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Negative Social Constructions of “Disability” and How Individuals with Disability May Better Transition from Childhood to Adulthood in the United States

A Capstone Project Submitted in Partial Fulfillment of the
Requirements of the Renée Crown University Honors Program at
Syracuse University

Estella Li
Candidate for B.A. Degrees
and Renée Crown University Honors
May 2014

Honors Capstone Project in Inclusive Education

Capstone Project Advisor: _____
Dr. Mario Rios Perez, Ph.D.

Capstone Project Reader: _____
Ms. Diana M. (Dee)
Katovitch, Assistant Director

Honors Director: _____
Stephen Kuusisto, Director

Date: May 5, 2014

Abstract

The objectives of this study are to assess the meaning of “disability” through etic and emic frameworks, to bring awareness to effects that negative social constructions have on individuals with disabilities’ self-worth, and to find more accommodating approaches to not only help individuals with disabilities grow in inclusive classrooms, but to also help them apply confidence, creativity, and problem-solving skills to their community after the age of 21 in the United States. Since the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA) fall short of providing individuals with disabilities adequate services and support for adulthood preparation, the study will analyze other effective programs, school initiatives, and technological services to propose for implementations of service support at the community level so that the gap between childhood and adulthood services may be bridged.

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Executive Summary

What is “inclusion” and how can curriculum development in schools and community involvement be modified so that individuals who are identified with disabilities in childhood may continue to succeed, both socially and academically after the age of 21 in the United States? Who should bear responsibility for planning and providing equal opportunities for individuals with disabilities? Inclusive education is a “philosophy supporting and celebrating diversity in its broadest sense” (Kugelmass, 2004, p. 3). Depending on the individual student’s disability, various methods such as instructional scaffolding, alternative media (i.e. large prints, audiotapes, or electronic materials), and shaping/modeling should be implemented so that physical, attitudinal, and systemic barriers in learning could be broken down, and students could efficiently learn and become engaged with lessons in meaningful ways that would help them grow not just in classrooms, but also in the community as well.

The Individuals with Disabilities Education Act (IDEA) requires schools to provide early intervention, special education, and other related services to over 6.5 million eligible youths with disabilities so that it may find and better serve greater accommodations to students with disabilities (SWD) that go beyond infants, toddlers, children, and youths with disabilities. Under IDEA, infants and toddlers from birth to two-years-old who have disabilities receive early intervention services with their family under “Part C.” Also, under “Part B,” children and youths from ages three to 21 receive special education and related services. However, beyond the age of 21, SWD who do not identify themselves with a disability will not be entitled to services and care. A continuation of community involvement for individuals with disabilities should occur where specific goals are targeted and met through the extension of “accessible, memorable, and sustainable services” (Kame’enui & Simmons, 1999).

The Peer-to-Peer (P2P) Lecture Series offer insight into how various universities and colleges may bring a wide network of support and inclusion on campus. Speakers Jackie Yingling, Kathy Costello, Stuart Carroll, and Missy Jones, talk about their experiences with The Advocacy Center, the Together Including Every Student (TIES) program, the Career and Community Studies (CSS) at the College of New Jersey, and several inclusion opportunities at the Northern Kentucky University, respectively. Together, the mission is to spread these programs and initiatives to other university and college campuses so that individuals with disabilities may transition better from childhood to adulthood with more resources and support to help them socially and academically develop.

Acknowledgements

This capstone project would not have been possible without kind contributions of time, effort, and invaluable insights given by Mario Rios Perez, an assistant professor at Syracuse University who specializes in the history of education, and Diana M. (Dee) Katovitch, an assistant director of the Lawrence B. Taishoff Center for Inclusive Higher Education. I want to also extend my infinite gratitude to participants of the Peer-to-Peer (P2P) Program for their great will and impact. Last but not least, I want to thank my friends and family for their unwavering encouragement and support throughout the entire process.

Advice to Future Honors Students

Since the capstone project involves a lot of time commitment to research, it is recommended for resources to be gathered once a topic is known. Also, it is easy to overestimate the time you have to analyze and summarize articles, so it is best to plan ahead of time and create an agenda to pace yourself. What needs to be accomplished in the given amount of time? An effective way to plan next steps is to create an outline of what needs to be done and how much time you can block off for those tasks in a given day. (Be certain to not push things to their last minute!) The capstone project may seem tedious, but it is less intimidating when small steps are taken to reach final goals. Do not be overwhelmed. Pick a topic of your interest, and have fun with it. Let your creativity and passion drive your desire to write. Best of luck!

Chapter 1

What constitutes “ability” and “disability?” The way a person with disabilities’ self-worth is determined is closely connected to his or her environment and social stigmas. People with a “disability” are often not seen as contributing citizens in society (Kliewer, 1998), and they are often alienated by snap judgments based on inequality and negative social constructions created through social media. Rather than viewing disability as human diversity (M. Damiani, personal communication, January 23, 2014), there is a “fault-finding perspective” (Goode, 1992, p. 200) in which people tend to dismiss certain abilities and skills that deviate from the standards that they impose on people with disabilities.

An ableist society is said to be one “that treats non-disabled individuals as the standard of “normal living”, which results in public and private places and services, education, and social work that are built to serve “standard” people, thereby inherently excluding those with various disabilities” (“What is Ableism?”, 2014). An ableist society sees people with developmental, emotional, physical, and psychiatric, and learning disabilities as inferior (“Social Justice Project”, 2013) and prefers abled-bodies who carry “normal” lifestyles with the ability to walk, talk, see, and hear.

Even though America was founded on the principle that all people, regardless of class, gender, and race, have an equal opportunity to life, liberty, and the pursuit of happiness (U.S. Constitution), individuals with a disability, or disabilities, often cannot be heard, and they are often viewed as part of a

disadvantaged and powerless minority where “fault-finding” (Goode, 1992, p. 200) exists. Americans tend to think that people should be able to pull themselves out of their misfortunes by their own bootstraps, in which minorities can somehow ascend in social, political, and economic rank without, or with little, help; however, America does not give everyone the opportunity to rise, especially when there is visible discrimination targeted at some groups in classrooms. Students from minority groups tend to have lower motivation to do well in school not because they do not want a better education or are dysfunctional to learning, but because they are dysfunctional to school because of social and political factors affecting their academic achievement (*Precious Knowledge*, 2011). The events in Arizona, as portrayed in the documentary film *Precious Knowledge*, reveals how difficult it is for marginalized communities to try to assimilate the American culture, especially when Americans are not as accepting as they should be. For instance, banners and signs on buildings state that minorities have “no right to endanger the rights of whites” (*Precious Knowledge*, 2011). There is a present notion that children of color don’t have anything useful to add to classrooms, and that they are jeopardizing white students’ education by breaking away from American traditions. Even though these children are not “disabled” in medical terms, they are deemed disabled by being closed off to certain opportunities, and this is relevant to the way in which individuals with disabilities are treated in American society.

