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Fleur Wiorkowski
Capella University, fwiorkowski@sbcglobal.net

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Abstract
This inquiry was conducted to describe the experience of individuals with autism spectrum disorders who have experienced the higher education system. All participants have been diagnosed with an autism spectrum disorder and experienced some aspect of the higher education system. Data was collected using primarily face to face interviews. The data was then analyzed using the heuristic methodology of Dr. Clark Moustakas (1990). Ultimately, many patterns and themes emerged from this analysis, culminating in a creative synthesis which sums up the experience. The themes showed the highs and lows of being a college student coupled with the experience of having a developmental disorder as an adult. The final creative synthesis focuses on the life altering changes that occur during the course of the higher education experience for students with autism spectrum disorders.

Keywords
Autism Spectrum Disorders, College, Higher Education, Heuristic, Personal Experience

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The Experiences of Students with Autism Spectrum Disorders in College: A Heuristic Exploration

Fleur Wiorkowski
Capella University, Fort Worth, Texas, USA

This inquiry was conducted to describe the experience of individuals with autism spectrum disorders who have experienced the higher education system. All participants have been diagnosed with an autism spectrum disorder and experienced some aspect of the higher education system. Data was collected using primarily face to face interviews. The data was then analyzed using the heuristic methodology of Dr. Clark Moustakas (1990). Ultimately, many patterns and themes emerged from this analysis, culminating in a creative synthesis which sums up the experience. The themes showed the highs and lows of being a college student coupled with the experience of having a developmental disorder as an adult. The final creative synthesis focuses on the life altering changes that occur during the course of the higher education experience for students with autism spectrum disorders. Keywords: Autism Spectrum Disorders, College, Higher Education, Heuristic, Personal Experience

Until recently, autism was considered a rare diagnosis. However, since 2000 the Centers for Disease Control have gradually increased their official estimates of the rates of autism, with the most recent statistics placing current diagnostic rates at 1 in 88 children (CDC, 2012). This increase in rates of diagnosis has caused an increase in funding for research into autism spectrum disorders overall (Singh, Illes, Lazzeroni, & Hallmayer, 2009). Much of the research regarding autism spectrum disorders focuses on the way the brain influences behavior, as well as genetics (Singh, Illes, Lazzeroni, & Hallmayer, 2009), with considerably less research on issues such as treatment and family services. Research regarding the experiences of individuals with autism spectrum disorders is not mentioned by Singh, Illes, Lazzeroni, and Hallmayer at all. This lack of research into the experiences of individuals with autism spectrum disorders presents a gap in current research regarding autism spectrum disorders. As Martin (2006) concludes, individuals with autism spectrum disorders are the experts in understanding their experience, so excluding their voices from research does a disservice to the research community, as well as those people who have ASDs.

In the past there has been considerable research into the outcomes of individuals with classic autism and, in more recent times, autism spectrum disorders overall. Much of this research has predicted a low outcome for children who are diagnosed with autism spectrum disorders. For example, Eisenberg and Kanner (1956) presented a longitudinal study in which 50 children diagnosed with autism spectrum disorders were followed into adulthood. Most of these individuals continued to have major social issues in their adult life and were not able to achieve in ways that are considered traditional, such as living independently and having a career (Eisebeerg & Kanner, 1956). These sentiments are reflected by many other authors who have followed those diagnosed with autism spectrum disorders in longitudinal studies (Rumsey, Rapoport, & Sceer, 1985; Rutter, 1970; Venter, Lord, & Schopler, 1992).

Of the authors that report a higher adult outcome for students who were diagnosed with autism spectrum disorders as children, the issue of higher education is often used as a measure of achievement. Kanner (1972) discusses several cases of individuals with autism spectrum disorders who were able to graduate with undergraduate degrees and one student who achieved
Brown (1978) discovered similar findings with 24 of the 100 individuals involved in her longitudinal study achieving some level of higher education experience. Both Kanner and Brown noted that despite receiving degrees, many of the individuals in their studies were employed at levels well below that expected for their education. These lower employment levels were due to the social difficulties that are a major part of autism spectrum disorders (Brown, 1978, Kanner, 1972). This trend of longitudinal studies reporting a small number of individuals with autism spectrum disorders who achieve degrees in higher education settings continues into modern research (Howlin, Goode, Hutton, & Rutter, 2004).

The CDC’s increase in diagnosis of ASDs has led other researchers to look into the challenges faced by students with autism spectrum disorders as they enter the higher education system. These challenges focus on issues of transition (Adreon & Durocher, 2007), scholastic issues (Luckett & Powell, 2003), and social interaction (Harpur, Lawlor, & Fitzgerald, 2004). Despite these challenges, several authors with autism spectrum disorders have described higher education as their ideal environment (Grandin, 1995; Perner, 2002; Prince-Hughes, 2002; Shore, 2003; Williams, 1992). A subset of these authors have chosen careers in higher education (Grandin, 1995; Perner, 2002; Prince-Hughes, 2002). These findings present a discrepancy between the views of researchers regarding the ability of individuals with autism spectrum disorders to achieve in higher education versus the view of the individuals themselves.

