Naming Her World: A Freirean Analysis of a Young Woman with Asperger Syndrome’s Post-High-School Experience

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Background
Paulo Freire (1970) contends “one of the gravest obstacles to the achievement of liberation is that oppressive reality absorbs those within it and thereby acts to submerge human beings’ consciousness” (p. 51). As we sought to appreciate the major life transition beyond high school of Francine, a young woman diagnosed with Asperger Syndrome (AS), we discovered Freire’s contention all-too-often resonates through her story. In this study we sought better to understand to what extent the Individual Education Plan (IEP), a written document developed for students with disabilities eligible for special education services, adequately prepared one girl for major life transitions following high-school graduation.

We gleaned vital information from Francine’s words in several in-depth interviews concerning the heart of our project, but her recommendation to others with disabilities was particularly telling. When asked, “What advice would you give to an incoming freshman who had disabilities?” she responds, “Use your teachers. Use the resources provided for you and get help when you need it.” Paradoxically, she admits she did not ask for help in high school, even though her mother is a teacher for special needs students. She eloquently summarizes her high-school experiences by explaining, “You are kind of scared because it’s your first year. The other freshman, they’re not going to help you because they are just as scared as you.”

During subsequent interviews with Francine about her experiences in college, she offers evidence her fears have not abated with maturity. Although enrolled in a local community college for two years, she still experiences an overwhelming sense of confusion and loneliness. It was as if she were waiting for life to begin as she failed to make the types of
decisions expected of a responsible adult. Keenly aware of difference, her self-perception seems anchored in being an outsider wrapped within a dread of independence. Even years after graduation, she still feels isolation from being categorized with a disability. How were we to explain why a process and plan meant to meet Francine’s unique needs would ring hollow in her experience? A Freirean analysis of Francine’s words and experiences helped us delve into why she struggled through much of her post-high-school transition. Perhaps this honest glimpse into her story will offer hope to other students with AS and the educators who work with them.

Recognizing the majority of special education research is composed of quantitative studies, we determined a qualitative investigation would allow us to delve deeply into a single participant’s complexities (Paul, Kleinhammer-Tramill, & Fowler, 2009). Our purpose was to explore the post-high-school experiences of a young woman with AS, and we chose a qualitative, single-case-study design to uncover her unique supports and needs (Heck, 2011). Because individuals with AS are distinctive in their strengths and weaknesses, a focused study was essential to identify factors of concern and to offer insights concerning the in-depth complexities of lived experience. Our research initially was guided by the questions: How does an individual with AS negotiate the journey into post-high-school life and, how might Francine’s experiences inform educators developing transition plans better to assist students with AS to be more successful while in high school?

**Review of the Literature**

**Characteristics of the Disability**

Asperger Syndrome was first identified by Hans Asperger in 1944, and is currently classified within a collection of disorders under the Pervasive Developmental Disorders (PDD) category of disability in the Diagnostic and Statistical Manual of Mental Disorders-IV-TR- (DSM-IV-TR) (APA, 2000; Wolf, Brown, & Bork, 2010). Included in the same PDD category are other conditions such as autism, Rett’s Syndrome, and childhood disintegrative disorder. AS is a genetic, neurodevelopmental condition with no known cause or cure. Understanding individuals with AS is a growing field of study, yet remains “shrouded in confusion and mystery” (Hesmondhalgh, 2010, p. 32). The Centers for Disease Control (CDC) (2012) recently released new data focusing on all areas of AS, estimating about one in 88 children are identified as having AS. However, CDC data sheds little insight on causes or effective treatments.

Individuals with AS are often considered highly functioning compared to others on the autism spectrum. While some argue the syndrome falls within the mild continuum of Autism Spectrum
Disorders (ASD), Raymond (2012) cautions, “mild does not mean ‘not serious’” (p. 7), further elaborating these terms represent decades of debate among researchers, parents, and educators. This controversy is expected to continue when changes to the classification of ASD and AS are released with the *DSM-5* in May 2013 (APA, 2011) since the newest diagnosis guidelines adhere to a more-stringent definition within ASD (Autism Research Institute, 2012).

While definitions of AS syndrome remain fluid and complex, typical characteristics include normal or above-normal cognitive functioning and limited interpersonal skills, including poor eye contact, diminished facial recognition, awkward body movements, challenges interpreting body language, impaired social interactions, and difficulty with organization.