In schools, racial groups and people with disabilities are frequently seen as students who cannot be as successful as their white and able-bodied counterparts;

however, what exactly does “success” mean? According to Judy W. Kugelmass, in “The Inclusive Schooling: Sustaining Equity and Standards,” “success involves much more than academic achievement” (Kugelmass, 2004, p. 1). Success also means “getting along with others, solving problems, thinking critically, contributing to the school and community, and attaining personal fulfillment and happiness” (Kugelmass, 2004, p. 1). Everyone deserves an equal opportunity to a quality education, and no one should be undervalued because of a disability that requires a different teaching style. With extra help that accommodates students with disabilities, successful participation and problem-solving in schools and in the community may be made possible. Students with disabilities may realize that they have the potential to succeed beyond others’ expectations of them.

However, there is fear that people with disabilities will be a burden – emotional, physical, and financial – on others (Mairs, 1996, p. 77). People with disabilities are often denied access to education, medical procedures, political views, and career opportunities because of others’ underestimation of their skills and abilities. For instance, Sandra Jensen, a woman with Down syndrome in Sacramento California, who had chronic respiratory distress and had difficulties circulating blood to her lungs, was denied a required heart-lung transplant for a yearlong survival at the University of California and San Diego Hospital and the Stanford University Medical Center (Bronston, 1995). Doctors and hospital representatives justified their refusal to treat Sandra by explaining that Sandra was an “inappropriate” organ recipient since her “serious mental retardation” would limit the medications she could take and hinder her ability to exercise regularly

during her recovery after the operation (Goldberg, 1996). Doctors “considered her a socially and culturally expendable human being: a community burden not worth the previous medical resources available to save her life” (Kliewer, 1998, p. 1) based on the fact that there was a trisomy of her 21st chromosome, which led to a genetic etiology of Down syndrome.

Negative social constructions have led people to separate themselves from “others” with disabilities. Because of a perceived inability for people with disabilities to perform and succeed as fully contributing members of society, there has been a rise in cultural inequality, where SWD struggle with cultural perceptions as to their “community value, capacities, potential, and worth” (Kliewer, 1998, p. 1).

Similar to stereotypes and the world view in stories and advertisements that manipulate people into thinking that “women are passive, men are strong, and people of color are either absent or evil” (Christensen, p. 65), the social concept of “smartness” is also misunderstood when it is based on perceived knowledge. In the same way that minorities were tormentors in stories, people who are deemed “mentally retarded” are viewed negatively and are closed off to opportunities that allow them to succeed or advance in a particular culture. Even though public or private discriminations based on race, gender, or disability violates federal law, they still exist today. Along with the misconception of “smartness”, there is inequality in the belief that “women are passive, men are strong, and people of color are either absent or evil” since there is a myth that equality can never surpass the empty realm of form, for the law is restricted by tradition and is

ineffective in the face of natural order (Hayman, 1998). However, laws and traditions are only what people choose to make them. “Superiority” and “inferiority” are not entirely natural, and they depend on the contexts people construct. Therefore, the American culture with Prince Charming and the “ideal” protagonist figures are “superior” to the minorities, such as Asians and Africans (portrayed as tormentors) only because the culture perceives it that way, similar to how “intelligence” is what people make it.

The way someone perceives another person, regardless of whether the person has a disability or not, is based on perspective. Is it an etic or emic perspective? Why are some people capable of empathizing with others why others find it challenging? While etic perspectives cause fault finding, emic perspectives lead others to better understandings of the “rationality, purpose, and efficiency of native behaviors” (Goode, 1992, p. 198).

In “Who is Bobby? Ideology and Method in the Discovery of a Down syndrome Person’s Competence,” Goode says, “In anthropology, objective, analytic, or clinical approaches to understanding culture and human behavior are called “etic” perspectives” and “emic” perspectives are “native, subjective, or insider point of view(s)” (Goode, 1992, p. 198). For example, etic perspectives are applied when hospitals and clinics evaluate and treat deaf-blind children’s behavior with a list of professionally located faults and technical solutions. Emic perspectives are often overlooked since, according to Goode (1992), preferences and self-chosen behaviors for children that are deaf and blind in his study were ignored in planning intervention programs. Instead of providing the best services

to children who are deaf and blind by thinking in terms of their best interests and looking at their differing competencies (Goode, 1992), many therapists are unable to move away from the “purely neurological, physiological, and psychoanalytical models of intervention associated with their profession” (Goode, 1992, p. 198) and are only able to see people with disabilities through an etic perspective.

An example of an emic perspective is shown in Goode’s research done on a small group of occupational therapists providing services to adults that had developmental disabilities and who were living in community placements. Going past etic descriptions of pathology, these therapists concentrated on their clients’ inner daily lives and tried to better understand their thoughts, feelings, and individual skills and struggles (Goode, 1992). Similarly, Collins, in “Ability Profiling and School Failure,” describes an eleven-year-old African American boy, Jay, through an emic viewpoint even though Jay’s school records did not “paint a similar portrait of his abilities” (Collins, 2013, p. xii) and Laura, Jay’s teacher, thinks he is “really emotionally impaired” (Collins, 2013, p. 33). While Collins sees Jay, through an emic perspective, as articulate, persistent, confident, intellectually quick, and as a “good learner” (Collins, 2013, p. xii), Laura disagrees and sees Jay’s performance through an etic perspective which assesses Jay from a distanced look. Even though Jay is able to extensively participate with creative analogies, as recognized by Collins who is able to see things through an emic point of view, Laura is unable to discover “the rationality, purpose, and efficiency” (Goode, 1992, p. 198) of his behaviors, such as noisily slurping his chocolate milk and disturbing the class by throwing out his breakfast wrappings in

the middle of class (Collins, 2013). Laura quickly identifies Jay as different and puts limits and societal standards on him as she recommends him to be psychologically assessed to see if he qualifies for special education services (Collins, 2013). Based on etic perspectives, Laura is in agreement of other students' exclusion of Jay, and further makes an assumption that Jay cannot work with anyone (Collins, 2013). As observed by Collins, Laura demonstrated "no attempt to encourage students to build off of each other's ideas" (Collins, 2013, p. 35). Rather than to a learning disability, Collins mentions that it seems as though Laura is just basing Jay's perceived "disability" off of her "evaluation of his social interactions, behaviors, and family history" (Collins, 2013, p. 36) since there is an overrepresentation of minority students in special education programs.