The increase in autism diagnosis reported by the Centers for Disease Control (CDC, 2012) suggests that more students with autism spectrum disorders will be entering the higher education system in the near future. In the past, researchers have found that the majority of individuals with autism spectrum disorders have been unable to achieve at traditional educational levels (Rumsey, Rapoport, & Sceer, 1985; Rutter, 1970; Venter, Lord, & Schopler, 1992), which is in direct contrast to the personal experiences of several prominent authors with autism spectrum disorders (Grandin, 1995; Perner, 2002; Prince-Hughes, 2002; Shore, 2003; Williams, 1992). Research into the needs of students with autism spectrum disorders in higher education has increased in recent years, the majority of the research addresses the question from a quantitative perspective (Adreon & Durocher, 2007; Harpur, Lawlor, & Fitzgerald, 2004; Luckett & Powell, 2003). While this perspective is important, it does not provide the rich data that can fully illustrate the experiences of students with autism spectrum disorders as they interact with the higher education system in a personal way. This difficulty was addressed by two researchers in the United Kingdom (Martin, 2005; Taylor, 2006). However, the education system in the United Kingdom is different than that in the United States. Therefore, it is important that a qualitative design is used to explore the experiences of students with autism spectrum disorders in the United States, which is the goal of this inquiry. The current inquiry uses a heuristic method to describe the experience of the participants who have experienced being a student with an autism spectrum disorder in the higher education system.

My own interest in the topic of autism spectrum disorders evolved from my diagnosis with Asperger’s syndrome as an adult. This diagnosis made me reconsider most of my life experiences, including many years of college education. Eventually my own reading about the subject led me to notice that there was very little research on the needs of adults with autism spectrum disorders generally and particularly in the area of higher education. With the increase in autism diagnosis in the United States, I could see a large gap in the research needed to help students with ASDs make the already difficult transition to college. Prior to my diagnosis I had achieved a M.S. in psychology and decided to return to complete my Ph.D. to address the research gap I had noticed. I was able to work my interest in ASDs and college students into my dissertation project for my Ph.D. My goal in presenting this research is to provide a piece of research that can help individuals working in colleges understand the college experience from the point of view of students with autism spectrum disorders.
Methods

The methodology used for this piece was chosen for several reasons. First, the lack of research in the experiences of individuals with autism spectrum disorders in college meant that there were very few prior specific research questions to focus on as the starting point of a quantitative study. In addition, it would be very difficult to quantify something as expansive and diverse as an experience. These initial realizations led to a shift from considering a quantitative methodology to a qualitative methodology. Many qualitative methodologies were explored and considered by the researcher. The two that stood out the most were phenomenology and heuristics. Because the researcher is an individual with an ASD who has experienced the higher education system, the decision was made to use a heuristic methodology so that the researcher’s experiences would not be lost. Moustakas’ method of heuristic exploration was finally chosen because the researcher was able to work with two mentors that had directly studied under Moustakas. Having such direct knowledge of an influential author was invaluable in conducting this research.

Participants

Participants were recruited by placing flyers in the information packet of a conference for individuals with autism spectrum disorders. This particular conference was chosen for several reasons. The conference is hosted by an organization that is committed to expressing the voices of individuals with autism spectrum disorders. Because of this commitment, many of the attendees at the conference are adults with autism spectrum disorders, several of whom had attended college. Participants were included in the study in the order in which they contacted the researcher provided they lived in the United States and were comfortable with a face to face interview process. Each participant made initial contact with the researcher via the telephone or email after viewing the flyer. The sample consisted of 12 participants, including the researcher. The participants were made up of five women and seven men, who ranged in age from 23 to 56. The locations of the participant’s residences were quite diverse with two participants living in California, four on the East coast, and six living in the Midwest. Ten of the 12 participants answered the guiding questions verbally while two participants used typed communication to answer the questions. None of the participants chose to discontinue participation after the interview process began.

This project was approved by the IRB of Capella University as part of the researcher’s dissertation studies. The interviews were conducted in a private location of the participant’s choosing, often a library or hotel near their location. The participants were asked if anything about the location was distracting or made them uncomfortable. Although no participants expressed concerns in terms of the location, any distractions would have been removed if noted. The research data was coded so that the participants contact information is not coded with their interview data. When specific quotes from the data are reported, they are quoted using a name a pseudonym is used to refer to the participant. Finally, all data will be destroyed after a period of 10 years to ensure participant protection.

