The Hushed Voices of Autism: Chronicling Social and Academic Experiences in College

Judith S. Cagaanan¹

Abstract

The number of students with autism (SWA) attending college has increased along with the growth of autism diagnoses in recent times. Individuals with autism, despite very strong potential academic advancement, often fail in college. Also, research on the academic and social life of college students with autism has been sparse. (American Psychiatric Association, 2013). The purpose of this study is to explore the lived experiences of students with autism in Mindanao State University-Iligan Institute of Technology (MSU -IIT), one of the biggest state universities in the Philippines thereby contributing to the existing literatures on autism and understanding SWAs better. Using semi-structured interviews to gather data and exploring the superordinate themes of academic and social life, this study hoped to address the following issues: 1) what is the academic performance of students with autism (SWA) who have sought a college degree in MSU - IIT; 2) what are the reported social experiences of these students?; and (3) what possible support program can be provided to help these students? Through phenomenological analysis, insights provided by participants revealed that autistic college students in MSU- IIT have the strong potential to succeed in their academic pursuits, but continually struggle with social issues that threaten to sustain their academic performance. Overall, results indicate the need for institutions of higher education like MSU - IIT to provide comprehensive supports, most importantly, in the social and emotional domains for students with autism (SWA) to succeed in academic environments.

Keywords: Autism Spectrum Disorder (ASD), students with autism (SWA), academic and social services

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¹ The author is a faculty member of the English Department, College of Arts and Social Sciences, MSU-IIT, Iligan City. Email address: judith.cagaanan@g.msuiit.edu.ph.

INTRODUCTION

Autism Spectrum Disorder (ASD) as described by the Diagnostic and Statistical Manual for Mental Disorders, 5th edition (DSM-5) refers to ASD as a mental health disorder stemming from a dyad of impairment; the social/communication difficulties and the repetitive behavior and restricted interests. Also, autism is an umbrella term for a group of developmental disorders which comes in a wide range, hence, a "spectrum" of associated symptoms, and levels of deficiencies in behavior, social and communication skills. There is not one autism but many types, caused by different combinations of genetic and environmental influences. Included in this spectrum of autism disorders are Autism/Autistic Disorder, Asperger's Syndrome and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). Autism affects one in two percent of the world's population cutting across race, culture, economic and political systems. Currently, nearly 1 in 50 children under 18 have been diagnosed with an ASD. Apparently, autism spectrum disorder is the fastest growing disability in the world. (World Health Organization, 2017).

Similarly, in the Philippines, the number of cases of children born with autism, once considered a low-incidence phenomenon is becoming prevalent. Approximately 1.2 million Filipinos have autism and the number is rapidly increasing.

In 2007, the Asia-Pacific International Seminar on Education for Individuals with Special Needs was held in Yokohama, Japan. Participants agreed in consensus that the Education for All (EFA) goals on inclusive education for children and youth with special needs be implemented by all countries worldwide. Hence, the Philippines, is one with the world in protecting the right of every child with autism, while at the same time recognizing their fullest potentials. The Philippine Constitution, Presidential Decree No. 603, and the Magna Carta for Persons with Disability have special mandates to uphold the right of all its citizens to quality education regardless of their circumstance. In line with this mandate, the Department of Education (DepEd) is instituted to create the Special Education (SPED) program that caters to various and unique needs of students with disabilities such as autism. SPED as a specialized education "earnestly seeks to make education inclusive and accessible to every Filipino child by establishing a framework for special needs education implementation nationwide. It also establishes inclusive education learning resource centers that will

be the source of appropriate instructional materials, tools, devices, gadgets, and equipment that educators can use in their classrooms to ensure that students with special needs are properly supported and enabled to learn alongside their peers." (Guidelines in the Admission of Students with Disabilities, 2009, p.3) Sadly, however, the country's education system is currently under- equipped to cater to the individual and unique requirements of students with special needs. Parents find it difficult to provide their children the education they need given only a few public schools have Special Education (SPED) centers. The SPED program and most of its educators also lack the necessary skills and training to accommodate students with special needs. Despite the circumstance, a handful of students with autism, most with high functioning cognitive abilities are able to make it through college. But in college, students with autism (SWAs) are continually faced with even more daunting challenges than in primary and secondary education such as navigating the campus, participating in academic and social activities (National Council on Disability Affairs, 2017).