In many instances, people are not able to see SWD's struggles with life through an emic perspective since people have a hard-wired default setting to focus on only the self and interpret almost everything through the lens of self (David Foster Wallace, 2008). It would be advantageous for people to be more open-minded and to be more willing to see things based on a person-to-person basis since everyone has a story to tell, and every story is different. When individual stories and needs are grouped into generic categories, it is easy for stereotypes or inaccurate representations to arise, and people will not be able to genuinely relate to people and see their "native, subjective, or insider point of view(s)" (Goode, 1992, p. 198).

Chapter 2

“Inclusive schools are designed to secure children’s basic human right to an individually, culturally, and developmentally appropriate education and to eliminate social exclusion” (UNESCO, 1997, 2000). Below is a broadened definition of inclusion, adapted from UNESCO, 1997; 2000:

1) All children attend the same schools and receive instruction in the same classes they would attend if not disabled or educationally disadvantaged.

2) Remedial, special education, and related services are provided within general education settings. Specialists work closely with classroom teachers to support all students and provide adaptations and specialized interventions to ensure successful participation and learning in the general education environment and curriculum.

3) When needed, accommodations are made in the general education curriculum so that all students attain skills appropriate to their chronological age and developmental needs.

4) The curriculum is conceived as promoting social-emotional and developmental growth, as well as providing instruction designed to help students meet age appropriate and grade-level learning standards in all academic areas.

5) All students are held to high expectations, while recognizing the need for individualization.

6) Classrooms are learning communities, in which all students are valued members who support one another.

7) Diversity in culture, language, ability, and student interests are all

celebrated and are seen as enriching the educational experiences of all children.

8) Families are active and integral members of the social community.

Resource: UNESCO, 1997; 2000

Ladson-Billings, Meier, Kliewer, Kimmel, and McGinnis and Palos discuss the importance of attempting to create a community of involved students in classrooms, and describe ways in accomplishing this by using different teaching approaches. Teachers may become a more active part of students' learning process by helping them embrace their social and cultural differences, teaching them the most recent scientific understanding of disability, engaging them in classroom activities without prejudice, and giving awareness to individual differences by examining areas in which students are both privileged and unprivileged to better understand society.

Ladson-Billings believes that developing a classroom community through culturally relevant teaching is important for the success of African American students, whether they have a disability or not. She found in her research that teachers who knew their students' families in urban schools and "had a sense of dreams and aspirations" for them (Ladson-Billings, 2009, p. 7) had a significant impact on helping students form a classroom community where they were able to embrace their distinct social and cultural backgrounds and see differences as strengths in a comfortable environment (Ladson-Billings, 2009, p. 10). Instead of viewing SWD as a burden to society, it may be beneficial for teachers to help them recognize individual differences and help them gain higher academic and personal successes through greater empathy and social development. Teachers

should also help students make connections between local, national, and global identities. The concept of “invisible privilege” (Kimmel, 2003) should not persist in a community of inclusion; the “standard” against which everyone else is measured should be changed to better fit a particular culture.

In addition to the discussion of “minorities” being undervalued and losing their voices in the community, Kliewer (1998) believes that “Down syndrome” is a “cultural illusion” (Kliewer, 1998, p. 18) and states that a greater community should be achieved where teaching techniques that carry the most recent scientific understanding of disability are displayed (Kliewer, 1998, p. 13). Kliewer says he notices that disability was shaped “in the dimensions and attitudes surrounding the child’s relationship to the wider world” (Kliewer, 1998, p. 14); and, with thoughtful planning and effort on the part of teachers, a classroom community may be developed when people realize how “normality and impairment are not absolute categories but instead reflect cultural traditions and the current authority of certain groups” (Kliewer, 1998, p. 15). Kliewer encourages opening engaging literacy experiences and recognizing students’ right to be included in classrooms reflective of the wider community (Kliewer, 1998, p. 14) so that students may feel a sense of acceptance and eventually become less sensitive to stigmatizing labels and biases society creates. Kliewer says, “The oppressive silencing of even one voice through any form of segregation eliminates that set of experiences from our collective conversation and diminishes the culture of community” (Kliewer, 1998, p. 5). Therefore, an enriched culture of community does not exclude anyone; everyone has an important contribution to make to society.

Meier also stresses the importance of a classroom community by engaging students in classroom activities, led by examples rather than by explanations (Meier, 1997, p. 7), that are without prejudice. For instance, two teachers, Daniel and John made their students a part of their own learning process by relying on them to hand in lunch money when they were not positive which students received reduced or free lunch and which students did not. Also, a sense of classroom community was fortified with the creation of classroom rules based on students' agreements. Daniel and John were able to help students smoothly transition into their first day of first grade by taking a genuine interest in students' feelings, and by being flexible with their teaching agendas based on students' contributions.

In *Precious Knowledge*, Latino students find themselves in a modern civil rights struggle as they fight for what they believe is justified in a society where education “simultaneously promotes equality and adapts to inequality” (Labaree, 1997, p. 41). “You are the other me. If I do harm to you, I do harm to myself.” These words are cited in class every morning as students are reminded that they should respect themselves and others. At Tucson High School, teachers such as Curtis Acosta and Jose Gonzalez offer students a “proper education” (Du Bois, 1935, p. 328). They attempt to promote equality and create positive changes by encouraging students to vigorously search within themselves and allow for fuller awareness. Teachers teach students to “familiarize themselves with questions of public interest and take sides with whatever they believe to be most in accordance with right and justice (Horn, 1922, p.348). Also, in ethnic studies, teachings of

critical reflection, reconciliation, forgiveness, and love move Latino students from the conviction that they are “ignorant” and “savages” (*Precious Knowledge*, 2011). Teachers try to change the mentality students have about not being wanted in school. Students are taught that they should not adapt to inequality and be told to “step outside the line” (*Precious Knowledge*, 2011). A student claims, “We are here together. It will never end because we will always be united as one” (*Precious Knowledge*, 2011). Classes cultivate understanding and try to reduce negativity that comes with discrimination.

