related to Shana signing her name. Shana described many lessons where she was required to practice signing her name over and over; yet, she could not recall being asked to sign her IEP. — Amy J. Peterson, "Shana's Story: The Struggles, Quandaries and Pitfalls Surrounding Self-Determination" (2009)

Citizens of Higher Education: An Inclusive College Course on Disability Rights, Self-Advocacy, and Citizenship

**Theresa:** People should overcome things. Like talk about your feelings, relationships, finding the truth for ourselves. You can meet the little voices inside your head.

**Theresa:** Everybody has a right to a voice.

Ashley: Why?

**Theresa:** Because they are strong people.

Theresa: Always listen to music. Everybody needs to

dance. Get out of your comfort zone.



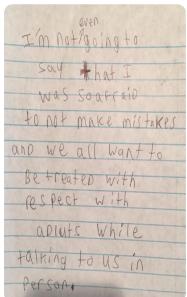
Josh: Mostly I just love being with all of the Colgate Students that helped on doing the projects that we did and also to learn on what self advocate means... To me it means is being a better person and to be a team member/team builder that is leading into the right path of freedom but with help from our teachers, professors and also our families that makes us humans that keeps the earth go round for everyday life.

### Wednesday November 11: What is Self-Advocacy?

I'd like to see the ADA have more teeth, and I'd like to see it define accessibility to help people with cognitive disabilities. Meaning that accessibility doesn't always mean a ramp, it could mean that people need to understand something, because big words are being used. My point being, that you can ask us the same things, but put it in language that we understand. It could be that people need to have signage to find something, because it's hard for them to navigate things. So different things like that. And the accessibility part of the ADA doesn't have that...And I think that it's real important to listen to people, even if they don't use words to communicate. We have to figure out how people communicated, and then it's up to us to figure out what they're saying. — Nancy Ward, Self-Advocate In What We Have Done by Fred Pelka (2012)

# Taking a Social Action: Projects for Change

**Ashley:** The course culminated in a student-driven social action project. The project was very open, requiring only that students work in mixed groups (of Otsego Academy and Colgate students)



to collaborate on a project that enacts change within their community. I told students the following: "Believe it or not, you have already been



involved in a social action project for some time now. In coming together, from Colgate University and Otsego Academy, you have been involved in transforming what it means to learn in a college classroom, what it means to work together across differences, and what it means to enact inclusion in learning and in social spaces. I have seen you support each other, challenge each other, and struggle to think about what it means to share space and learn with and from one another." Students were expected to produce a product that could be shared with the wider Colgate community. Three of the four groups chose to make videos while one group chose to do a campus survey and presentation surrounding the use and meaning of the "R" word on campus. We will highlight two of the films here.

### Speak Up!

https://www.youtube.com/watch?v=GmH\_3NC9ju8

**Ashley:** This film focuses on finding voice, identity, and speaking up with and for people with disabilities. It features students and staff from around Colgate University and Pathfinder Village campuses holding up signs with messages of empowerment and

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voice. In asking "Can you hear me? Try to listen!" the students implore others to respect the rights and voices of those perceived as different, and to pass on that message to others. One of the unique things about this group is that the three students initially struggled in communicating with one another and in deciding upon a topic and medium for their project. The final product was, therefore, a result of a great deal of critical engagement, listening, and struggle on the part of all group participants. As is so often the case, process was as if not more important than the product.

### Inclusion U

https://www.youtube.com/watch?v=blSCMS3Te2o

Ashley: Students in this film chose to emphasize the importance of what they called "Inclusion U," or the project of inclusive higher education. The film focuses on students' strengths and weaknesses, highlighting their individuality as well as their shared struggle with what is clinically labeled adaptive behavior. The highlighting of similarities is expressed in the sentiment "more alike than different" and through the way that the students construct their identities in opposition to stereotypes or negative assumptions (e.g. "I am not basic," "I am not a child"). One of the students discusses his experiences being called a slur in school and challenges others to be kind and to treat all people with respect. This group challenges the notion that people with disabilities are other or less than, and advocates for more opportunities to learn across ability differences in higher education.

### **Going Forward**

**Ashley:** This course represented an impassioned, localized effort to generate meaningful engagement for students with



By Theresa:

and without disability labels in an academic setting in higher education. It is our collective hope that collaborative efforts like these will aid in dismantling the persistent and stubborn barriers that prevent people with intellectual disability labels from participating in higher education.

**Josh:** Thank You for taking your time of reading my article.

Citizens of Higher Education: An Inclusive College Course on Disability Rights, Self-Advocacy, and Citizenship

### References

Aspis, S. (2002). Self advocacy: vested interests and misunderstandings. British Journal of Learning Disabilities, 30(1), 3-7.

Baglieri, S., & Shapiro, A. (2012). Disability studies and the inclusive classroom: Critical practices for creating least restrictive attitudes. New York: Routledge.

Biklen, D., & Burke, J. (2006). Presuming competence. Equity & Excellence in Education, 39(2), 166-175.

Danforth, S. (Ed.). (2014). Becoming a great inclusive educator. Peter Lang.

Docherty, D., Hughes, R., Phillips, P., Corbett, D., Regan, B., Barber, A., & Izzidien, S. (2005). This is what we think. In L. J. Davis (Ed.) Another disability studies reader (pp. 29-49). Taylor & Francis.

Jenny Hatch Justice Project (2014, April 30). Introduction to Supported Decision-Making [Webinar]. In Supported Decision-Making Three-Part Webinar Series. Retrieved from http://jennyhatchjusticeproject.org/043014\_sdm\_webinar.