Globally, students with special needs in higher education has always been an uphill battle. It is estimated that over forty percent (40%) of individuals with an ASD enroll in college, but eighty percent (80%) of this population does not complete a degree. (Harvard Review of Psychiatry, 2014). The most common problem is the lack of autistic-specific accommodations. Consequently, students in the spectrum either fail or drop out in college. A study conducted by Pennsylvania House of Representatives (2008) confirmed this finding; thus, advised higher academic institutions to prepare students with autism for college and prepare colleges for the arrival of students with autism. Sadly, most universities and academic institution are ill equipped, thus ill prepared, to deal with autistic students to succeed in academic environments.

Several universities abroad such as the University of Michigan, Syracuse University and many other even before have long taken heed to this call and have put programs in place to secure the academic success of these students with diverse needs. In developing countries like the Philippines, however, there are still instances of persons with disabilities not being admitted in colleges and universities due mainly to seemingly lack of information and preparation by the school administrators and teachers alike on how to handle students with disabilities, thus resulting to loss of

opportunity to enjoy their right to education. Despite this, the Philippines continues to craft laws and policies to safeguard the right of every individual with autism to pursue higher education. In fact, the Commission on Higher Education (CHED) issues the CHED Memorandum Order (CMO) No. 23, Series of 2000 known as "Quality Education for Learners with Special Needs in its commitment to raise the level of educational attainment of persons with disability in the country. Firstly, it urges higher educational institutions to admit learners with special needs. Secondly, it promotes inclusion of SPED programs for teacher training institutions. Finally, it facilities that academic equipment be modified to ensure quality education is made accessible to learner with special needs. (Commission on Higher Education, 2017).

In Mindanao-State University - Iligan Institute of Technology (MSU-IIT), every person with autism is never denied admission for as long as the student passes the System Admission Exam for Admission and Scholarship (SASE). Recently, students with autism (SWAs) are starting to trickle in the Institute. Interestingly, incidents involving students with "weird" behavior, infuriating both classmates and professors are becoming noticeable. Most importantly, these students with "quirks" are apparently observed to start college with a strong academic potential, but gradually digress falling into the cracks of tardiness, absenteeism, and eventually very poor academic performance. Obviously, these students need immense help. Thus, this study is designed to allow individuals with ASD to provide information regarding their experiences and challenges as college students in MSU-IIT.

Furthermore, it is important to point out that neurobiological difference in autism is viewed as a medical condition by the general community who consider autism as a disability with a host of accompanying social and communicative deficits. Any learning community could be baffled at SWAs's social and communication issues and misconstrued them as "weird", "abnormal" or "mischievous" behavior. As such, autistic individuals are treated as people with disabilities who need to be 'fixed'" (Bagatell, 2010). It goes without saying that traditionally people with autism have been stigmatized as people with an abnormality. The Commission on Higher Education (2017) highly encourages universities and colleges to include in their institutional research agenda the understanding of the uniqueness and needs of all people with

special needs for them to gain full access and fully benefit from the learning opportunities.

Utilizing the framework of neurodiversity, the present study upholds the notion of self-advocacy among individuals with autism and discusses possible applications to policy and intervention by mobilizing the community to raise awareness of autism-related issues, building stronger support systems and fostering notions of inclusion and diversity in a society such as the academic community. (National Symposium on Neurodiversity, 2011).

Furthermore, the concept of neurodiversity as applied in this study hoped to heighten awareness on the presence of students with autism (SWA), recognize and respect their social and academic challenges, and ultimately for the general community to develop a positive acceptance of students with autism (SWA) as neurodiverse individuals pursuing careers in academic institutions such as Mindanao State University - Iligan Institute of Technology (MSU-IIT).