**Legislative Mandates**

Preparing for and understanding the post-high-school needs of individuals with AS is a new and widely understudied area of research (MacLeod & Green, 2009). Effective secondary transition planning for students with disabilities plays a critical role in their post-school-life success (Kochhar-Bryant & Greene, 2008). Legislative mandates for effective transition planning were first enacted in the Individuals with Disabilities Education Act’s (IDEA) 1990 reauthorization, and again in 1997 (Wehmeyer et al., 2007). Then transition services were vaguely defined as a means to assist disabled students to achieve independent living skills and increase post-high-school employment opportunities (Kochhar-Bryant & Greene, 2008). The most current reauthorization of IDEA in 2004 tightened the mandate for transition services while ushering in a contemporary design for transition programs for students with an IEP. New emphasis was placed on the concept of transition as a synchronized action plan to prepare students for adult living. However, findings from several ground-breaking research studies on disabilities and post-school success, such as the Special Education Elementary Longitudinal Study (SEELS), determine those students labeled ASD have the poorest outcomes in employment, advocacy and social skills (Wagner et al., 2005).

**Transition and Post-High-School Success**

Transition services are known to be critical for ASD students’ successful post-high-school employment, independent living, and social skills. It is therefore wise for teachers to embed transition goals within the student’s IEP, thus actualizing these skills across the curriculum based on the student’s strengths and needs to provide a coordinated set of activities engaging a wide range of community resources. This overarching, forward-looking strategy is built on a backward preparation design to the post-high-school world. Although well established in the
literature, how this design strategy looks in actual practice is often a nebulous, ever-changing ideal. Despite an influx of legislative and curriculum-based approaches, post-school outcomes for individuals with disabilities lag far behind their non-disabled peers, resulting in devastating consequences (Barnard-Brak, Lechtenberger, & Lan, 2010; Higbee, Katz, & Schultz, 2010; US Department of Labor, 2011). Raymond (2011) finds special education may inadvertently promote a lifetime of learned helpless behavior if self-advocacy and social skills are not embedded within one’s IEP. Her caution reverberates with Freire’s (1970) suggestion that people can only become fully human when they are subjects who actively participate in transactional mediations with their world. In light of the many documented historical inequities in special education, it is imperative educators focus significant effort to assure IEP goals are well established and incorporate a wide continuum of services so students have every opportunity for success upon public-school graduation. However, as Freire (1970) generally argues, success is dependent not simply upon support in the objective sense, but also necessitates those with disabilities like Francine are humanized throughout schooling processes so they may have the confidence and knowledge to act upon their world.

Theoretical Frame

Through his literacy work with Brazilian peasants, Freire (1970) theorizes oppressive relationships fundamentally are dehumanizing and prevent individuals and groups from acting as equal participants in society. He defines oppression as those situations in which guidelines and choices of those in power are imposed upon, and consciously internalized by, the oppressed. Oppression is manifest in both subjective consciousness and objective conditions that prevent people from becoming fully human or constructing their own understanding of reality. Those oppressed are likely to doubt their abilities and defer to others as capable beings with the necessary knowledge and answers for shaping the world. Freire maintains the hierarchical organization of and lack of dialogue within traditional schools sustains the systematic oppression of larger society.

Freire contends traditional schools adhere to a “banking model” of education in which information is deposited from the knowing teacher into his or her passive students. Student-teacher relationships therefore consist of a one-way narration of a “motionless, static, compartmentalized, and predictable” reality (p. 71). The role of students in this paradigm becomes to accept information without questioning—or even understanding—meaning or purpose. Content is often foreign to students’ lived experiences and, by consequence, students are unable to make worthwhile contributions and rendered dependent upon their teacher.
Liberation becomes possible only when oppressed peoples engage in reflection and action to replace the guidelines of oppressors with “autonomy and responsibility” (p. 47). Freire’s idea and implementation of *praxis* addresses both subjective consciousness and objective conditions with the aim of transforming and, ultimately, liberating the world. Freire (1970) argues reality is not static and set, but constantly remade, so those in search of liberation should understand their present place in history as a point of departure for becoming. Therefore, “to exist, humanly, is to *name* the world, to change it” (p. 88), and those oppressed must become able to see their world as a problem “in need of new *naming*” (p. 88) through assigning language to reality. The traditional dichotomy of oppressive interactions can then be replaced by dialectical relationships that engage participants as co-equal investigators. Dialogic relations among people, with consideration of objective conditions, allows for naming.