Kennedy, M. J. (1996). Self-determination and Trust: My experiences and thoughts. In Sands, D. J., & Wehmeyer, M. L. (Eds.), Self-determination across the life span: Independence and choice for people with disabilities (pp. 37-49). Brookes Publishing Company.

Leake, D. (2014). Self-Determination Requires Social Capital, Not Just Skills and Knowledge. Review of Disability Studies: An International Journal, 8(1). Pelka, F. (2012). What we have done: An oral history of the disability rights movement. Univ of Massachusetts Press.

Petersen, A. J. (2009). Shana's story: The struggles, quandaries and pitfalls surrounding self-determination. Disability studies quarterly, 29(2).

Valle, J. W., & Connor, D. J. (2011). Rethinking disability: A disability studies approach to inclusive practices. McGraw-Hill.

# "In my SU life, I am happy" The Social Media Representations of a First-Year Student in Inclusive Higher Education

By Cleo Cornelius Hamilton, with Katherine M.J. Vroman and Beth A. Myers

### Introduction

leo Cornelius Hamilton is a 24-year-old sophomore in the Syracuse University InclusiveU initiative. He grew up in Syracuse, New York. He sings in the Syracuse Community Choir. At SU, Cleo has taken

classes in Religion in Sports and CPR, and he is majoring in sports management. This article is a selected compilation of Cleo's Facebook posts reflecting his experience in his first year of college.

















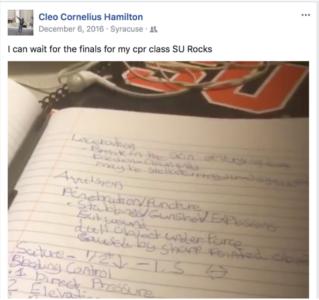




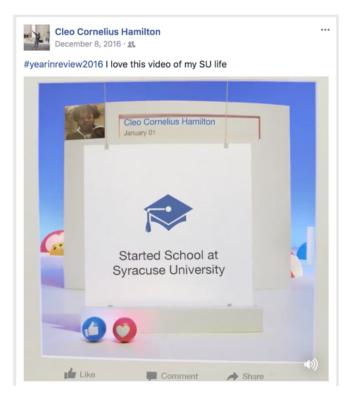


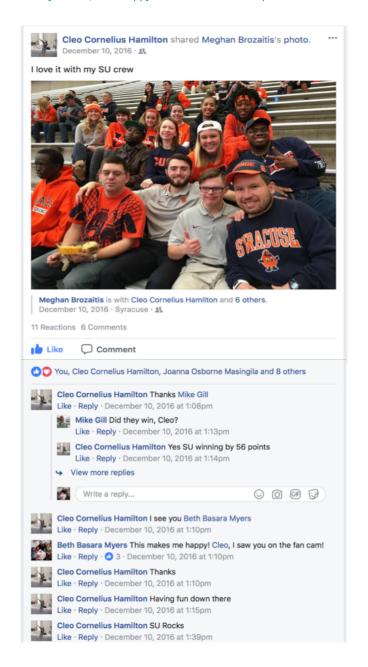


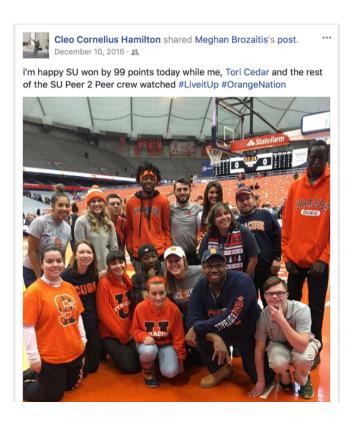














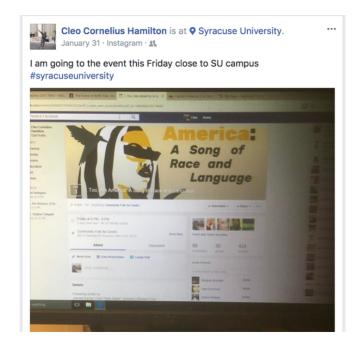










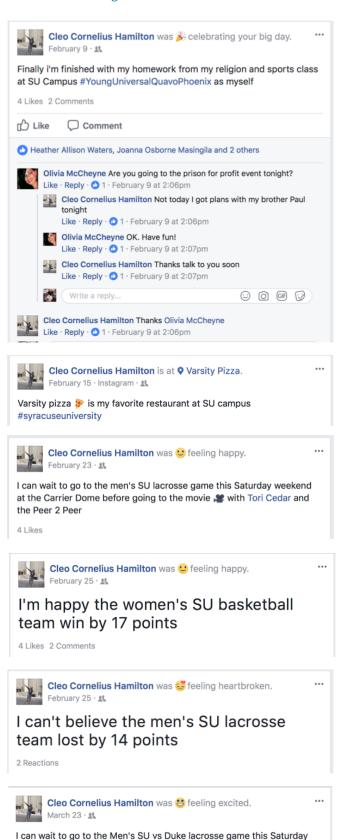


"In my SU life, I am happy" The Social Media Representations of a First-Year Student in Inclusive Higher Education