Procedures

Each participant contacted the researcher via email or telephone after viewing the recruitment flyer included in the conference presentation materials. The researcher then emailed the participant a copy of the materials for the study for the participant’s review. These materials included a face sheet, the guiding questions for the study, and the consent documents for the study. The face sheet requested basic demographic information about each participant.
The guiding questions were eight questions written by the researcher that were used both to give the participant a preview of the contents of the interview and as a way of restarting a stalled conversation during the interview itself. The questions were designed to both provide a complete picture of the participant’s experience and to touch on common themes that had been addressed in the few prior studies addressing individuals with autism spectrum disorders in higher education. The questions were as follows:

1. What is your experience of higher education overall?
2. How would you describe your social experience of higher education?
3. How would you describe your experience of classes in higher education?
4. How would you describe your interactions with people who work for the university?
5. How did your experience of higher education change your day to day life?
6. What is making you or did make you successful in higher education?
7. Are there any particular feelings that describe your experience of higher education?
8. Is there anything I didn’t ask you that you would like to tell me about your experience of higher education?

After the participant reviewed the materials and confirmed their continued desire to participate, the researcher made arrangements to visit a neutral location that was convenient to the participant. Ten of the eleven interviews were conducted in local libraries, while one interview was conducted in a private hotel conference room. The length of the interview was determined by the participant, but averaged about an hour. Each interview was recorded using two digital recorders and then transcribed by a professional transcriptionist. The resulting transcribed document was reviewed by the researcher while listening to the initial recording to ensure accuracy.

The researcher was also a participant in this inquiry. To access personal memories of experiences in higher education the researcher journaled extensively regarding each guiding question. These journal entries were included in the data analysis process as if they were an interview in themselves. The journal entries were also used by the researcher to identify and remove any biases regarding the research topic and potential expected experiences of the participants. The researcher also consistently considered that each individual has had their own experience which is unique to them. This understanding guided the analysis process and the researcher’s goal to preserve the individuality of the experiences being represented.

The data was analyzed using the six step model proposed by Clark Moustakas (1990). This model focuses on discovering meaning within the data by engaging it in all areas of the researcher’s life as well as viewing participants as co-researchers. The first step of Moustakas’ model is initial engagement which involves discovering the topic of consideration and formulating the question itself (Moustakas, 1990). Immersion is the next stage and consists of the researcher realizing the implications of the topic both in the research literature and the world as a whole. The researcher engages the topic and discovers that the topic is around them all the time (Moustakas, 1990). After this period of intense interest in the topic the researcher retreats from the topic and is aware that the topic may present itself at times as realizations regarding the topic are made at the subconscious level. This stage is called incubation. Moutakas (1990) likens this process to the common experience of finding one’s lost keys after ceasing to look for them. During the period of incubation, various realizations regarding the topic will present themselves as the subconscious mind continues to consider the research topic. These realizations are called illuminations. They are sudden pieces of understanding regarding
the topic being researched (Moustakas, 1990). Next, these illuminations are carefully considered during the explication phase of the heuristic data analysis method. During this phase patterns and themes are recognized within the data. These patterns and themes are considered and explored by the researcher (Moustakas, 1990). Finally, a creative synthesis is created regarding the research question as a whole. This creative synthesis is a way of encapsulating the entire experience being studied in a few paragraphs (Moustakas, 1990). It is important to note that each of these steps is conducted for each individual participant and then for the data as a whole, which allows the individual experiences of each participant to be synthesized into the overall creative synthesis for the experience itself (Moustakas, 1990).

For this inquiry, the data analysis process began with highlighting all the statements within each transcript describing the experience of being a student with an autism spectrum disorder within the higher education system. These statements were then removed from the transcript and placed in a separate document. The researcher reviewed each quotation and wrote a short statement that summarized the experience being described. These statements were then analyzed for common patterns. Finally, the patterns were compiled into themes that were interwoven within the interview. These themes were supported by direct quotes from the participant interviews. After this process was conducted for each interview, the patterns discovered within each interview were considered as a whole to find themes for the entire experience. These final themes were analyzed and considered to construct the creative synthesis at the conclusion of the project.

Results

During the analysis process detailed above, 31 patterns were discovered regarding the experience of being a student with an autism spectrum disorder who has experienced the higher education system. These patterns were then distilled into 7 themes: interacting with academic subjects, social experiences, personal growth, learning about learning, issues caused by disability, learning about and understanding the future, and feeling proud and positive. These themes and their component patterns will be briefly summarized below. A few quotations from participants will be used to highlight the experiences. Finally, the creative synthesis of the project as a whole will be summarized.

Theme 1: Interaction with Academic Disciplines

The theme of interacting with academic disciplines is the only theme which directly deals with the academic aspects of the college experience. This theme encompassed several patterns: exploring academic subjects, strongly disliking academic subjects, and discovering an area of intense interest. Exploring academic subjects was enjoyable and allowed the participants to begin to understand their personal interests. Often these interests evolved into lifelong fascinations with particular subjects. For example, one participant continues to explore foreign policy and politics as a source of enjoyment. This interest was fostered by her experiences in college.