Freire proposes a problem-posing education encourages students to view the world and their position in it critically, but to do so the student-teacher relationship must be revised as authority gives way to co-operative and committed engagement. The current, dichotomous roles of teacher and student must be blurred so students are also free to act as teachers and teachers as students. The task of students therefore becomes not merely to take in knowledge about topics alien to lived experience, but to work as co-investigators with teachers to identify pertinent problems in need of investigation. The efforts of liberatory pedagogy “must coincide with those of the students to engage in critical thinking and the quest for mutual humanization” (p. 75). Through this process students can come to see reality re-presented as a problem they are fully capable of acting to affect.

**Methodology and Methods**

A qualitative, single-case-study design was utilized for this project to provide in-depth insights to the experiences of an individual with AS. Case-study research historically has been used to capture the unique, complex needs of individuals with AS (MacLeod & Green, 2009). While the strengths and weaknesses of people with AS differ significantly, social interaction difficulties and repetitive behavior are common characteristics that cause difficulties with independent living. As MacLeod and Green (2009) state, “Young people with Asperger Syndrome are trying to make sense of a complex condition which [affects] every interaction they have and it can be difficult for them to recognize what support they need” (pp. 638–639). Francine’s case provides an important example of those struggles typical, recent, high-school graduates with AS may encounter. We are interested in Francine’s case for its similarities to the experiences of others with AS, but also for
the deep insights we stand to gain from better understanding the singular ways she navigates the complexities of adult living (Stake, 1995).

Data consisted of transcripts from semi-structured, audio-recorded interviews conducted over a span of three, consecutive years. Data analysis was accomplished through the use of open coding, line-by-line analysis, identifying themes, and categorizing subcategories until themes emerged. We then identified indigenous themes through analytic processes of constant comparison, data coding, analytic statements, and descriptive analysis. Triangulation then strengthened and confirmed the identified themes through the convergence of multiple data sources, such as field journals, member checks, and peer debriefing.

**Our Participant**

Francine was diagnosed as having AS when she was in high school, but previous psychoeducational testing from her middle-school years determined she was eligible for special education services based on the category “Other Health Impaired” due to her severe anxiety, depression, and attention deficit hyperactivity disorder (ADHD). Francine’s last re-evaluation in 11th grade indicated AS with a comorbid diagnosis of anxiety disorder and ADHD. She graduated three years prior to our first interview. She identifies her ethnicity as Caucasian, and currently lives with her adopted mother and father in a small rural home in the Midwest. Francine was chosen through purposeful sampling (Patton, 2002), specifically recruited as a former student of one researcher while in high school.

**Themes**

Several compelling themes emerge as Francine describes her experiences. In all three interviews she seems unable to articulate disability. Her conscious powerlessness is coupled with an equally troubling revelation; she cannot perceive how her disability affects the objective conditions of almost every aspect of her life. A second theme centers on her ability to self-disclose and self-advocate. Other subthemes include issues of socialization, occupational success, and functional independence. At times, these threads seemed to dovetail, weaving in and through one another, creating a tightly woven weft representative of Francine’s challenging world.

**Articulating Disability**

When first asked to identify the disability category making her eligible for special education Francine says, “I think it was autism, but I’m not sure.” Subsequent interviews reveal persistent, contradictory understandings of her disability. For example, when asked the same question during the second interview, her response is, “I don’t know that I ever knew. I think my mom just told me I was going to be in
special education.” By the third year, however, she seems to have
developed a growing perception of her disability: “I have, what is it my
mom said? I have low-scale Asperger’s or something.” Her inability
consciously to understand her disability results in a lack of competence
necessary to advocate for her own needs while in college. Sadly, a review
of her IEP reveals the ability to articulate her disability was never a part
of her high-school-transition goals.