Currently, there is very little empirical work (e.g. Elias R, White SW.J, 2018; Elias, R., Salinas, C. E., Capriola, N., Conner, 2016) guiding the development of postsecondary programs for individuals with ASD. Within the context of neurodiversity, the study hoped to give voice to a growing population of students who have a strong potential for postsecondary success, but failed due to lack of awareness and the accompanying struggles of an autistic person.

Utilizing interpretative phenomenological analysis, the study explored three major distinct themes:1) academic performance of students with autism in MSU-IIT; 2) social experiences of these students; and 3) possible support programs of these students to succeed in college?

METHODOLOGY

Locale

The Mindanao State University-Iligan Institute of Technology (MSU-IIT) is a premier institution of higher learning in Mindanao. MSU - IIT is part of a university system composed of ten constituent universities spread throughout ten campuses in Mindanao. Established in 1968, its special mandate is to integrate the cultural communities in Mindanao, especially the Muslims into the mainstream of the nation's socio-cultural and political life by providing them with opportunities for quality and relevant public education for self-development. Known for quality and affordable education, MSU - IIT receives of admission applicants from almost everywhere in the country. The University admits an average of three thousand freshmen students every year through the Mindanao State University (MSU) System Admission and Scholarship Examination (SASE). MSU-IIT has no known provisions and policies regarding admission of SWAs and those with other disabilities.

Participants

Participants in the study are two male and two female students with autism spectrum disorder. Three of the participants received formal diagnoses of ASD at age three - years old. The study, however, included one ASD self-diagnosed autistic student following the assumption that the stigma attached to autism makes it unlikely for an individual to claim to have the diagnosis without the symptoms (Brownlow, 2010). Currently, participants are taking undergraduate courses at Mindanao State University - Iligan Institute of University (MSU-IIT).

Homogeneous sampling was used in this study to describe in depth the lived experiences of students with autism (SWA) in MSU - IIT. The data were all collected using face-to-face and semi - structured interviews. No incentives were offered to participants. Their real names, however, were kept confidential to protect privacy thus, pseudonyms are used instead. Participants and their parents were informed about the nature and purpose of the study. Finally, the study was granted approval by the University.

Data Gathering Procedures

This is a phenomenological study which used semi-structured interviews which were conducted face-to-face at different locations chosen by participants. Three participants opted for a familiar location at the MSU-IIT campus. One interview, however, was conducted in a nearby restaurant and the informant was accompanied by a classmate.

To reiterate, all interviews were conducted one-on-one and in person within a time frame preferred by participants who requested for personal contact during the interview to help them "get the question right". The interviews lasted from 30 minutes to an hour. Data analysis was completed using interpretative phenomenological analysis (IPA). To do this, each interview was analyzed individually according to emerging patterns of the following themes: 1) social experiences 2) academic experiences, 3) potential support and services.

RESULTS AND DISCUSSION

The two male 19-year old participants indicated that English is their primary language since they were not raised in the Philippines. On the other hand, the other two eighteen year- old female participants had Cebuano as their first language. All four students were diagnosed with autism spectrum disorder at an early age of three. Three were eldest children, but one is a middle child in the family. The four participants do not have formal disclosure of disability to any administrator or personnel of MSU - IIT. Two female participants, however, indicated that they were comfortable enough to disclose their disability to classmates and some professors. Parents of male participants informed instructors of their disability the first tell-tale signs their sons had trouble performing academically.

Table 1: Demographic Characteristics of Participants

	John	Gilbert	Ivy	Elize
Gender	M	M	F	F
Age	19	19	18	18
First	English	English	Cebuano	Cebuano
Language				

Table 1. (Cont'd.)

No. of	2	3	2	1
Siblings				
Ordinal	First	Second	First	First
Position				
Primary	PDD-NOS	Asperger's	PDD-NOS	Asperger
Diagnosis				's
Formal	None	None	None	None
Disclosure				

It is evident in the high Systems Admission School Examination (SASE) scores and cumulative general percentile averages, the four students with autism enrolled in MSU - IIT seemed show a strong potential to perform academically well as evidenced by a high rating in the (SASE). Also, three participants are taking technology and science courses. However, one participant was enrolled in the AB English program which is a language and literature program. Participants are enrolled in degree programs which are highly correlated to each of their admission scores with three participants scoring high in science, math and language, but one was rated very poorly in math but quite good in language use.