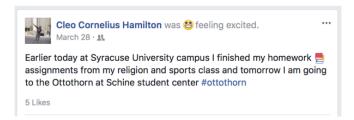




weekend at the Carrier Dome before I go to the InclusiveU board game











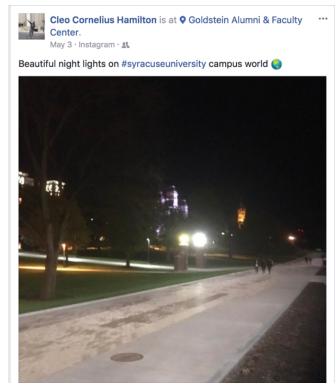


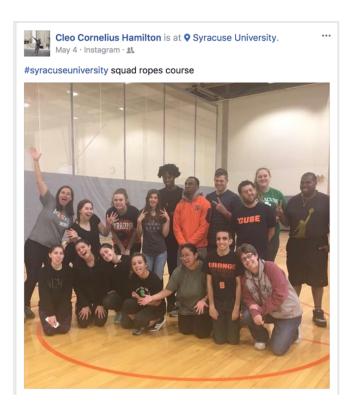


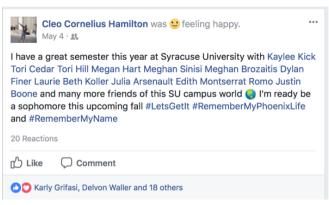




















### **Poetry**

By Miss Kaye with Cara Alexis Levine

iss Kaye is the pseudonym for a 33 year old poet and Syracuse University student in the InclusiveU program.

Addicted to writing and reading, her favorite authors are Henry David Thoreau, Mattie Stepanek, and Shel Silverstein. She has sponsored 14 children from across the globe through Children's International and keeps up with every one of them. Her writing was previously published in UNIQUE, The Art & Literary Journal of ARISE. The poems included in this journal span the course of her writing career, with some over 20 years old, while others were written weeks before submission.

"The Night I caught my Train" is Miss Kaye's first poem, written when she was in the 6th grade. She shares that "I spelled cemetery with an s- I corrected it one time, then I said no, no, I'm just going to leave it" stating that the spelling is unimportant to the meaning of her work.

### The Night I caught my Train

9/11/96

When I went down to the semetary on a cool summer night, I looked over the trees and on top of the hills, with towers, and lights, and there was a beautiful sunset that night. And while I was staring at this incredible sight, the most terrific sound, in the distance rung. It was a train whistle with the greatest sunset and towers and lights on top of the hills and over the trees I stood, I stood in the semetary at night, the night I caught my train.

Miss Kaye wrote this poem after learning that her longtime friend and former elementary school teacher was retiring. Her inspiration to write poetry often stems from individuals or characters who have touched her life. As illustrated below, Ray taught Miss Kaye to love writing.

### **My Friend Ray**

5-5-09

Ray was my teacher Many years ago. He taught me to Love writing.

With an assignment
I wasn't looking
forward to,
and a brand new
PaperCutter- edition composition book.
Yet with one story
I was hooked
For life.

Though we've both grown older, and God willing older still,
My teacher, my mentor,
My friend Ray,
Will always be young
In my heart.

Dedicated to my teacher and friend since September of 1992, Raymond C. Fuller, Jr.

Authenticity is a commanding force in both the construction and presentation of Miss Kaye's poetry. She is intentional about preserving her voice, and does not correct or edit her spelling or grammar, as illustrated in "The Poet's Delema." Miss Kaye is adamant that she does not include the errors as a gimmick or to "play dumb", but because she finds them apropos.

**Poetry** 

### A Writer's Delema

6/19/14

Like a painter Who is colorblind,

I'm a writer who cannot spell.

Like a commentator Who cannot speak,

Grammar is all frustration to me.

Like the chef who cannot smell,

Punctuation is all guesswork to me.

Miss Kaye was given an assignment to write about a color in her 8th grade writing class. While she initially disliked this assignment, she soon found herself activated and enthralled. This experience helped her to find her poetic voice and she continues to write poems about color.

### **The Senses of Purple**

2/2/98

Lonliness is purple
It sounds like the hollowness
of the tinman's chest.
It feels like the ache of loss.
It smells like the thick air
of a jungle.
It tastes like the cold sting
of ice.
Purple is all around me.

### **Senses of Blue**

6/5/17

Reflectiveness is blue
It sounds like the ocean spray hitting the rocks on the shore.
It feels like standing under a waterfall in the summer.
It smells like the first mist of spring
It tastes like blueberries
Blue is soothing.

Many of Miss Kaye's poems communicate empathy to those who have experienced grief in loss. She wrote a "A little something from the heart" to encourage couples who have lost children to stay together. "Hurting" explores her personal experiences wrestling with the contradictions and confusions surrounding grief and suicide.

### A little something from the Heart

5/20/08

I don't believe that you Should lose your best friend even if you've lost something you created together.

The last thing you should do is turn away from each other, but towards each other for comfort.

For only the two of you knows how the other feels.

Only my opinion.

#### **Poetry**

### **Hurting**

6/09

I'll never know
what you went through
a small part of me
doesn't want to know;
but a big part of
me does
I feel I should be
hardened, but somehow
I remain soft.
Unscathed though I seem,
the hurt is three times
as big.

Just because of the three men in my life who took their own.

Much of Miss Kaye's poetry utilizes tiny, often overlooked details- a slow squeak, hairy arms, prickly weeds- as metaphorical instruments to communicate her feelings, longing, and dreams. In the final three poems- "Single Memory", "Lot for Sale", and "Making the Rose"- Miss

Kaye reflects on her relationships with people, as well as her relationship to memory.

### **Single Memory**

2/9/05

I tiptoe towards the green rocker recliner.

Maybe he will acknowledge me.