Because Francine is largely unable to identify her disorder, it is not
surprising she also is unable to specify what accommodations and
modifications are appropriate for her, evident in her attempt to ask for
assistance in a college math course. She explains, “I said that I had a
math disability to see if I could get different colored paper or
something.” Although the use of colored paper is appropriate for some
individuals, Francine has never utilized this particular accommodation.
Calculator use is listed as an accommodation in her middle- and high-
school IEPs, and yet, in college, she seems to equate its use to cheating
when she recalls, “[The professor] said we could not use a calculator
because we need to depend on our brains. But I cheated and used a
calculator anyway!” Most surprisingly, her mother enforces the
professor’s view, “If she sees me sitting at the kitchen table using a
calculator, she says, ‘Does Mr. Smith let you use a calculator?’ ‘No,
Mommy.’ ‘Then put it away.’ ‘Yes, mommy.’” A hired math tutor
exhibits a stronger grasp of Francine’s needs by allowing her to use a
calculator. Francine says the tutor’s reasoning was “because most of
these problems I can’t do in my head.” Interestingly, she does not view
an accommodation used in school for many years as necessary in college.

During her matriculation at the local community college, Francine
communicates conflicting explanations concerning her need for
modifications. At the time of her first interview, she was attending
summer classes and claims she does not need to disclose her disability
because it is unnecessary. However, by the end of her first full year of
study she recognizes she needs help because classes are becoming more
difficult. Francine indicates poor organization causes her to struggle
in her classes when she discloses, “I am not motivated if it is not in front
of me, then I don’t really think about it.”

She further expounds upon her feeling of isolation in college when
she says, “I was on my own. I would go to class and [the instructor]
would do the lecture and she would say, ‘Your homework is this and this
and this.’ And then that would be it.” She cites her lack of organization
as the reason for finally dropping out of college, “If I could write down,
then I think I’ll be better.” Instead of articulating an understanding of
her disability, she attributes her college failure to being “lazy.” She says,
“I just wasn’t motivated to study. I have to get off my lazy butt and do
this.” By the third interview, however, she recognizes some of her needs, saying, “My math probably was the hardest, that was the worst…and I just didn’t want to do it.”

Whether due to maturity or intervention by vocational rehabilitation services, Francine is able clearly to articulate nascent self-understanding by the third year of data collection. She remarks, “I always knew I was different from other people because I could tell by the way I interact with them.” When asked if knowing about her disability helps her, she responds, “What it means to me, basically, it helps explain why I have trouble connecting to people. I think different than other people.” This statement represents a prodigious move forward for Francine. It signals she is able finally to recognize who she is, appreciates her unique strengths, and may be able to initiate processes of self-disclosure and advocacy. However, her understanding of how her disabilities fully affect her life is, even now, both incongruous and not fully realized.

Shortly after her diagnosis with vocational rehabilitation services, she begins to develop more confidence and an elevated sense of self-esteem. Between the second and third interviews, she begins work at a job she genuinely enjoys. Her work with a vocational-rehabilitation job coach seems to make a difference in her employment success compared with previous short-lived jobs. Her coach mentors her and her manager about various nuances of ASD. Francine articulates her transformation in her third interview when she reflects, “I think I’m braver. This job helped because I have to have more confidence in myself, and I’m not afraid to try new things now.” Her increased confidence at her place of employment translates to school, but that confidence is short-lived. She admits, “I was braver in my classes, but I wasn’t as brave to ask for help. I should have asked for more help, especially when I started having trouble. I thought, well, I think I’ll be okay…and I wasn’t.”

**Growth**

By her third interview, Francine articulates growth that seems to grow both from her formal diagnosis by Vocational Rehabilitation Services (VRS) and her new job. Although steps taken over the three-year time span are small, she begins to realize her dream of happiness and independence in adulthood. Some specific illustrations concisely demonstrate her growing strengths. Francine employs a self-accommodation when she begins taking a friend with her to talk to one of her community-college professors. This accommodation affords her the assurance to overcome some of her fears as she admits, “I still need my big security teddy bear.” Francine’s friend even convinces her to join several clubs and participate in various on-campus activities. Francine recognizes she is uncomfortable in social settings, explaining, “The more people there are the more scared and nervous I get. I don’t like big
groups of people. I’ll just sit there and be quiet.” However, she also acknowledges the need to become more involved in the college community and she looks for ways to overcome her fears.