Part of this exploration involved discovering academic subjects that were not interesting. Sometimes these subjects were disliked because they seemed boring and redundant, but they were also sometimes avoided because aspects of the participants ASD interfered with understanding and excelling in the subject. One participant discussed his fear of taking a history course due to his inability to remember names. Another participant described his frustration at being able to complete an economics class with the grade he would have liked. This student had excellent grades in the classes in his major, but had difficulty with a new subject of study:
But then there was something else on, 300 level economics that was not very good, nope. I tried to use that to fulfill the humanities, social science requirement, but it was not what I was interested in. I thought the material to be very difficult, you know, too abstract. Couldn’t grasp it. Failed. Took it pass fail, so I had no effect on my GPA.

A third pattern involved finding an area of intense interest. This was the discovery of an area of fascination, which often continued to be pursued into adulthood and ideally would be turned into a career. If discovered, the area of intense interest came to permeate all aspects of a participant’s life. This could sometimes be seen visually as in the case of one participant who was covered in tattoos representing his interest, while another participant who was involved in urban design offered to take the researcher on a tour of the town where he lived and worked and various areas that he had designed. The fascination each participant felt for their area of intense interest permeated much of their discussion of their college experience.

The participants who had discovered their area of intense interest were aware that this interest was not necessarily something everyone would find as fascinating as they did:

It was fun. I mean, I thought some of the classes were fun. But then how many people think that comparative communist political systems is a fun class? I—I thought it was, you know, the cat’s meow.

**Theme 2: Social Experiences**

Social issues are a primary aspect of autism spectrum disorders (Adreon & Durocher, 2007) so it is not surprising that social interaction formed a theme. The patterns that made up the theme were as follows: enjoying social interaction, feeling let down by social experiences, experiencing prejudice, learning to interact with others, working with others, learning personal social needs, and helping others/giving back.

The first two patterns of enjoying social interaction and feeling let down by social experiences can be seen as two sides of one experience. On one hand, social experiences were often much more positive than in high school. Some participants expressed the idea that these improved social experiences might be due to increased diversity and maturity in higher education.

All the bad kids were gone. All the immature kids were gone, people were more understanding. The universities I attended, both (universities) were very careful in making a very open and positive, welcoming environment. Appreciating things like diversity and all the different backgrounds.

Not all social experiences were positive, however. Negative social experiences tended to revolve around not feeling accepted and finding that other students would exploit the participant’s knowledge and skill in an academic area.

At (university name), I was in the business fraternity but I got kicked out. . . . They were talking about getting initiated, where you were going to have to go to some dark field. Well I heard that shit and I’m like, eh, and that was my first experience where I came across as not being a team player.

A related social difficulty resulted from the participants focus on academics rather than being social. Several participants felt they had to choose between being social and being successful.
academically. This resulted in a feeling that social interaction had to be abandoned in favor of academic success. This outcome is not necessarily negative in the sense that others caused a difficult situation, but it is negative in that social opportunities were missed.

The third pattern that emerged within the social theme was the experience of direct prejudice. Sometimes these experiences were the result of misunderstandings that could be related to some aspect of the participant’s disability.

And they also seemed to target people who were different. And all of my friends were almost denied a degree at the last minute for some obscure reason. I had a friend in biology who was gay and um, senior year of college, they say, oh you need to take this course, we didn’t tell you about it, and we don’t even offer it. But you need to take this course if you want your degree in May. And things like that.

In other cases participants felt that their ASD symptoms were not severe enough to be taken seriously. They felt that instructors and other students did not believe that there was a disability present.

It was having a hidden disability and looking the way I do, and being moderately articulate. They assume I’m making it up... because not only with the autism but with my hand issues, I’ve got two invisible disabilities.

This issue seemed to be particularly severe for students who were attempting to pursue degrees in education, possibly due to the focus on student teaching in education programs.

He was pretty bad and I really think he made such a big deal about the social stuff. That seemed to be his whole thing, socializing with my cooperating teacher. He said, I mean he criticized me for not taking my lunch break with her, yeah; he really seemed to care about things that I didn’t think were all that important. And the reason I didn’t eat lunch with my cooperating teacher was that she and her friends would be constantly trashing their jobs and I wanted to get away from that and my lunch break was like the only way I could get away from that...

Finally some students had experiences that were difficult to interpret in a way that did not involve direct prejudice.

And my first semester there, while sitting down with one of the deans over something, I don’t remember what it was at this point, she said she wished freaks like me wouldn’t enroll.

The fourth pattern that emerged regarding being social was learning to work interact with others. As discussed in the first pattern of the social interaction theme, many participants had not interacted with others extensively in high school. This meant that learning social interaction in an academic setting began in college. Often the first part of this social interaction involved the participant proving their competency to be in a college environment.

And I know some people and, that includes students, look at my behaviors and think I’m somebody who’s not a student until I start communicating. Uh, we have to prove ourselves so people don’t take us at face value.
Often interaction with others began with interaction with other groups where social interaction was a challenge. One participant learned a great deal about social interaction by talking to students from foreign countries about their social experiences in college, but other participants found that simply being in a college environment fostered increased social exploration and interaction.