Next to him, I carefully examine

his slicked back hair, his thick black rimmed glasses

at the tip of his nose,

his hairy arms,

and his plaid shirt.

He doesn't look over at me.

He is reading the newspaper.

Doesn't he see me?

Now I am afraid that if I disturb him

he will get angry.

So, back on tiptoe,

I keep walking.

I do a Uturn in the opposite direction.

He turns the page of his paper as if I was never there.
At 21, almost 19 years after his death,
I can still describe him from when I wasn't even three years old, but it saddens me that I never really got to know the man
I still call Grandpa.

### **Lot For Sale**

3/12/04

It wasn't a very big lot

or a very good one at that. The only thing that grew on it was that rough, weed-like grass, the kind that cut your legs. But boy, oh boy, you sure could see everything from up there.

It was the kind of lot that nobody wanted their house built upon, yet the "For Sale" sign remained. None of the lots up there were particularly nice, but this one in particular was nothing but a rocky cliff.

I actually hope nobody ever buys that lot.
I want it to stay overgrown with those prickly weeds, just so I can go up there time and time again.
The familiar sting on my legs and the ever-changing view, always there to remind me, no matter what,
If I can still stand on that empty lot,
I can always know that home is never very far away.

### Poetry

### ~To my Daddy~

### **Making the Rose**

3/29/03

I sat on the swingset over a little patch of pavement in my yard.
I had nothing but the slow squeak of the rusted chain.
It was early, but the sky was grey.
The roses smelled so good that I stopped the swing.

I reached to my left to pick one off the vine.

My hand came back to me suddenly. A sharp pain ran through my arm And a tiny drop of blood splattered the white concrete below me.

Knowing better, I just took a peice of grass, and laid it in the blood to make the rose I couldn't get.

### **Connecting Through Art**

By Matti Poole

attingly "Matti" Poole, has always been fond of arts and crafts. But at the age of 7, Matti's parents began to see her flourish through the crafts and really fostered the interest. The discovery happened during a play date at a friend's house, where a group of children decided to make paper dolls. While the other children eventually became bored with the task, Matti continued creating.

She spent hours creating these dolls, dressing them up, and eventually created a village of characters that her friends adored. Born with a hearing impairment, Matti did not speak frequently, as effective communication was difficult for her. This lack in communication made it difficult for her to connect with fellow peers and family. Through her arts and crafts, Matti discovered her voice. She now had the ability to express herself and connect with others in an alternate way. Her peers and family began to understand and feel her thoughts and emotions more deeply. Blossoming into a talented painter, her preferred medium, Matti loves all art forms and devours opportunities to learn other techniques. Her ability to capture emotion and feelings into her paintings is truly amazing. During her downtime, you can find her painting or engaging in a craft, something she hopes to do for a living as a UI REACH alum.

Matti is 21-year-old artist from Cincinnati, Ohio who graduated from the UI REACH program at the University of Iowa in May 2017 and is returning for the 3rd year option. Matti is looking forward to learning apartment management and cooking skills where she will continue her love of art and running (see the article "Self-Advocacy: Independence and Confidence through the UI REACH Program").



### "UI REACH"

The painting displays various characteristics of individuals with disabilities that have inspired Matti in her life. She incorporated bits and pieces of many people into each character so as not to create a representation of an actual person. Matti painted this piece for the UI REACH program.

# Connecting Through Art



# "I CAN'T HEAR YOU"

A final project for a University of Iowa art course Matti took capturing elements of life as a person with a hearing impairment and cochlear implant.



# "Myself"

This self-portrait is an award winning piece that resides in the U.S. Department of Education office in Ohio. Matti painted this piece during her senior year of high school.

# **Self-Advocacy: Independence and Confidence through the UI REACH Program**

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he office is quiet now. The graduation, golf tournament, and the fashion show are over. Last week was a joyous time, and parents, students, and graduates left energized. Our office is located in Iowa City on the University of Iowa campus. You can find me and my colleagues in the Lindquist Center, home of the College of Education. Together, we supported 57 students with intellectual and cognitive needs (ID) through the UI REACH program this past school year. Of those 57 students, 33 students graduated, and 24 second-year students will be returning to campus in the fall. In a few weeks, we will be meeting with 20 incoming first year students and their families for our Summer Orientation. This will be the first time the new cohort comes together, and for many parents and students, the reality of "going to college" begins to set in.

The UI REACH program is in its ninth year. Our program was the first post-secondary education (PSE) program for students on a BIG 10 college campus. In 2010, UI REACH received grant funding from the Higher Education Opportunity Act of 2008, and today is officially recognized a Comprehensive Transition Program (CTP). This CTP accreditation allows students accepted in the UI REACH program the opportunity to apply for financial need-based grants (i.e., Pell Grant).

Although I am sad to know our graduates will not be back in the fall, I am reassured by their confidence, eagerness, and independence. A few years ago about this time of year, I found myself talking to a student about his plans for the summer. About two minutes into the conversation, I stopped and realized that I had worked with the student during his first year on campus. The growth that the student made socially was truly astounding. As one of our recent graduates put it last week when reflecting on his time from UI REACH, he said, "I came in as a seed. I turned into a tree. Now, I am a man."