Over four semesters, three participants in the science and technology programs were able to maintain a high level of academic performance as indicated in their average cumulative grade of 1. 75. One was a consistent honor student in one of the programs of the College of Business Administration and Accountancy (CBAA). Two of the students with autism enrolled in the College of Engineering and Technology (COET) and CBAA programs are consistent honor students who have a General Percentile Average (GPA) for four semesters. Meanwhile, one participant enrolled in one of the programs of the College of Arts and Social Sciences (CASS) is struggling to keep his grades afloat. It is important to note that the student scored relatively high in language use and English is his first language. An important issue emerged from this result being that academic readiness is not a sure ticket for SWAs to perform academically well.

Table 2: Academic Performance of Participants

	John	Gilbert	Ivy	Elize
SASE General				
Rating	104	97	117	111
Cumulative				
GPA	1.97	3.20	1.58	1.65
Delinquent				
Grade	2 INCs	4 INCs	None	None
Remarks				
Current	24 units	20 units	23 units	23 units
Academic				
Load				
Year Level	Second-Year	Third - Year	Third - Year	Third - Year

The academic performance of students in MSU - IIT are measured at the end of each term using this grading system: 1.00 and 1.25 - Excellent; 1.50 and 1.75 - Very Good; 2.00 and 2.25 - Good; 2.50 and 2.75 - Satisfactory; 3.00 - Passing 5.00 - Failure; Inc. - Incomplete; Drp — Dropped

Academic Experiences

Using Interpretative Phenomenological Analysis, participants in this study discussed two superordinate themes of academic and social struggles. Embedded within these major themes indicated their hopes for special support and accommodation.

Firstly, participants reported a high degree of academic success. However, it seems that such perceived academic success is constantly challenged. In response to open - ended question on specific academic struggle, Ivy noted, "My greatest academic struggle is working in groups because I prefer to work alone." She further reported that as much as possible, she avoids activities and organization that require social interaction. Unfortunately, she cannot altogether drop socializing.

At most times, she had to take a backseat role during group requirements and sulked in a corner when academic tasks require close interaction with classmates. In

one public speaking class, however, she found the courage to talk openly about her autism. At present, Ivy reported getting overwhelmed with her major subjects and is on the verge of failing three major subjects the next semester. She has been missing classes for a number of times now and could be dropped by two of her professors due to unexplained absences. Ivy indicated getting "sick and tired of endless studying and doing worksheets" that she watched a good number of Korean movies on the internet. Unfortunately, she was hooked to it and could not stop watching online movies even during class hours.

On the other hand, Elize reported: "I am motivated to excel in academics. My professors have been very good; they appreciate my diligence and are willing to spend time outside of class discussing course content or expectations." She said she is making a number of friends because she is fun to be with. Her greatest issue, however, is some classmates are calling her O. A. (overacting) and a professor in one of her subjects find her "too noisy" to deal with and called her rude several times. She thinks Aspergers made her "talk a lot and move a lot." Many times, she failed to recognize social cues of when to start or stop talking. All she knew is she has to talk incessantly and immensely so anxiety will get in her way of socializing.

Meanwhile, John described his IIT life as a "rollercoaster". Awarded "The Math Wiz" and "Best in Calculus" several times in high school, John described himself as having an exceptional talent in computer tinkering and Math. However, in MSU - IIT, he had to enroll in Calculus several times until he was advised to shift to Information Technology. John noted that it was not the lesson that stumped him, but rather decoding what professors wanted especially that he could hardly understand Cebuano. Often baffled by instructors' instruction and overwhelmed by academic work, asking help from his classmates or professors was extremely difficult especially when they appeared busy. John had very few friends, so his mom had to call him often and informed a few his of his professors about his disability for a few academic considerations. John reported:

"My greatest academic struggle is preparing for exams and quizzes. I tend to get anxious over the very long coverage and felt so overwhelmed by it. But John added: "I have already overcome myself because my mom taught me a lot about God and prayer."