I avoided it for quite a while, but it slowly worked its way out. Uh, people I’ve worked with in labs. Um, people that have just seen me using the computers that I use and start asking questions. Um, other people in the honors program. We just slowly start to merge together and hang out and it’s been a fairly organic experience with that.

The fifth pattern within the arena of social interaction was learning to work with others. This pattern progressed from pattern four in which the participants learned to interact socially. The next step was working with others toward a common goal, such as an assignment or project. For several participants the ability to work with others was initially difficult to develop but came to be viewed as vital for both college and career success.

In and it’s a good way to observe; like for instance if you notice a student that’s in more than one of your courses it’s a chance to exchange numbers, email addresses uh so that if one of you is absent the other can get the homework or things of that nature from and maybe even take the opportunity to ask do you want to go get lunch or coffee or something like that and so that again ties into the connections and networking and seeing what this person knows and who they know.

For a few participants this ability to work with others developed into an ability and enjoyment of public speaking.

People would rather die than speak in front of their peers. So once you conquer that fear the world is your oyster. And so I can confidently get up in front of an audience, give a speech and I have done so both in and outside of the school environment.

The sixth pattern that emerged in the area of social interaction involved the participants learning about their own social needs and desires. As the participants interacted with others they began to discover and compare their own social desires and needs with those of others. Often these needs involved being able to be alone and independent for a time to allow for social interaction to be successful.

And I found that I preferred my own room because I really needed my space. I liked having my own bedroom and I always wonder, and it’s hard for me to be on twenty four hours and it’s really hard for me to share a room with a roommate, especially somebody who I don’t know too well. But then, you know, when I had a single room, but I had some very good relationships with my neighbors.

The final pattern to emerge from the theme of social interaction was a desire for the participants to give back to others, often others with a disability or other disadvantage in their lives. This pattern can be seen as a culmination of the social learning that occurred during the
college experience. The participants realized that they can influence the social arena in a way that will benefit others in the future. For several participants these ways of giving back involved helping others within the disability community.

I also worked with the college-bound program. I did that earlier last year in I think early July. And the students in there, autism, Down’s Syndrome, they really responded with a great level of attention to the funny animal videos that I was pulling up on YouTube during my speeches, because they enjoy goofy stuff like I do. And one of them made a comment, “Uh, does he have autism?” Yeah. “He seems like one of us.”

Whatever I study, I bring in autism in some way. Some professors have me talk about it to the students. I see it as my way of making a difference.

Theme 3: Personal Growth

A great deal of change occurred during the course of the college experience for all the participants. This change caused an evaluation of prior ways of viewing the world. Often these views were changed or revised, which resulted in personal growth. This theme is divided into the following patterns: learning through new experiences, rethinking the world, discovering personal strengths, clarifying values, and discovering the complexity of life. Each of these patterns can be seen to build on the lessons learned in the pattern previously discussed.

The first pattern involved learning about the self through new experiences. This pattern represents a form of surprise at personal reactions to new experiences. As the experiences occurred the participants realized that they were more open to new encounters and could perform better in new areas than they had expected.

You know it’s part of the identity of the college, you know how can you do how can you know do this and I went into this whole and I don’t even remember it now. I went into this whole thing and uh you know and he just stared at me and I went into this whole thing about it; like a ten minute thing. I was I surprised - I really surprised myself.

As participants had many new experiences they were required to integrate these experiences into their world view, which required a rethinking of the world as a whole. Understanding other’s motivations was one area in which the college experience changed the participant’s world view.

So that really opened up my mind to having everything being open to debate and there are exceptions and that’s; they should all be explored.

It’s almost independent living aspect of the higher education experience as well as studying the technical aspects of what you like doing the most. Those had both had, had a positive experience on me. And knowing that most the people in the community are very good people and there’s going to be a few bad people, but since most the people are good people.

The third pattern to emerge under the theme of personal growth was discovering personal strengths. This pattern could encompass two aspects. The first was discovering a skill in a particular academic area. The second aspect was discovering a skill in a more complex
area, such as public speaking, memorization, or understanding other cultures. After the personal strength was discovered it was often applied in unique ways that made many aspects of life, both within and outside the college experience, more fulfilling.

The variety of changes in world view and personal discovery experienced during higher education forced the participants to clarify their world view. Participants discovered that they had a level of commitment to themselves and their education that they had not previously realized. For two participants this clarification of world view resulted in a religious conversion that has persisted into their adult life.

Finally, the participants came to some fundamental realizations about the complexity of their life and the college experience as a whole. These realizations resulted in an understanding of their place in the world and the great effect that their college experience had on the course their life would take after college. The participants realized that their understanding of the world and their place in it had changed vastly during college.

I came up with a quote that when you’re in college life no longer comes to you; it’s up to you to come to life and it was a big hit amongst my fellow directors and amongst the students.

I mean I sit here before you and you see me really, really coherent but (university name) really pulled that together.