Much of the growth that takes place with our students has to do with simply being on the University campus, living in the dorms, taking college classes, and participating in a variety of student organizations, groups, and clubs. If I had to pinpoint the one thing that changes the most in students (e.g., seed compared to a "man"), I would say that our graduates possess a significant increase in their ability to self-advocate. For instance, it would not be uncommon for a parent or two to refer to their student or child as a "rule follower" during the interview process. However, in order to ensure that we are on the same page, I ask, "Well, what would you do if your student comes to campus and decides to not follow the rules?" This usually takes a few clarifying questions before we come to a mutual agreement that the UI REACH program in conjunction with the parents will offer the support needed to each student while attending college. We also take a moment to recognize that as a program or as parents, we cannot control everything that is going to happen—the good, the bad, and the ugly. College is a time for personal growth, and for many UI REACH students, it is growth in self-advocacy.

Many students with ID need to be explicitly taught how to advocate for what they want and how to achieve their goals starting early on in life. However, research indicates that parents and teachers tend to be the primary advocates for students in the K-12 setting, thus not providing the instruction or opportunities to practice and hone this important skill. Keeping this in mind, we begin discussing the importance of self-advocacy for college success during the interview process. To begin, all students entering into the UI REACH program must possess a level of self-advocacy for safety. As a program, we need to know that a student

#### Self-Advocacy: Independence and Confidence through the UI REACH Program

will be safe living in the residence halls as well as navigating campus with limited support. Despite this requirement, we know that in order for our students to reach their personal, academic, and employment goals, growth in self-advocacy is a must.

Our self-advocacy instruction begins early in the interview process by conducting a brief analysis of the things that the potential student currently does independently. Note, this is very different then looking at all things the student is capable of doing independently, which is impossible to quantify. However, for many potential UI REACH students, parents admit to waking their young adult up for school, cleaning his or her room, making all meals, and even washing all their son's or daughter's clothes. As others have found, "Parents often have trouble letting go, students may need to be encouraged to demonstrate that they are responsible for their own actions, and if they need assistance in a college setting, they will seek it out" (Brinckerhoff, 1994, p. 10). Therefore, we recommend that parents begin immediately with transferring over the responsibilities to their child as soon as possible—responsibilities that all college students must take on.

# **Self-Advocacy on Campus**

All first-year students take a Life Skills class. This class is the first class students have in the week—Monday morning at 8:30 a.m. The purpose of the Life Skills class is to explicitly teach the skills need to live independently on campus. In addition to teaching students the location of stores to buy things such as personal hygiene supplies, UI REACH staff introduce, model, and provide multiple opportunities for students to practice goal setting, and how to advocate for wants, needs, and desires using "1" statements. Students are also taught a variety of stress management techniques and take part in a numerous nutrition and health lessons.

As I sit here looking at my running shoes in the corner, I quickly reflect on how this past year, many UI REACH students and staff embraced physical fitness to reduce stress, increase health, and as an opportunity to socialize. In addition, I can think of many examples of how UI REACH students used running as a forum to develop, practice and enhance self-advocacy skills.

For example, Matti, a second-year student, has found how running can take her mind off of negative social situations, increase her confidence, and prove to others that one's disability is not the sole, defining attribute of a person. Matti's advisor said she feels that running gave Matti the confidence and the pride that she needed to feel comfortable advocating for herself



Image 1. Matti and her sister after crossing the finish line during cross country.

in a variety of settings. Matti, also a talented artist (see Image 1), explained how she became interested in running:

In high school one of my girlfriends wasn't very nice to me and told me no I couldn't do track and field. I went ahead and tried track, to prove my friend wrong but I didn't like it. So then I decided that I would try cross country. I never gave up, and I really like it and the races. There was a race I ran with my younger sister. My parents told me to beat my sister. I said she was too fast and that I couldn't beat her. But I beat her. I was very happy to beat my sister, I was proud of myself. I never gave up.

Upon coming to UI REACH, Matti struggled with staying active, which is not unusual for college first-years. However, Matti's advisor knew about her love of running and encouraged her to continue her passion. During her second semester, Matti began training for her first half-marathon, and with the support of her advisor, joined a community running club. Matti said,

I ran with my advisor and teacher to train for my first half marathon. It was hard to wake up at 6 a.m. to train. I really

#### Self-Advocacy: Independence and Confidence through the UI REACH Program

enjoyed running a half marathon, and I was super proud of myself for finishing. I was very happy with my time.

With increased confidence, during her second year, Matti heard about a local Color Dash event and asked (i.e., advocated) her advisor if she could participate. Not only did she initiate running in this community event, she recruited fellow students and staff to participate with her. In all, a total of 15 students, 3 staff members, 2 parents, and 1 former staff member ran the race (see Image 2). When asked to describe the run, Matti reported,

I was really happy that I got the idea to do something for fun and I was really happy that everyone liked it and that they wanted to do it again. It was so cool to get all colorful. I really wanted to help UI REACH and get others to have fun and show them how I like to run for fun.

Matti encouraged others to start running, like first year student Ellie. Although, Ellie did not run the Color Dash race, she did train for the event with her peers and was out on race day to show her support. When asked about her experience she said,

I was not really a runner. I wanted to get out of the dorm and get out in the community more. I trained with four other UI REACH girls with a coach. I wanted to be social with these girls. I liked talking with them and being out in the nice weather. Even when it was cold, I would still go out.

When Ellie decided to start running, her parents and advisor were shocked. Ellie's mom wrote,

Ellie observed her friends participating in the Color Dash and was inspired to train for a 5k. Ellie took great pride in training with her friends during biweekly practices. Although she did not actually run in the event, her friends inspired her to push herself outside of her comfort zone and work to improve her endurance. This training gave her an opportunity to improve her fitness level and socialize with her peers.