“You think you’re teaching Peter things, but Peter’s the one teaching us things.”

In a short American documentary, *Educating Peter*, directed by Gerardine Wurzburg, the audience is able to see how Peter Gwazdauskas, a student with Down’s syndrome, in Blackburg, Virginia, gradually shifts the attitudes and behaviors of his teacher and peers from negative to positive ones of him and the concept of “disability”. Initially met with aversion, Peter’s peers did not have expectations for Peter and saw him as someone who continually disrupted and hindered classroom learning. However, negative views that were associated with Peter decreased when the teacher and peers decided to approach Peter with a more understanding and supportive attitude. His teacher and peers discovered “the rationality, purpose, and efficiency” (Goode, 1992, p. 198) of Peter’s behaviors, and had more respectful feelings toward Peter. Peter learned to follow instructions and answer questions asked of him. Peter also understood tasks that he was supposed to do, and he attempted to complete all his assignments. He successfully read, ran, caught things, and sang along with his peers because his teacher and

peers were able to participate in the “unfolding process” (Goode, 1992, p. 201) of seeing him in action in various settings every day.

Ming-Te Wang and Jacquelynne S. Eccles at the University of Michigan researched and conducted a study in 2012 to examine the relative influence of social support from teachers, parents, and peers on student engagement in upper divisions of education (grades 7, 9, and 11). They evaluated this by measuring different indicators of engagement: school compliance (positive behaviors), participation in extracurricular activities, school identification (interest and enjoyment), and the subjective value of learning (intrinsic motivation). On each of these four measures, student engagement declined on average between grades 7 and 11. However, two of the more significant findings were that teacher support played an important role in declines in compliance, school identification, and value of learning; and, while students were more likely to participate in extracurricular activities, see value in learning, and identify with school when they had peer support, results for compliance were varied and was reliant on the type of peer support and the values that were adopted by a student’s selected friend group. The researchers stated that, “Across all of the behavioral components of school engagement, peers are just as likely to exert positive influences on adolescents as negative influences.” (p. 891).

Although people think the thoughts and emotions they are expressing toward people with disabilities are appropriate, a short video, “A Credo for Support,” invalidates some people’s seemingly appropriate gestures and sayings.

Below are some beliefs expressed in “A Credo for Support” by people

with disabilities that others, looking from an etic point-of-view, may not recognize:

- “Do not see my disability as a problem. Recognize that my disability is an attribute.”
- “Do not see my disability as a deficit. It is you who see me as deviant and helpless.”
- “Do not try to fix me because I am not broken. Support me. I can make my contribution to the community in my way.”
- “Do not see me as your client. I am your fellow citizen. See me as your neighbor. Remember, none of us can be self-sufficient.”
- “Do not try to modify my behavior. Be still and listen. What you define as inappropriate may be my attempt to communicate with you in the only way I can.”
- “Do not try to change me, you have no right. Help me learn what I want to know.”
- Do not hide your uncertainty behind “professional” distance. Be a person who listens and does not take my struggle away from me by trying to make it all better.
- Do not use theories and strategies on me. Be with me. And when we struggle with each other, let me give that rise to self-reflection.
- Do not try to control me. I have a right to my power as a person. What you call non-compliance or manipulation may actually be the only way I can exert control over my life.

- Do not teach me to be obedient, submissive, and polite. I need to feel entitled to say no if I am to protect myself.
- Do not be charitable to me. The last thing the world needs is another Jerry Lewis. Be my ally against those who exploit me for their own gratification.
- Do not try to be my friend. I deserve more than that. Get to know me. We may become friends.
- Do not help me even if it does make you feel good. Ask me if I need your help. Let me show you how to better assist me.
- Do not admire me. A desire to live a full life does not warrant adoration.
- Respect me for respect presumes equity.
- Do not tell, correct and lead. Listen, support and follow.
- Do not work on me. Work with me.

The messages presented through the words of people with disabilities suggest that pity is not the strongest way to express understanding; rather, people should learn to accept, include, empathize, and help in individual ways that do not offend. Nancy Mairs, in “Waist-High in the World: A Life Among the Nondisabled,” says, “Effort and will have lost their meaning. But the craving for personal independence remains as alive and well as it was fifty years ago...myelin dissolves, nerves short out, muscle atrophies, but the the old brain, riddled now with sclerotic patches, goes on wailing, “I can do it myself” (Mairs, 1996, p. 70). Even though there is an inevitable part of eventual dependency on others, individuals with disabilities often, like Mairs, prefer some solitude and silence as well; and, they appreciate people who know, through experience or empathy,

what they need “without direction and provides it all but invisibly” (Mairs, 1996, p. 73).

Mair acknowledges that the attention can sometimes be “offensive” and that she lacks the sociability to take care from others (Mairs, 1996, p. 71), but she also sees her “crippled life less as a contest than as a project, in which others must participate if it is to prosper” (Mairs, 1996, p. 71). Even though some people with disabilities dismiss help and persist in willful independence, they sometimes need the help, and would like to receive it in ways that are gentle, kind, and truly understanding through an emic approach where feelings, thoughts, and meanings are considered.

Chapter 3

From birth to age five, the implementation of the Education of the Handicapped Act, as amended by P.L. 94-142, increased programs to provide education and related services to children with disabilities. Since 1984, thirty-eight states mandate services to some portion of preschools where students with disabilities attend from birth through age five. Four federal initiatives – the Education of the Handicapped Act (EHA-B), the Preschool Incentive Grant Program, the State Implementation Grant Program, and the Handicapped Children’s Early Education Program – have supported and encouraged greater preschool programs and have attempted to provide an equal opportunity to an appropriate education. For secondary and postsecondary age students, 24 states have mandates to serve youths with disabilities up until the age of 21 if they have not graduated from high school. Many states also permit local schools to provide services to youths through at least age 21 even when a mandate does not exist. Through many optional programs and monitoring of state plans of EHA-B funds, Special Education Programs strive to provide technical assistance to the states as required by Section 617 (a)(1)(A) of EHA-B.