Finally, Gilbert is a student with autism who seems to find every academic task an insurmountable hill to climb. In particular, he found it mindboggling to remember class schedule, room assignments, and face as well as names of professors. As a result, he missed a good number of course requirements and inevitably failed in many of his subjects. Also, the student expressed vehement protest against having to move to this country and enrolled in the AB English program. He said he is a very good artist and wants to take an architecture course. When asked to describe his academic experiences in the University, he wrote three times "hell, hell, hell". When asked why, Gilbert refrained from elaborating, but expressed serious concern that his parents might know of his personal protest.

Social Experiences

On the whole, three participants reported a generally pleasant social experiences. They found MSU - IIT peers friendly and professors helpful. However, social and communication inadequacies keep them quite isolated. Three participants reported having the greatest difficulty during their first year in college. Two participants who were very close to families from distant places did not report getting homesick. Instead, they relished their new independence, but getting into routines, losing their way around the campus, and academic activities that require close social interaction are painfully difficult. Consequently, participants either get sick or perform poorly in classes. Eventually, these students have learned to adjust in their new academic environment but with serious consequences in their academic performance.

In response to the open-ended question "What is your most difficult social challenges?" Ivy reported, "I have made quite a number of friends already, but I still have difficulty trying to mingle out because I prefer to be left alone". However, once in her public speaking class she delivered a piece which talked about her autism. The classmates and professor were surprised since she apparently showed no signs of being "abnormal". Currently, Ivy showed extreme difficulties coping with academic demands of major course load that she started missing classes a number of times and could fail or drop several of her course subjects this semester. Apparently, she could be dismissed from her academic program due to poor performance in major subjects.

On the other hand, Elize disclosed "talking a lot sometimes gets me into trouble." Elize reported getting overwhelmed by anxiety prior to a social or academic activities. But she has learned to develop a strategy to overcome the "jetters". She either keeps totally quite or talk immensely. She revealed that talking a lot makes her forget her anxiety while keeping quite overcomes her with paralyzing social fear. She develops this talking strategy at age three from preschool teachers who devoted their time improving her communication skill by giving her the most significant role in school plays.

Meanwhile, another student John noted, "looking for a suitable boarding house" whose owner and other occupants could understand my special need was especially hard for me. His mom had to go door to door to every boarding house close to IIT until she met a faculty member in the University whose daughter was also on the spectrum. After two years, John was staying with a relative and now in a boarding house which suits him well.

Sadly, one participant, Gilbert described his social encounters in the campus as "hell". He said most of his classmates ignored him while his professors did not appreciate him. Gilbert was reluctant to elaborate his answers that classmates and some of his professors were asked about their social encounters with Gilbert. They reported social problems associated with him such as being aggressive, disrupting the classes by asking never ending questions, drooling, and picking his nose.

Support Services and Programs

Table 3 in the next page shows the support services and accommodation as reported by four participants as their desired support services and accommodations maybe taken into consideration:

Table 3: Potential Support Services and Academic Accommodations

Support Services	Reduced course load		
Priority registration	reduced course load		
Housing accommodations	personalized academic advising		
Independence and Self-Sufficiency	Peer mentor		
Training			
	Opting out for spontaneous questions		
Adjustment and Transition Program	in the classroom or allow ample time		
	for verbal responses.		
Guidance and counselling on life skills	Alternative individual than group		
such as personal hygiene, dorm	classroom activities. At the same time,		
decorum, time management and	providing concrete examples for		
organizational skills.	complex topics in exams and		
	assignments.		
Extensive mental health care	Preferential seating in classroom		
Academic and social skills training	Provide a specific schedule and		
appropriate for a university and adult	priority time for assignment and exam		
life such as the following:	preparation as well as extended time		
Academic planning and prioritizing	for test taking. Provide ample and		
Making advantage of academic	detailed feedback on assignment and		
opportunities	exam.		
Working independently and in groups			
Negotiating the social nuance of			
professor-student relationships.			