Overall, Ellie really enjoyed the process and building stronger friendships with her peers. She thinks she will complete a 5k with friends next year as a second-year UI REACH student.

Similar to Ellie, Justin, a first-year student, has embraced the sport of running. When asked about his new passion, he said staying active is a good way to get you out of the residence halls and to avoid being bored. He says it helps students "stay out of trouble," and that he runs "sometimes as a stress reliever." After Justin joined the running club, he asked some of his friends to join with



Image 2. UI REACH students and staff before the Color Dash.

him. One of his friends who came along was Greg, a third-year student who is also an avid runner. Greg and Justin will typically run between one and five miles together. However, running five miles is not unusual for Greg. Greg goes out for a run or to the wellness center on campus almost every day. When asked about a typical workout, Greg wrote,

I stay active by going to the Rec Center working out. Just about every day. I like to run a lot. I like to run because it's good health. On April 15, I ran 8 miles from the Rec Center to North Dodge and back to the Rec Center. Then it started to poor [sic] down rain right as I got to North Dodge Athletic Club. When I got back to the Rec Center I worked out some. Then I rested for a long time. Then on April 16, I ran 11 mile from the Rec Center to Coralevile [sic] Mall and back to the Rec Center. On April 23, I ran from the Rec Center to the green way path by the river to Hy Vee to Cycomore [sic] Mall and back to the Rec Center. Then I went to Dairy Queen to get an orial cookie doe blizzert [sic]."

Although there are many examples of how UI REACH students practice and demonstrate self-advocacy, running has been a way to for students to increase confidence, advocate for wants, and create social opportunities. As the semester comes to an end, Matti, Ellie, Justin and Greg say that they all are making plans to stay active in the next year and will be encouraging their families and friends to participate in running events this summer. More importantly, the pride and confidence they have received from running has positively contributed to their growth—a growth in their ability to advocate clearly and effectively.

Self-Advocacy: Independence and Confidence through the UI REACH Program

# **References**

Brinckerhoff, L. C. (1994). Developing effective self-advocacy skills in college-bound students with learning disabilities. Intervention in School and Clinic, 29 (4), 229-237. doi: https://doi.org/10.1177/105345129402900407



Image 3. UI REACH students and staff at the finish line of a 5k, Kickoff to Kinnick.

# The Muse of Love

By John Smyth

n the world of muses, Love powerfully leads those who illumine ownership of all within the Silence. Where Love is present, so is light. The purer the Love, the greater the light. Musically speaking, we vibrate a song wherever we are. As Silence gives life awareness, so music gives motion, slowing or speeding vibrations of life. Music lifts the soul wanting union with Love toward her.

Feelings of song touch us in so many ways, from the vibrations impacting our cells and unique place in the universe to lyrical potential to align our thoughts with personal connectivity to ourselves and others. Love sources our abilities for this. How we know Love is in the warmth of life breaths, each a gift in the Silence. United with Love, we access and own all within the Silence. Intending pure Love, music can unite us with the Silence and all within it.

Holding the rich and poor in her bosom, Love gives music to all, including souls trapped in bodies and unwept by rushing humanity as we feast on the plenty in our worlds, from sunshine to tasty morsels on our tables to communications exchanged between beings. Love's light, lifelong losses, and joyful gains mingle as real, powerful, and present tunes beneath conscious thought, lifting ill-prepared streams of goofy words font-like from inspired vibrations in the subconscious. Like a symphony, personal favorites in song, such as "Jesu, Joy of Man's Desiring" augment and complete our longstanding stasis of rest. From here we come into the moment, reaching places within our beings and others' that we never expected.

Kind actions of thought and word till spacing around our beings to be receptive to our vibration, even as it finds union with spires of lofty notes in Love's everlasting presence. Lost behind these are principles of power that govern eternal truth for intellectual alignment with the spiritual. When eternity connects internally as potent energy for omniscient thought, Life holds us as if spirited, meaningful creation writes a new chapter. And here, our time and

precious life energy uniquely give being to our eternal imprint on creation.

What many miss is the melody of tasty powerful vibrations emanating from each of us in this silent eternity of time and space, and the poor attention we frequently bring to our powerfully playing, truly tearful song of life. Alone with what we



John Smyth

hear, we staple ourselves to assumptions we regard as true in our world. To assumptions we hold, serious values are welded that shape our biases and behavior.

No one is alone. Love is holding each of us as we write the rules and story we alone are meant to contribute. Persons appreciative only of sadness and suffering appear to many as if their lives assume a lesser meaning or lower place. Jeering absolutists sound fury that those who ask in poverty will not witness to Love but to works seldom smelled as flowers of innocence within heavenly realms. This outlook is mistaken. Of Love's greatest gift, there is a kinship with poverty. Framed as sacred opportunities realized and missed, spiritual sounds emanate from loyal hosts of Love who appreciate the eternal meaning of each gift in reality assigned to all. We have no do overs as our record of moments yesterday and tomorrow are memorialized in song and light.

The potential for where our tune plays and who each of us is for others, harmonizing, centering, deepening years of peasant listening in our own ignored imparting of loved beingness, as symbolic as it is real, should hold us in awe. What mercy makes this possible? What did we do to earn this? Who inspires who we sacrifice ourselves powerfully to be? Is that person or thingness of sufficient value to merit our life energy? Easily the majority of us hear these questions deafly if at all. Wanting something within our limited imaginations, we allow ourselves to be trapped in boring melodies of little resonance.