The Individuals with Disabilities Education Act (IDEA), formerly called the “Education for All Handicapped Children Act”, states that “states receiving funding under the Act must ensure that children with disabilities are educated in regular classrooms with nondisabled children ‘to the maximum extent appropriate’” (“Oberti v. Board”, 1993). The IDEA requires schools to provide early intervention, special education, and other related services to over 6.5 million

eligible youths with disabilities so that it may find and better serve greater accommodations to students with disabilities that go beyond infants, toddlers, children, and youths with disabilities. Under IDEA, infants and toddlers from birth to two-years-old who have disabilities receive early intervention services with their family under “Part C.” Also, under “Part B,” children and youths from ages three to 21 receive special education and related services. However, beyond the age of 21, SWD who do not identify themselves with a disability will not be entitled to services and care.

In 2004, there was a reauthorized Individuals with Disabilities Education Act (IDEA), which became closely associated with the No Child Left Behind Act (NCLB) and a “cousin” (Turnbull, 2005, p. 1) of the 1996 Welfare Reform Act. This reauthorized act imposed strengthened personal liability expectations on SWD and their parents. There is a bilateral concept that the Congress, the SEAs, and the LEAs will “assume shared responsibilities for educating students with disabilities and benefiting the parent, but that the students and their parents must take on more responsibilities for their own behavior and for their relationships with the State Educational Agencies (SEAs) and Local Educational Agencies (LEAs)” (Turnbell, 2005, p. 1).

In support of the reauthorized 2004 IDEA accountability principle, NCLB adopted a second principle, which requires teachers to be highly qualified (Secs. 601(10) and 612(a) (14)) in order to support students’ outcomes and parents’ responsibilities for them. A third principle was also established, which was for

teachers to use scientifically or evidence-based instruction. The IDEA restates the scientifically based instruction through different provision listed below:

1. It disqualifies a student from IDEA benefits if the student's educational needs or deficiencies result from "a lack of appropriate instruction in reading, including the essential components of reading instruction," as defined in section 1208(3) of the Elementary and Secondary Education Act of 1965, as amended by NCLB (Sec. 614(b)(5)).

2. It restricts a student from being classified as having a specific learning disability by authorizing an LEA to "use a process that determines if the child responds to scientific, research-based intervention as part of the evaluation procedures" (Sec. 614(b)(6)).

3. It requires a student's special education, related services, and supplementary aids and services (as set out in the student's Individualized Education Program; IEP) to be "based on peer-reviewed research to the extent practicable" (Sec. 614(d)(1)(A)(i)(IV)).

4. It authorizes the SEA and LEAs to support pre-service and professional development (in-service) activities that train educators to use "scientifically based instructional practices" (Sec. 601(c)(5)(E)).

5. It authorizes "whole-school approaches, scientifically based early reading programs, positive behavioral interventions and supports, and early intervening services" that can prevent students from being classified into special education (Sec. 601(c)(5)(F)).

6. It defines "highly qualified" teachers in terms that originate in NCLB (Sec. 602(10) and 612(a)(14)).

7. It authorizes the SEA and LEAs to expend Part B money for "early intervening services" that are coordinated with their NCLB activities (Sec. 613(f)).

8. It sponsors research, training, demonstration, and other programs that align with NCLB (Part D).

Resource: Turnbull, 2005

However, despite the aforementioned support services available to students with disabilities, there are limitations on the IDEA that makes it fall short of providing individuals with the skills and provision necessary to have a confident transition from childhood to adulthood that will leave them with many educational and work opportunities in the community after the age of 21. Beyond the age of 21, SWD who do not identify themselves with a disability will not be entitled to services and care under the IDEA. While this may be seen as a positive occurrence where students and their parents may continue to take on more responsibilities for their own behaviors and become more independent, it is beneficial to have stronger bonds with the community in which it provides civic engagement and support for individuals with disabilities to foster mutual understanding without negative social constructions of "disability" and the disabled-body being inferior to "ability" and the abled-body.

Stronger bonds within family, both extended and nuclear, and neighborliness can strengthen civic engagement and support for individuals with disabilities. After all, the family is the "seedbed of virtue" where we are civilized,

socialized, and moralized (Lasch-Quinn, 2003, p. 29). Family engagement can reinforce children's school performances (Heckman, 2008) and close the achievement gap between unequal educational systems that children from different backgrounds and disabilities obtain. Heckman argues, "Family factors can influence children from as early as when they are in the womb, but disadvantaged mothers, as a group, talk to their children less and are less likely to read to them daily... [they] tend to encourage their children less, adopt harsher parenting styles, and be less engaged with their children's school work" (Heckman, 2011, p. 80). Even though Heckman is mostly referring to parents who have children of color, this also applies to parents who have children with disabilities, as racial discrimination and disabilities intersect in terms of disadvantages in schools.

Based on statistics from the General Social Survey since 1974, the proportion of Americans who socialize with their neighbors more than once a year has steadily declined over that last two decades, from seventy-two percent in 1974 to sixty-one percent in 1993; therefore, there should be an extended principle that not only authorizes scientifically-based early reading programs, positive behavioral interventions and supports, and early intervening services at school (Sec. 601(c)(5)(F)), but also at home and around the neighborhood, so that it may further prevent students from being classified into special education in later life. There should not only be teachers that are "highly qualified", as suggested in NCLB (Sec. 602(10) and 612(a)(14)), but there should also be parents and neighbors that are well-educated about disabilities and who are willing to help

SWD succeed and fill their educational deficiencies caused by insufficient components of reading instructions.

Despite disadvantages at home, where parents have to face working with their child or children with one or more disability, homes and the surrounding environment should foster competence and encourage SWD to find interest in learning through the development of social relationships that support and value achievement. As Gottfried, A.E., Fleming, J. S., & Gottfried, A.W. (1998) summarize, “The active pursuit of cognitive stimulation in the home,” which fosters “curiosity and exploration,” promotes inquisitiveness, and provides opportunities to develop competencies” (p. 1457).