Theme 4: Learning about Learning

All the participants in this inquiry discovered that learning in high school versus college involved very different skills and ways of understanding. This change in the way material is learned allowed each participant to discover the ways in which they were best able to comprehend new material, which lead to the discovery of a personal learning style. The participants also came to understand their reasons for entering and persisting in higher education. The patterns which make up this theme are: discovering personal learning preferences, understanding learning style, viewing learning as practical, mixed emotions about learning experiences, and feeling let down by college as a whole.

The first pattern of discovering personal learning preferences encompassed a realization about types of learning and instruction that made a class easier or harder. One participant, for example, took a statistics class and had to drop it because of the instructor. The second time he took the class he quite enjoyed it, which he felt was due to the style of the instructor. He felt this class could have kept him from graduating had he not discovered the second instructor. A second part of this pattern was the type of assignment. Each participant discovered their personal preferences for assignments, often finding structured and sequential assignments to be particularly easy to excel in.

The second pattern of understanding learning style came from discovering personal learning preferences but encompassed more than just learning preferences. This pattern includes types of learning experiences that make a class enjoyable and allows for application of the learning that occurs in the class. Abstract concepts and subjects, such as algebra, symbolism in literature, or social sciences, were mentioned by some participants as being particularly difficult. Several participants expressed a preference for learning that occurred in an experiential way and learning from a professor who had experience in their field. These kinesthetic or personal experiences made the subjects easier for the participants to grasp and understand.

Another pattern that was part of learning was viewing learning as practical. Several participants entered the higher education environment with specific goals in mind. These goals
included specific skills such as learning to write and speak at a higher level, but they also included long term goals. One participant commented that she felt that she would not be taken seriously in her field until she achieved a Master’s degree. Another participant realized that she would be unable to achieve the salary that she wanted without a graduate degree. While she had a negative experience during her undergraduate experience she returned to school to get a master’s degree purely for practical reasons.

The next pattern to emerge was having mixed emotions about the college experience overall. While some learning experiences were very enjoyable and worthwhile, others seemed to have less purpose. The participants sometimes felt that these less enjoyable experiences were due to not being in the right class for a subject or even choosing the wrong time for a class. Other experiences were considered as just being a part of the “bumpy road” of the college experience.

Finally, several participants expressed being let down by the college learning experience as a whole. These difficulties stemmed from several sources. One participant was particularly frustrated with the amount of administrative work that had to be done to get assistance from the university, while another participant had difficulty with choosing a major and received no assistance from the university. Other participants just felt let down by the experience overall in every respect. When asked to describe her college experience one participant stated her frustration in the following way:

Ennui. I just found it distressing that it was the same thing over and over, just packaged differently. Nothing new, nothing different.

**Theme 5: Issues Caused by Disability**

Entering the college system with an identified disability came with its own set of challenges for the participants in this inquiry. At times several participants questioned their decision to disclose their disability and even to enter the college system overall. The patterns that made up theme five are as follows: mixed emotions about accommodations, feeling academically behind, and understanding the impact of disability on education.

Having accommodations was essential for the participants to attend college and be successful, but some participants found that their accommodations could almost be more trouble than they were worth. Several participants were particularly bothered by the idea that another classmate had to volunteer to take notes as part of the participant’s accommodation. This seemed unfair to the volunteer student and caused a participant to choose not to use their accommodation. Another participant felt it was unfair that he had to spend his own time taking tests in the testing center, as opposed to taking tests during class time. He felt that this arrangement took time away from his research and other classroom interests. In rare instances professors refused to allow the use of accommodations, which was very frustrating for the participants. Accommodations overall were a source of mixed feelings: they were essential for success but tedious at times.

Feeling behind academically was a pattern for several participants. These participants had often been in special education classes in their elementary and high school education experiences. These classes often did not teach them the basic skills they needed for college classes, particularly in science, math, and English. These participants were forced to work harder than other students from the beginning of their college experience and often adjusted their choice of major around their skill set as opposed to their interests.

Finally, participants came to understand the impact their disability had on their educational experience overall. Sometimes this impact was realizing that a particular environmental situation was not conducive to doing well in a class. For example, one
participant was unable to excel in a class if he felt any sort of time constraint. Another participant sat near the front of the class to minimize auditory distractions. The realization of these types of impacts and the ways to minimize them was as much a part of the higher education learning experience as any academic class.

**Theme 6: Learning About and Understanding the Future**

For students with autism spectrum disorders, part of the learning process in higher education was realizing that there was a future to plan for and the impact that planning can have on that future. Theme six consisted of the following patterns: seeing the need to plan for the future, enthusiasm for the future, fear of the future, and seeing the impact of the future.

The first pattern was simply realizing that there is a future. This realization occurred for several participants and might have come from the structure of time and semesters that is inherent in the college environment. The understanding that there is a future that needs to be planned for came to dominate the college experience for some participants.

With my day to day life I would have to say just I’ve found that I have a lot more structure and purpose. Or I have an idea of how I want to look ahead rather than just focus on today or maybe look at tomorrow or next week and maybe plan an event or something for my own benefit.