Where is the power to grow our spirits, to reach our greatest

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potency? Isn't it in harmonies in the soul vibrations of others we touch? Isn't our song only present with the playlist of others? Within this great gift of mutual power, don't we discover our love for ourselves and others? Autism aside, isn't life amazing, owning just the breaths we take for free?

Witness to the creator of life of gratitude inspires giving back. Each of us is called to do this. Where does an autistic unworthy fortunate man do this? For me it is in the many moments of love that I can justify existence of each day. Niceties are not love, and gratitude is. What song will play not only in my mind but also in my actions? Will who I be serve anyone?

Using these questions as fulcrums within the construct of a sacredly spiritual musical world of wellness, vibration, and love, quiet power amazes when it shows us where our song will reach the most souls, move the most oases of inspired song, and walk within the beings of the most people. In this, I choose love's work among whoever says they hold no voice, have no sound, share no purpose for being. Under heaven's stars, there are only signs and symbols of what was meant to be. Poorly offered in a manger among farm animals, the greatest gift to the lost and voiceless arrived. Seemingly without a home for years knowing others were killing to get to him, offending none and only with poor parents who loved Scripture, upper class only in reality of the spiritual realm, He powerfully gave himself back to his Father to heal others. In our own time He called us to do the same.

Love knows no special time or season. Inspired angels, singing hymns of praise, enkindle life notes with quiet affect on those sharing our inspired peacefulness. They will our souls to be known for His peace, joy, and lasting Love in humanity's song. How Love sings is in the illness physically or psychologically joyfully embraced, in love song of gratitude for life governing our places to serve the poverty and neglect of another, that they be lifted to song themselves by our own song. How our power works is through our brothers in need of love, comfort and forgiveness.

With inspired spirits of generosity, our love only knows another's love witnessing to our own. As little and lowly as immediately we appear to be, only Love is lastingly able to work its magic, musically sounding notes. When one is heard, another is necessary. Addiction to Love, as to music, is beautifully refreshing. In what gardens the sounds inspire, let us tend to their beauty and illumine all within the Silence.

Popular music lovers listen outside of the experience of each inspired song's creator. Special songs move millions of people in ways that lift the spirit listening behind sensory interpretations. We are abased in our souls as life draws all quietly through all littleness of amusing maintenance in what we shall eat or wear. Powerful sounds of melody lift us from this. We renew as if on eagle's wings. Songs carry us beyond the moment to a greater place of connection. The quiet soul inspires assumes a wider, alighted sincere serenity. Walking quietly with the music is transformational in so many ways. The assumptions peacefully in our varying backgrounds and waiting for patient listening after life lessons work their ways into songs as sad, happy, or emotionally witnessing words of quiescent knowledge aberrations whispering who we sincerely find in the song that waited for wanted outside recognition from within our surprising love and acceptance.

Orphans of our thoroughly essential awareness, long accounting for reality, toasted as opportunity only of the song to Orwellian totalitarian wonder about all programming within us, lonely listeners must inspect oases of thoughts. Quite aware, alone in that awareness, we are swimming within a sea of theses about wherever our mind will go. No one can predict his next thoughts. Where, please, is the distinction between me and my thoughts? How useful is this information? Of what significance is it? How does it connect me to all thinking really all music and all yesterdays and tomorrows of thought and music? Is Descartes' statement, I think therefore I am dearly sacred or imposter to Hume's representation that only my senses and never my thoughts give me pure truth?

# Trish and Antonio's journey: Creating friendship through peer engagement on campus

By Patricia Walsh and Antonio Reyes

# Introduction

his piece is written by Antonio Reyes, a student from Bloomfield High School and Patricia (Trish) Walsh, a Teacher Education student from Montclair State University, both of whom were participating in the Increasing Access to College (IAC)
Project at Montclair State University. Together
Antonio and Trish navigated various academic
and social aspects of campus life and jointly
shared their experiences in this photo essay.



I am Antonio and I was at Montclair State University this past year. I am from Bloomfield High School and I am graduating next year. For my last year before graduating, I will be back to Montclair State University through the Increasing Access to College Project.

#### — Antonio

This is a picture of my friend Antonio and I standing in front of Montclair State University's emblematic Red Hawk statue. I'm an undergraduate at Montclair State University and I am about to start my Master's degree in the fall.

#### - Trish

Trish and Antonio's journey: Creating friendship through peer engagement on campus



The class was pretty hard for me in the beginning. At first, I had a staff from Bloomfield High School come to class with me. Then Trish came in to help me out and that changed everything. If Trish had not been there for me, I would have quit the class. She helped me with everything in the class; it was so exciting when she came in with me. It also helped that Trish knew how to understand what the professor was saying and she knew how to use some of the Apps and Technology.

#### Antonio

Antonio and I spent the last semester taking a media toolkit class together and learning the skills of visual storytelling. This course invited us to explore the journalist process by using special camera equipment and video editing software to complete projects.

Admittedly, as a humanities major, this was challenging for me; Antonio was new to these technologies, too. We truly had to step outside of our comfort zones and approach each task with an open mind. Thankfully, we discovered this wasn't so daunting with the support of each other and our peers.

#### - Trish



Trish and Antonio's journey: Creating friendship through peer engagement on campus



The Increasing Access to College (IAC) Project at MSU provides opportunities for young adults with disabilities to experience campus life. Just as each undergrad's experience is individual and unique, this mission takes countless forms for our program fellows. Many IAC participants take classes, like Antonio, and enjoy other campus amenities like playing sports in the recreation center and hanging out in the student center lounge.