The P2P lecture series, held at Syracuse University, focused on working towards universally designed campuses for all college students with disabilities, gave insight into what programs universities and colleges may offer to help effectively include and facilitate all students on campus with their learning and growth. Speakers Jackie Yingling, Kathy Costello, Stuart Carroll, and Missy Jones, talk about their experiences with The Advocacy Center, the Together Including Every Student (TIES) program, the Career and Community Studies (CSS) at the College of New Jersey, and several inclusion opportunities at the Northern Kentucky University, respectively. Together, the mission is to spread these programs and initiatives to other university and college campuses so that SWD may transition better from lower to higher education with more resources and support to help them socially and academically develop in adulthood.

The Advocacy Center began in 1954 with a group of families and professionals at Rochester, New York, who worked together to advocate for a broader range of service options for people with disabilities. A coordinating group, called the Monroe County Coordinating Group, was later formed in 1954 with the mission of supporting personal goals for people with disabilities in strong, inclusive communities. The Advocacy Center is a “Parent Training” and “Information Center” funded by the United States Department of Education. It is also a “Special Education Parent Center” funded by the New York State Education Department. Its associated agency is WNYADD, Inc., which provides advocacy services to guarantee full access to inclusive educational program, accessible housing and employment opportunities, healthcare, and other financial

powers.

The Together Including Every Student (TIES) Program at SUNY Geneseo promotes the participation of all students in extracurricular and community activities. In 32 districts, the TIES program aspires to include all members of campus communities by providing students with greater personal, academic, and career opportunities and support. The interactions of volunteers with SWD in the TIES program help people become more accepting towards others. To develop a strong, inclusive community, the TIES program focuses on building knowledge of developmental disabilities and encouraging a more positive approach to inclusion and diversity. The TIES program also emphasizes on basic skills such as communication and understanding through empathy. One of the purposes of the TIES program is to create a web of willing volunteers and participants that are immersed in opportunities for fun, support, and growth.

In addition, Stuart Carroll at the College of New Jersey talks about the Career and Community Studies (CCS) liberal arts program designed to better prepare students, ages 18-25, for their adult life, through “academic rigor, career discovery and preparation, and peer socialization” (S. Carroll, 2014, personal communication, February 6, 2014). Students who are a part of this program are required to present a disability that is considered limited in both intellectual functioning and in adaptive performance. Also students must be highly motivated; and, after obtaining extensive education services in either public or private schools, want a post-secondary experience on a college campus with a strong support system. Mentors in CCS program go to classes with SWD and help them

note-taking, pre-teach and post-teach, and understand real world applications through teaching. The CCS program includes two weeks of modules on liberal arts and science topics which challenge SWD and help them develop skills necessary to creatively problem-solve and participate more in school and community activities.

Missy Jones, a professor at Northern Kentucky University, says programs that support SWD learning and growth “started with one student, one parent, and one ‘champion’” (M. Jones, personal communication, February 6, 2014). Northern Kentucky University offers non-degree students creative classes, such as photography, dance, and theater, so that students with intellectual disabilities and others may have opportunities to use creativity to open up their minds. Mia Peterson, in a self-advocacy newsletter for people with Down syndrome, says, “I started to notice that I did not like the classes I was taking called special education. I had to go through special ed. all my life. I wanted to take other classes that interested me. I had never felt so mad, I wanted to cry” (Peterson, 1994, p. 6). Non-degree students typically enroll in 30 semester hours and are encouraged to seek symbiotic, co-planning relationships where mentors act like a facilitator, a friend, a social companion, and an ally to help mentees naturally thrive in certain school and community environments. Mentors go through mentor training that requires them to not just tutor, but to also enjoy their experiences with their mentees and highlight similarities through common interests. Mentor to mentee partnerships promote problem solving together along with greater understanding of each other through explorations of all perspectives and future

options. Jones says, “Never underestimate the power of natural supports” (M. Jones, personal communication, February 6, 2014).

At the Taishoff Center for Inclusive Higher Education, at Syracuse University, a Peer-to-Peer (P2P) Program is created to partner non-traditionally enrolled students with intellectual and/or developmental disabilities with traditionally enrolled students so that there may be additional enrichments in personal and academic work. Like mentor training at Northern Kentucky University, the P2P program gives an overview of postsecondary inclusion and offers examples of how students should handle different situations. The P2P program also wants both partners to benefit from their self-scheduled time together. Rather than seeing mentees as a client, a project, a stereotype, a child, or a charity (M. Jones, personal communication, February 6, 2014), the P2P program encourages peer partners to have an inclusive mind and to approach peers as they would with their other friends – with respect, openness, interdependence, and equality.

To gather thoughts on peer partners’ experiences with the P2P program and other services related to education for individuals with disabilities, I administered a small survey to traditionally enrolled and non-traditionally enrolled P2P peer partners.

Two traditionally enrolled peer partners currently in the program participated in

the survey and provided answers as follows:

1) From your experiences working/volunteering at Peer-to-Peer, what kind of progress do you see in your non-traditionally enrolled partner?

-“With my experience with P2P as a partner and now trainer, I have worked very closely with three different partners. After spending time with M.W. last year, both in and out of the classroom, I saw an ability to challenge and really think about our class material. I have known C.A. and L.N. through P2P and I have seen great academic progress from both of them” (Peer Partner #1, personal communication, February 18, 2014).

-“I think they become more opened to meeting other people and talking to other people. My peer was always happy to meet my friends, and was very friendly when talking to others” (Peer Partner #2, personal communication, April 11, 2014).

2) What drives your passion to help students with disabilities both socially and academically succeed?

-“What drives my passion to help students with disabilities both socially and academically succeed is for the students themselves to realize the progress they have made. It is very important that the students know where they have grown because that will hopefully give them motivation for future success” (Peer Partner #1, personal communication, February 18, 2014).

-“The experience and knowledge that my major (Inclusive Elementary and

Special Education) provided me to working with students with disabilities help drive my passion in working with students with disabilities. Those experiences have taught me that disability does not mean different, it means unique and I want everyone else to be able to understand it” (Peer Partner #2, personal communication, April 11, 2014).

3) What emphasis do you think should be placed in schools to help enhance learning for students with disabilities?