Francine shows additional strength by disclosing her disability to her employer. She confesses her difficulty with money, and allows the VRS coach into her place of employment. “After she talked to them, I noticed they didn’t treat me different, but they would step in and ask if I needed help.” This collaborative approach supports her growing self-assurance by allowing the safety of making mistakes without fear of ridicule. “I started changing because I started asking for more help.” Emergent confidence equate with Francine’s deeper self-actualization: “I’m not ashamed of my disability, but I don’t want to broadcast it because I am afraid that people will treat me different. I’m different, but I’m NOT! I’m the same kind of person as you.”

**Analysis, Findings, and Implications**

Francine’s dehumanization is evident in her initial, post-high-school experiences because she is unable successfully to address the subjective and objective conditions of her reality. Those who are oppressed can only achieve liberation when “they perceive the reality of oppression not as a closed world from which there is no exit, but as a limiting situation they can transform” (Freire, 1970, p. 49). Initially, there is little indication Francine saw her reality as something she could affect and, not surprisingly, she does little to liberate herself. Some growth is discernible by her final interview, but still she struggles to translate subjective growth into changing objective conditions. Subjective consciousness and objective conditions are often interconnected and cannot be separated in lived experience. However, for the purposes of our argument, we offer evidence from Francine’s story pertinent to each aspect of praxis.

**Subjective Consciousness**

Even though Francine’s disability was addressed extensively in her high school IEP, she struggled to articulate or name her disability and what it means for her life. The fashion in which she discusses her disability is typical of someone who has been “told” a diagnosis, not someone who has been engaged in a meaningful dialogue about the intricacies of her strengths and needs. For example, this lack is evident when Francine exhibits self-deprecation by deferring to her mother’s knowledge of her disorder. She seems to distrust herself and often seeks out others for “knowledge and to whom [she] should listen” (Freire, 1970, p. 63). She also seems to have internalized negative connotations often associated with being labeled a person with a disability. Francine’s experiences at the local community college reveal a hesitancy to be
considered “different,” even when she must articulate her needs to be successful.

For many individuals with AS, the ability to disclose or self-identify as having a difference may be hindered by many factors: fear, embarrassment, lack of support, communication difficulties, or self-esteem. Yet, if students with AS cannot name their world then they are likely to be at a loss as to how to change it. MacLeod and Green (2009) observe that, like Francine, many individuals’ AS is identified later in life. Indeed, Francine is not able correctly to identify her disability until she is 24 years old. Dependence upon others to name disability characteristics and then make accommodations for instead of with AS students in high school can be oppressive as it renders students passive spectators of their own lives. Students with AS face enormous challenges as they move from the highly structured, parent/teacher-supported environment of high school into the adult world where they face the daunting task of having to advocate for themselves, seek assistance from countless agencies, and navigate reality, often with limited communication and social skills. While numbers of students with all disabilities are growing in post-secondary education, they remain at highest risk for dropping out (Barnard-Brak, 2010).

Freire (1970) argues those who are oppressed cannot be explained to, but must be dialogued with, as they develop their own understanding of and plan for their lives. Wehmeyer et al. (2007) argue for the importance of teaching students with disabilities self-determination skills in order to equip them with a better understanding of how their differences affect their place in the world. School personnel can work collaboratively with students to cultivate self-determination skills that might affect more positive outcomes in a student’s adult life compared to those that do not. Ideally this process begins as early in the educational process as possible. Waiting for the IDEA-mandated age of 16 for students to become a part of the IEP process proves far too late. Components of self-determined behavior include: choice-making skills, problem solving, goal setting, and self-advocacy. All these characteristics must be understood by students in meaningful and relevant ways and then generalized to be effective. A dialectical approach to cultivating self-determination skills encourages students’ subjective understanding through active participation so objective conditions might be addressed.

Unfortunately, if both sides of praxis are not addressed then liberation will fall short. Freire (1970) contends dialogue without action results in mere verbalism and action without dialogue results only in activism. For example, throughout three years of interviews Francine talks of a need to be organized in order to be successful in college.
However, she is never able to equate the use of her assignment planner in middle and high school with her college planner. Her ability to transfer that skill once she leaves the structured environment of high school sadly is lacking, so her objective conditions remain unaffected.