- Trish

When I was at Montclair State, the rec center was fun. I liked playing TK17 (video game) and basketball. I loved spending time with my friends and other adults. It's not just about the games, they also teach you a lot and I want to go back. I did not know anything about cameras until I learned about them in my class.

Antonio

Trish and Antonio's journey: Creating friendship through peer engagement on campus



I think that anyone would like to go to Montclair State because it is the best school in the world, even if it is not cheap. At first when I got there, I felt nervous. But then I got to take a class, and that felt good for me. It was also good to meet other students like Trish and meet new friends. Meeting other students was good, because they had already been to college and knew more about college than I did.

#### — Antonio

I have worked with the program for about two years as a peermentor and research assistant. The picture on p. 45 is from a Poster Presentation that I helped present at a faculty meeting at the College of Education and Human Services on Public Scholarship. This privilege has been an incredibly formative part of my MSU career. I've enjoyed knowing and learning from every person who contributes to the IAC Project, and sharing my knowledge about the university to make it more accessible for all who wish to join the Red Hawk community.

#### - Trish



The device in the student's hand is a recorder and you talk into it and record. That day was fun that the student taught me about this, and I did not know about recording before. I think peer supports are really helpful. They give you confidence to try new things. In the end, I am proud of the pictures I took and my photo essay "My Friend, Mr. Miller." Mr. Miller is my boss where I work at the Elementary School and he is the head custodian at the school.

#### — Antonio

This project was our first attempt at editing a video and skilled students in the class were always happy to help whenever Antonio and I were stuck. These relationships were so special because they made us feel comfortable learning these new skills, even when we didn't get them right the first or second time. Not only did Antonio and I support each other, but each student supported the success of the entire class community. These relationships embody a core aim of the IAC Project: promoting inclusive campus experiences by welcoming and supporting every community member. These relationships made this experience successful and memorable for both of us.

#### - Trish



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# **NEW!**

Welcome to **TASH Amplified**, TASH's new podcast series. This series seeks to transform research and experience concerning inclusion and equity for people with disabilities into solutions people can use in their everyday lives.

# **Season One Episodes**

A Brief History of PBIS

Teaching Math to Students with Disabilities: What We've Learned in 10 Years

Reflections on 40 Years of Agency Community
Supports

Faith and Flourishing: Equipping Your Church to Reach Out to People with Disabilities

Faith and Flourishing: Welcoming Children with Disabilities and their Families

Faith and Flourishing: Hidden in Plain Sight

Special Education Teachers and the General Education Curriculum

What Matters to Family Members when a Relative Transitions to Community Living

Building Communities to Support People with Disabilities

Presentations on Recreation and Leisure for People with Disabilities at the TASH Annual Conference

Barb Trader Reflects on a Lifetime of Accomplishment in Disability Rights

www.tash.org/amplified

Equity, Opportunity and Inclusion for People with Disabilities since 1975

TASH is an international leader in disability advocacy. Founded in 1975, TASH advocates for human rights and inclusion for people with significant disabilities and support needs – those most vulnerable to segregation, abuse, neglect and institutionalization. TASH works to advance inclusive communities through advocacy, research, professional development, policy, and information and resources for parents, families and self-advocates. The inclusive practices TASH validates through research have been shown to improve outcomes for all people.

# **Policy Statement**

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities. Items in this newsletter do not necessarily reflect attitudes held by individual members of the Association as a whole. TASH reserves the right to exercise editorial judgment in selection of materials. All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH's publishing and advertising policy, please visit www.tash.org.

# **TASH Mission & Vision**

As a leader in disability advocacy for more than 35 years, the mission of TASH is to promote the full inclusion and participation of children and adults with significant disabilities in every aspect of their community, and to eliminate the social injustices that diminish human rights. These things are accomplished through collaboration among self-advocates, families, professionals, policy-makers, advocates and many others who seek to promote equity, opportunity and inclusion. Together, this mission is realized through:

- Advocacy for equity, opportunities, social justice and human rights
- Education of the public, government officials, community leaders and service providers
- Research that translates excellence to practice
- Individualized, quality supports in place of congregate and

segregated settings and services

 Legislation, litigation and public policy consistent with the mission and vision of TASH

The focus of TASH is supporting those people with significant disabilities and support needs who are most at risk for being excluded from society; perceived by traditional service systems as most challenging; most likely to have their rights abridged; most likely to be at risk for living, working, playing and learning in segregated environments; least likely to have the tools and opportunities necessary to advocate on their behalf; and are most likely to need ongoing, individualized supports to participate in inclusive communities and enjoy a quality of life similar to that available to all people.

TASH has a vision of a world in which people with disabilities are included and fully participating members of their communities, with no obstacles preventing equity, diversity and quality of life. TASH envisions communities in which no one is segregated and everyone belongs. This vision will be realized when:

- All individuals have a home, recreation, learning and employment opportunities
- All children and youth are fully included in their neighborhood schools
- There are no institutions
- Higher education is accessible for all
- Policy makers and administrators understand the struggles of people with disabilities and plan – through laws, policies and regulations – for their active participation in all aspects of life
- All individuals have a way to communicate and their communities are flexible in communicating in alternate ways that support full participation
- Injustices and inequities in private and public sectors are eradicated
- Practices for teaching, supporting and providing services to people with disabilities are based on current, evidence-based strategies that promote high quality and full participation in all aspects of life
- All individuals with disabilities enjoy individualized supports and a quality of life similar to that available to all people
- All individuals with disabilities have the tools and opportunities to advocate on their behalf