The second and third pattern can be seen as the direct opposite of each other. In some cases realizing that there is a future created positive feelings of happiness of excitement, while for others thoughts about the future turned only to fear. Several participants came to enjoy the college environment extensively. They discovered their passion and felt that they had the potential to become influential in their chosen field. They were excited to complete their degree and begin to work.

I’m finally pushing myself to an achievement that I need to go towards. ‘Cause it’s kind of a waste – the Aspergarian-obsessive hobbies that I’m so good at with my IQ, as well, that I could be a real driving force to the field I’m going into.

For other participants, considering the completion of their education brought only feelings of fear and failure. This fear seemed to focus on the idea that the future could be overwhelming.

The final pattern that made up theme six was seeing the impact that the past has had on the future. Some participants began to see the impact that their early placement in special education classes had on their current educational skills. This could be viewed as negative in terms of the deficits mentioned in theme five. However, for others, the lessons learned in special programs simply contributed to their overall pride in their achievement and goals for the future.

I think it’s been very helpful because I’ve been able to take what I’ve been learning throughout high school and college and graduate school and apply it toward getting ready to be in the workplace helping other person with intellectual differences pursue their passions and attain their goals.
Theme 7: Feeling Proud and Positive

The final theme describes the pride that each participant felt in their college achievements. Even for those participants who felt that their overall college experience was negative there were elements of the experience which could be described as positive. Each participant challenged themselves in some and met their challenges during their educational experience. Theme seven is made up of the following patterns: enjoying learning, feeling accepted and supported, feeling successful, and feeling pride.

The first pattern of enjoying learning involved both discovery of subjects of interest and enjoying having access to a great deal of knowledge. Several participants mentioned enjoying having experts in various fields to discuss new ideas with. Other participants enjoyed having the opportunity to learn about a variety of fields.

I really like it. I find it really stimulating to be with other people in an academic setting. I like having deadlines. I like having other really sharp bright minds to bounce things off of. I like being able to go immediately to professors and ask them things and have them be really interested in you and have their experience to talk about.

I love learning. I love showing how I’m smart. And I love the structure of, I think I have a quirk…I fall apart in the summer.

The second pattern of feeling accepted and supported was particularly important. This was the first time that many participants felt that they were accepted for who they were both academically and socially. In some cases this involved a very important mentor relationship but at other times it was simply being accepted and supported by peers and classmates. This acceptance was expressed as a new experience that had not been felt prior to college.

You know to understand and be understood, I think is such a rare gift for some people. I mean people want to be accepted as who they are. And our culture does not make it easy.

The next pattern, feeling successful, can be seen as the summation of several of the prior patterns and themes in this inquiry. The higher education setting was often the first time that the participants felt successful for their own achievements. This success frequently came after several false starts, but once achieved success was enjoyed and viewed as a motivation for future endeavors.

It just boggles my mind that I’m doing this well. So my confidence is through the roof, finally. Which, obviously, I think is where it should be on something like this.

The last pattern in theme seven is feeling pride. Pride was felt even by participants who did not feel that the academic experience was positive overall. Each individual was able to achieve in their own way, often beyond what was expected of them. This resulted in a great deal of pride, especially if a degree was completed. Education was seen as a way of expressing an ability to achieve to those who may have doubted the participant’s ability or even overall intelligence.
When I graduated I think I had sense of pride because I had started out in that institution, they didn’t think I’d get through high school. So, okay, I proved these people wrong.

I can flaunt my degree in the faces on naysayers…judgmental assholes.

Creative Synthesis

The final step in the heuristic process is the discovery of a concept that describes the experience under study completely (Moustakas, 1990). For the experience of being a student with an autism spectrum disorder the concept was change. While change occurs for many students who attend institutions of higher education, for students with autism spectrum disorders this change was life altering. Several participants went from being largely socially isolated to discovering an enjoyment of interacting with others and public speaking. Others discovered a subject of passionate interest that will guide their careers in the future. Independence and a realization that self-direction is possible was first found in the college environment as well. The changes that occurred during the course of higher education will allow the participants to progress in their lives and careers in a way that likely would not have occurred outside the higher education environment.

Discussion

This inquiry discovered several themes and patterns that fit in with the prior research and others that were unique to the study. While the use of a qualitative analysis makes generalization of these findings difficult, they are worth exploring. The findings are divided into academics, interests, and being social and interacting with others.

In the academic arena two findings stand out. The first is a difficulty with abstract concepts (Grandin, 1995), which is presented as the preference for experiential learning in Theme 4 of this inquiry. Focusing on examples and the personal experiences of instructors can be seen as a way to make concepts that are abstract more personal and manageable. A second academic finding was that participants in this inquiry were not particularly drawn to scientific fields and seemed to have a preference for social sciences or business. This finding is quite different from the fields of interest suggested by other researchers (Luckett & Powell, 2003). One reason for this difference may be the methodology used for the study. Participants who are involved in technical scientific fields may be less apt to volunteer for a study which involves extensive interviewing when compared with students in business or social sciences.