Embedded within the superordinate themes of academic and social experiences is the subtheme exploring on possible support services and accommodations for students on the spectrum. Students with autism in the study pointed out several times that they do struggle to adjust to the challenges of college particularly in terms of the following: dormitory living, sudden independence, rigorous classes, and a new social world in an academic environment such as the MSU-IIT. The same list of challenges many typical college students may find very challenging. However, for people with an autism spectrum disorder (ASD), the transition can be more abrupt and dramatic. Unlike their typical peers, students with autism generally still need other grown-ups like their parents but who are no longer available, or welcome, to advocate for them in college campuses. Hence, SWAs' struggles with communication, organization or interpreting social nuances can multiply exponentially in college, away from the watchful eye and structured world of

parents, principals and special education teachers in previous schools. Also, college students with autism are often tempted to keep their needs quiet. They see college as a step toward independence and students on the spectrum who are determined to make it on their own do not want to admit they need help. But they do need help (VanBergeijk, Klin, & Volkmar, 2008). It is crucial then to listen to the "hushed voices" of these students and take into considerations autism - specific services and accommodations which do not necessarily jeopardize the academic standard of the Institute.

CONCLUSIONS AND RECOMMENDATIONS

The study showed that the School Admissions System Examination scores and the General Percentile Average (GPA) of students with autism (SWA) indicate that they are well prepared to pursue college education in the Institute. Notwithstanding, students may have achieved a relatively high level of academic success while struggling with the non-academic aspects of college such as navigating the social environment and difficulties with communication and interaction with peers and instructors. Furthermore, SWAs in MSU - IIT reported loneliness and suicidal tendencies. These difficulties reveal the importance of offering emotional support to these students in the form of developing social supports, advanced social skills training, and offering counselling services. The implication of this conclusion is that students with ASD require comprehensive support in the academic, social, and psychological domains. Considering the increasing frequency with which college students especially autistic individuals who are extremely vulnerable to anxiety, depression, and other psychiatric problem, it may be more critical than ever before that the University provides these students with services and programs to acquire more advanced social skills and stress-coping strategies. The informants of the study have varied levels of social and emotional needs despite their common diagnosis, it is crucial to create autistic-specific programs and services addressing each of these students' unique challenges. Connected to this issue is that individuals with ASD do not necessarily fulfill common stereotypes. It is a common misconception that autistic people are primarily concentrated around math, computer and engineering, not liberal arts or other fields of interest. Careful considerations must be made not to mistakenly advised students with autism toward majoring in academic fields, when in reality they

can achieve success in a variety of college majors. Understanding the interests of the individuals is very important when having these individuals participate in college/career planning. Forcing these students to enroll in certain programs could come with debilitating effects on the academic and psychological aspects of their life.

Besides emotional and social challenges, students with autism reported encountering intense struggle to adjust to the challenges of college: finding a place to stay, sudden independence, rigorous classes, and a new social world. While it is true that typical students without autism may encounter the same challenges in the new academic environment, however, for most people with an autism spectrum disorder (ASD), the transition can be more abrupt, dramatic, painful and extremely difficult. It is recommended that a student with autism peculiar needs for certain academic, social and emotional supports be taken seriously.

Meanwhile, the likelihood for students with autism and their parents to disclose their disability emerged from participants of the study casually informing their peers and instructors about their diagnoses to solicit a few academic considerations. The comfortable disclosure of this sample exemplifies the fourth and final issue, which is the importance of self- disclosure for students with autism as a pre-enrollment requirement in MSU - IIT. The disclosure of disability policy will be crucial to provide a supportive campus of SWAs' needs to become socially integrated in the campus, developed advanced social skills, and success in college.

This study has limitations with the sample size being small while recruitment of participants relied on acquaintances and self-reports. Therefore, it is recommended that a large-scale study exploring the challenges and investigating the many issues involving students with autism inevitable presence and growth in academic institution be conducted.

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