-“To help students with disabilities learn in schools, a major influence should be placed on inclusive education. Making sure every student feels a part and welcome to the classroom is essential to students’ having positive attitudes about learning. If the student needs or wants a support staff with them while in the classroom, that should be given to them” (Peer Partner #1, personal communication, February 18, 2014).

-“Inclusion. Stop pulling students out of the classroom and have the special education teachers come in the classrooms to work with both special education and general education students. Build a community in the classroom” (Peer Partner #2, personal communication, April 11, 2014).

4) The Individuals with Disabilities Education Act (IDEA) requires schools to provide early intervention, special education, and other related services to over 6.5 million eligible youths with disabilities. However, beyond the age of 21, students with disabilities who do not identify themselves with a disability will not

be entitled to service and care. What do you think about this?

-“I think that a student with a disability who does not identify with having a disability should know what services they are not going to receive by identifying without a disability. It is crucial that students with disabilities know their rights and what services they are entitled to or not by identifying with or without a disability. Support staff, friends, and family members can help a student with a disability dealing with this process” (Peer Partner #1, personal communication, February 18, 2014).

- “I do not like that idea. If you have been growing up with all these interventions, there needs to be some support for you even after 21. If you have been growing up with all these interventions, it would be difficult to transition out of all that immediately” (Peer Partner #2, personal communication, April 11, 2014).

5) What main educational change(s) would you like to see in the next three or five years for students with disabilities?

-“In the next three to five years I would like to see more schools over fully inclusive classrooms and educational settings. Nobody should ever be turned away because they have a disability. In order for this change to start, a significant amount of current and future educators must change their attitudes on students with disabilities” (Peer Partner #1, personal communication, February 18, 2014).

-“Students with disabilities should be included in classrooms and treated fairly” (Peer Partner #2, personal communication, April 11, 2014).

Three non-traditionally enrolled peer partners currently in the program participated in the survey and provided answers as follows:

1) What do you think of the P2P program and your partner?

-“It is great. The peer partners are nice” (Peer Partner #1, personal communication, February 24, 2014).

-“I like the P2P program and I enjoy spending time with my partner. I think it is a good program and has helped me make friends on campus. I cannot attend many evening events because of my schedule, so it would be nice to have more daytime activities” (Peer Partner #2, personal communication, March 11, 2014).

-“The program is great. My peer partners are awesome and we have a lot of fun and we go to the gym, Starbucks, and bookstore” (Peer Partner #3, personal communication, April 12, 2014).

2) Do you often feel included in conversations and classes on campus?

-“I do not usually get involved with that stuff” (Peer Partner #1, personal communication, February 24, 2014).

-“I feel included in most conversations if people make an effort to speak to me, not AT me. I feel included in some classroom conversations, but it would be nice to have other options to contribute my thoughts other than speaking up in class, such as writing or gestures” (Peer Partner #2, personal communication,

March 11, 2014).

-“Very often when we get into groups, I answer what the paper said” (Peer Partner #3, personal communication, April 12, 2014).

3) What are your goals for the future?

-“Get traditionally enrolled in college. Get a girlfriend” (Peer Partner #1, personal communication, February 24, 2014.)

-“I would like to get a job or volunteer position working with the elderly, such as in a nursing home” (Peer Partner #2, personal communication, March 11, 2014).

-“What it has in store for me and I just plan it out, like move to Los Angeles and get that house” (Peer Partner #3, personal communication, April 12, 2014).

From the survey, responses reveal that even though there are services provided to non-traditionally enrolled students that allow them to actively participate in inclusive classrooms that provide co-teaching, these students with disabilities have larger aspirations in their lives to accomplish beyond upper education. Also, they want to meet the same expectations as other students by getting traditionally enrolled, engaging in more volunteer work, and having greater opportunities to participate in classroom activities that are in other forms of communication – such as in writing or in hand/body gestures.

In order to help individuals with disabilities communicate better beyond

verbal communication, there was a rise of technological support to empower individuals and help them receive an enhanced education. The Center for Applied Special Technology (CAST) was developed by five clinicians, Anne Meyer, David Rose, Grace Meo, and Skip Stahl, from North Shore Children's Hospital in Salem, MA. In 1984, with a grant of \$15,000, CAST began to extend laboratory services to children with physical and sensory challenges. CAST identifies ways in which technology could be brought into classrooms to enhance literacy for students with disabilities. The CAST is now implemented in 16 New England schools, which promotes a CD-ROM-based instructional program called *WiggleWorks* for special curriculum development. The approach to understand how education may be enhanced through flexible methods and materials is called Universal Design for Learning (UDL). CAST's mission is to "expand learning opportunities for all individuals, especially those with disabilities, through the research and development of innovative technology-based educational resources and strategies" (CAST website).

Technology-based solutions emerged as Apple Computer introduced the Macintosh, and cyberspace appeared. In 1985, CAST established a Learning Lab that offers evaluations, which matches students' needs with computer solutions, and computer-based tutorials which uses application and instructional software. Classrooms began to implement CAST's suggestions as the Apple Macintosh's graphical interface and built-in text-to-speech service improved learning for individuals with disabilities. Apple releases HyperCard in 1987, which was among the first successful hypermedia systems before the World Wide Web.

HyperCard combines database capabilities with a flexible, graphical, user-modifiable interface and features audio digitizing devices, including HyperTalk where objects exist in a message path hierarchy and respond to messages created by either the user or the system itself, such as timers. Accessible digital books that talk and function with single switches also appeared in 1987, which gave easier reading accesses to SWD.

In 2001, the Universal Learning Center (ULC), a service of the Center for Applied Technology (CAST) introduced a digital curriculum for teachers in classrooms to support students with learning, sensory, or physical disabilities (“CAST Debuts”, 2001). Started out by featuring 9th and 10th grade social studies and literature reading materials, the Universal Learning Center covered a wider range of core curriculum materials which included textbooks and existing public digital materials (“CAST Debuts”, 2001). The Universal Learning Center, a part of the Universal Design for Learning (UDL) approach and an extension of the National Center on Accessing the General Curriculum (NCAC) at CAST, is compatible with screen readers, desktops, hand-held technologies, and other devices that students with disabilities use. The ULC provides “improved teaching, learning, assessment, and the presentation of the curriculum” (“CAST Debuts”, 2001). In general education classrooms, ULC ensures that students with disabilities may have the proper resources necessary to achieve higher educational goals set for them.