The next major area of discussion involved personal interests. In particular having an area of intense interest is presented as negative by researchers who do not have an autism spectrum disorder (Breakey, 2006) but very positively by individuals who have an autism spectrum disorder (Grandin, 1995; Prince-Hughes, 2002). This inquiry found that finding an area of intense interest was of extreme importance and could direct the entire college and career experience, which is similar to the experiences described by Grandin and Prince-Hughes. The reverse also occurred in that participants who did not find their area of intense interest or felt they were unable to pursue that area felt more negative about their higher education experience. One participant in particular had completed his higher education experience about 20 years prior to being interviewed. He still expressed great regret at not following his true interest in college and felt that his life would be much improved had he gotten a degree in the area he truly desired. A second finding regarding interests is also related to the idea of studying an area of intense interest. The participants who had experienced both graduate and undergraduate education unanimously enjoyed graduate education more. Each participant expressed the same
ideas: in graduate education it was possible to pursue their area of interest without the
distractions of core classes and/or less motivated students. Again, this finding shows the great
importance of the area of interest in steering the higher education experience for students with
autism spectrum disorders.

A third area of discussion involves social interaction. Many participants expressed the
idea that being social was a much larger part of the higher education experience than they had
expected, which fits well with the findings of Taylor (2005). For most participants this focus
became ultimately positive. The exception occurred for participants who had chosen to pursue
a degree in education. They found that their social difference became a barrier to completing
their education, especially when it came time to complete student teaching requirements. The
issue of group work in this inquiry represented a departure from prior research. Martin (2006)
and Wolf, Brown, and Bork (2009) suggested that group work was difficult for those with
autism spectrum disorders and went on to state that group work should be removed from the
curriculum for students with ASDs. While participants in this inquiry found group work to be
challenging at first they ultimately found that they learned a great deal about social interaction
through group work. This knowledge was applied both in school and subsequently in the
workplace. These participants would greatly disagree with Taylor’s recommendation that they
not have an experience with group work. A second finding in the social area involved a desire
for social interaction. Several researchers stated that individuals with autism spectrum
disorders may not need social interaction (Holliday-Willey, 1999; Luckett & Powell, 2003).
The participants in this inquiry greatly enjoyed social interaction and felt that it was something
that had been missing in their lives prior to the college experience. Often success in social
experiences was attributed to the focus on diversity and the opportunity to interact with more
people with various differences in the college environment. This is similar to the experiences
of other authors with autism spectrum disorders (Shore, 2003; Williams, 1992). Finally the
issue of living arrangements during college was addressed by the majority of participants in
this study, particularly if they had lived in a dorm environment. This fits with the focus on
having an individual room in the dorm which is mentioned by several authors in their research
and writings (Adreon & Durocher, 2007; Palmer, 2006). However, the participants in this
study extended the concept by stating that having a private room allowed them to be more
social because they had a place to retreat to when they felt overwhelmed or were simply
finished with social interaction. These participants felt that being forced to be social constantly
by having a roommate would have ultimately made them less independently social. Finally, it
is important to note that several of the findings in this inquiry about social needs and desires
may be influenced by the methodology used. Participants with who were extremely
uncomfortable socially likely did not volunteer for a study which involved extensive face to
face interviewing.

Areas for Future Research

The heuristic methodology allowed for the collection of a great deal of rich, personal
data. However, this methodology may have excluded individual with autism spectrum
disorders who are less comfortable socially. The use of a mixed methodology study which
relies on an online survey, possibly highlighted with a few personal interviews, would
overcome this limitation. In addition, the use of a survey would allow for data collection from
a much larger sample of students. A longitudinal study involving following students with
ASDs from their entry into the higher education community until their exit or even into their
workplace would be very interesting. A longitudinal study could document the changes that
occurred during the higher education experience as they occurred. Studying the experience of
students with autism spectrum disorders internationally would also be useful as the higher
education system is organized differently in each country. Finally, specifically addressing the experiences of students with ASDs who use typed communication would be worthwhile as these students mentioned unique challenges in their higher education experience.

Students with autism spectrum disorders will continue to enter the higher education system in larger and larger numbers as the rates of ASD diagnosis go up. It is important for the higher education system to be prepared to encounter these students, both for the sake of the students and their future contributions to their areas of study. The passion for individual areas of scholarship expressed by the students in this inquiry lends itself well to great contributions to their field. It would be a detriment to many fields of study if these students were unable to pursue their passions due to inhospitable institutions of higher education.

References


**Author Note**

Dr. Fleur Wiorkowski has studied psychology in a variety of settings for over 20 years. Most recently she completed her Ph.D. in educational psychology with a focus on bringing the needs of college students with autism spectrum disorders to the attention of other researchers. Correspondence regarding this article can be addressed directly to: Fleur Wiorkowski at, fwiorkowski@sbcglobal.net

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