Francine’s inability to translate plans into action also leads to her eventual dropping out of community college. Although she attempts to locate the Office of Disability Services (ODS) to self-identify, she is never successful in accomplishing this quest: “I must not be going into the right thing because they said they would not be able to take on my case. I asked, ‘Is this not the place you go when you have disabilities?’ So I was really confused.” Francine’s experience is consistent with recent research uncovering how students with disabilities in higher education face segregation “and experience both overt and more subtle forms of discrimination” (Higbee, Katz, & Schultz, 2010, p. 8) due to their inability to navigate the maze of paperwork, identify appropriate personnel, or perform self-disclosure.

**Objective Conditions**

Francine’s inability to name her reality, much less communicate a nuanced understanding of that reality, results in her powerlessness to “change it” (Freire, 1970, p. 88), evident in numerous circumstances where she remains unable to obtain appropriate, needed assistance. Fortunately, Francine seems liberated when she is able to advocate for herself and once vocational rehabilitation services helps her better to name and disclose her disability.

Francine is able to produce the most favorable changes in her post-high-school life when she works in association with others. Taylor and Seltzer (2011) report individuals with AS and a comorbid psychiatric disorder such as Francine have limited independence and diminished social functioning in adulthood compared to those with an AS identification alone. For such students, additional post-high-school supports are critically needed to assist in their transition from high school to adult life; recall Francine only realizes occupational success with the help of her VRS job coach. Because many people who need VRS are not eligible or are placed on lengthy waiting lists for services, it becomes all-the-more critical transition skills are explicitly addressed in students’ IEPs.

**Implications for Objective Conditions**

Students with disabilities should also be taught to understand the unique accommodations necessary to address individual strengths and needs. Role-playing scenarios with directed teacher feedback can assist in this regard. VanBergeijk, Klin, and Volkmar (2008) suggest the use of
a personal digital assistant (PDAs) for a visual representation of an organizer. Other accommodations include: audible alarms, hard copies of class notes or lecture slides, breaking down large assignments into more manageable chunks, and assistance with abstract terms. These evidence-based accommodations easily can be called upon in myriad situations in which a student might find him or herself.

In the high-stress world of higher education, it can be especially critical institutions construct a structured environment for AS students in order to counterbalance the social difficulties they encounter. Although an IEP is not valid in higher education, ADA mandates are in place to assure individuals with disabilities have equal, accessible instruction. Accessible curricula and academic programs must also be implemented if higher education is to become a reality for all people, regardless of ability. Lechtenberger and Lan (2010) attribute the lack of accessible university curricula and programs to universities’ failure adequately to provide for this population’s diverse needs.

Although never explicitly stated, Francine could tell some of her professors considered her as different, as defective: “Some teachers, they don’t mean to, but they are just so used to what they are teaching and it’s so obvious to them, so their answers just kind of come out like they think you are stupid.” Francine’s experience is referred to by Higbee, Katz, and Schultz, (2010) as “marginalization of language” (p. 10), a situation in which oppressive ways and demeaning language can work to segregate those with learning differences. Many students’ classroom difficulties may be the result of professors’ misinterpretation of AS characteristics, a key reason why mutual cooperation is imperative to successful adaptation. For example, individuals with AS exhibit limited response to facial cues, which may be misinterpreted by faculty, other students, or administrators as rudeness or disinterest (Wolf, Brown, & Bork, 2009). Most universities do not provide training to faculty and staff on working with students with learning differences, but some ways to assist faculty and staff may be through the dissemination of fact sheets or through small workshops that focus on marginalizing language, perceptions of labels, and help for parents.

Concluding Thoughts

Results from our case study may be significant at several levels for students with AS. We argue Francine would have benefitted if both thoughts about her situation and her ability to translate these ideas into action were addressed more fruitfully throughout her education. Ultimately, we maintain liberation is only made possible through the “profound love” (Freire, 1970, p. 89) of educators and other individuals willing fully to engage in co-operative dialogue with students like
Francine. A transformation must begin with the student’s inclusion in dialogue during, and even before, the creation of his or her high-school-IEP transition plans. Additionally, Francine could have benefitted from immediate support as she transitioned from high school to higher education, for she required a learning design welcoming and supportive of students of all abilities. While, ultimately, Francine does not achieve her goal of college graduation, we hope others with AS and those who support them can work to create a more robust, accommodating environment for students with AS so others, like Francine, may liberate their fullest potential.

References