Together, with inclusion opportunities at Northern Kentucky University, The Advocacy Center, TIES Program, Career and Community Studies (CCS), and

Peer-to-Peer (P2P) Program, there may be greater awareness of ways to spread support and services to other programs and organizations at the community level so that same expectations and equal opportunities could be achieved even after individuals with disabilities reach the age of 21. Along with technological support for individual empowerment, perhaps a digital curriculum could be set up for future employers to support individuals with learning, sensory, or physical disabilities, just like how classrooms use a Learning Lab to offer evaluations and match students with disabilities' needs with computer solutions, and computer-based tutorials which uses application and instructional software. In order to continue to enhance literacy and communication for individuals with disabilities, the implementation of graphical interface and built-in text-to-speech service should be available in most work places in the United States.

Chapter 5

In order for change to happen, society should avoid viewing people with developmental, emotional, physical, and psychiatric, and learn disabilities as inferior (“Social Justice Project”, 2013). Going past etic perspectives of “disability”, there should be better understandings of the “rationality, purpose, and efficiency of native behaviors” with individuals with disabilities (Goode, 1992, p. 198).

I propose for two policy changes. Part of my proposal requests for community members is to attend at least one required panel discussion in the community that addresses issues of negative social constructions, constitutions of “disability” versus “ability”, and how we may make changes to decrease fault-finding and discriminations on visible and invisible levels. At the end of the panel discussion, community members who do not have disabilities will be required to anonymously write down confessions of initial negative thoughts or experiences they have had, or heard of, related to individuals with disabilities that led to discriminations. As a part of civic community engagement, these community members will be required to form a co-planning relationship with one of the attendees with a disability/disabilities, and to act like a facilitator, a friend, a social companion, and an ally to engage in one of randomly assigned “confession activities” (which are activities that are designed based on confessions that are made) to debunk negative social constructions of “disability” and the “disabled-body”. For example, if a confession was made in which a community member thinks that that individuals in wheelchairs need help in supermarkets because they are inconvenient to other shoppers due to space and time, and are incapable of

shopping alone without assistance, then the community activity would require a chosen community member to go on a grocery shopping date with a panel discussion attendee and to treat him/her with fairness and equal opportunities for independence where help is only given when asked. Also, it will be asked of community members to enjoy their experiences with their peers by reaching greater understanding of each other through explorations. As an incentive for attending one of these annual panel discussions and participating in a community activity post-panel discussion, there will be different biweekly activities free of charge for six months, such as biweekly courses of sign language and other language courses of interest.

There should also be an active pursuit of cognitive stimulation in work places which fosters “curiosity and exploration,” promotes inquisitiveness, and provides opportunities to develop competencies” (Gottfried, A.E., Fleming, & Gottfried, A.W., 1998). A second part of my proposal asks for a digital curriculum to be included in companies’ meetings for inclusive employers who are open to hiring individuals with disabilities with skill sets that meet their expectations. A Learning Lab can offer evaluations and match individuals with disabilities’ needs with computer solutions, and computer-based tutorials which uses application and instructional software. This may help younger individuals with disabilities transition into adulthood with more stable work environments that have support services available to them. The implementation of graphical interface and built-in text-to-speech service, that is requested to be available in most work places in the United States, should work to enhance literacy and

communication for individuals with disabilities and help them achieve greater work opportunities in later life.

Shaping and modeling should not only be implemented in classrooms, but should also be available in the community and workplaces so that physical, attitudinal, and systemic barriers in learning could be better understood. Since IDEA creates a gap in service and care between childhood and adulthood for those that do not identify themselves with a disability, support staff, friends, and family members can help a student with a disability dealing with this process” (Peer Partner #1, personal communication, February 18, 2014). There should be social relationships that support and value achievement, such as those in The Advocacy Center, TIES Program, Career and Community Studies (CCS), Northern Kentucky University, and Peer-to-Peer (P2P) Programs. Since it is difficult to transition out of childhood support services and into adulthood after the age of 21, “it is crucial that students with disabilities know their rights and what services they are entitled to or not by identifying with or without a disability” (Peer Partner #1, personal communication, February 18, 2014). Also, not only can support staff, friends, and family members help these transitioning individuals better prepare for adulthood, community members and employers can also contribute by being supportive and accommodating.

With these two recommended policy changes, I hope to see an inclusive community that enables individuals with disabilities greater opportunities to later grow in supportive working environments with further developed social and communication skills. Even though society has gone far in eliminating negative

social constructions, discrimination still inevitably exists today. Focusing on “disability” and what constitutes it, proposals of change are made to help community members and employers better understand individuals with disabilities through emic perspectives. Without service and care provided to individuals who do not identify themselves with a disability after the age of 21, the ultimate purpose is to help these individuals find more accommodating services to help them better prepare for adulthood. Programs such as The Advocacy Center, TIES Program, Career and Community Studies (CCS), Northern Kentucky University initiatives, and Peer-to-Peer (P2P) help individuals feel a sense of belonging that helps them emotionally thrive and achieve life objectives. With the expansion of these programs and initiatives to the community and work level, individuals may eventually break free from society’s stigmatizing labels and biases and recognize “community value, capacities, potential, and worth” (Kliwer, 1998, p. 1).

“You must be the change you wish to see in the world”

-- Mohandas K. Gandhi

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Appendices

Survey questions for traditionally enrolled peer partners in the Peer-to-Peer (P2P) Program:

- 1) From your experiences working/volunteering at Peer-to-Peer, what kind of progress do you see in your non-traditionally enrolled partner?
- 2) What drives your passion to help students with disabilities both socially and academically succeed?
- 3) What emphasis do you think should be placed in schools to help enhance learning for students with disabilities?
- 4) The Individuals with Disabilities Education Act (IDEA) requires schools to provide early intervention, special education, and other related services to over 6.5 million eligible youths with disabilities. However, beyond the age of 21, students with disabilities who do not identify themselves with a disability will not be entitled to service and care. What do you think about this?
- 5) What main educational change(s) would you like to see in the next three or five years for students with disabilities?

Survey questions for non-traditionally enrolled peer partners in the Peer-to-Peer (P2P) Program:

- 1) What do you think about the program and your partner(s)?
- 2) Do you often feel included in conversations and classroom activities?
- 3) What are some of your goals for the future?