

Voices of Students with Autism in Higher Education

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Abstract

This research paper focuses on the experiences of students with autism in higher education. There is not much published work on the experiences of students with autism in higher education because diagnoses and awareness about autism is still limited and people tend to make similarities with autism, learning disabilities and mental retardation. This paper aims to explore in depth and from their own perspectives, the experiences of a small number of students with autism and give them the opportunity to share their life experiences. The research paper aims to try to develop a comprehensive account of the lives of university students with autism and the ways of coping adopted by them. The environment is found to be particularly challenging by students who decide to study away from home for the first time. The participants in the study had been diagnosed with autism with mild symptoms and had received special education at initial age.

A sense of personal independence for students with autism is first experienced when they step into higher education. This becomes more difficult in a country like India where awareness about autism is limited and people tend to find similarities between autism, mental challenges and learning disabilities. In higher studies, because of lack of awareness, people misunderstand the characteristics of autism with other disabilities. This can create more difficulties. Students with autism are likely to face many challenges that include living in a new environment, the workload of curriculum, deadlines, making new friends and adjusting to social circles.

Studying for a higher degree is a decision taken independently by any person. The students who participated in this study had willingly chosen to attend university and were had a strong determination to accomplish their goal. They discussed their aims about higher education and

professional ambitions. In this paper, educational experiences of students with autism currently in university have been explored, in order to give voice to their experiences. The attempt is to explore the experiences of students with autism currently studying in universities of India. This will allow them the opportunity to express their thoughts and beliefs regarding any difficulties, if any, that they have experienced in education; what coping mechanisms have they employed and the kind of support that is available to them. Further, the interviews with these students will explore the effects that autism might have had on their self-esteem and social lives.

When autism has been diagnosed early in the lives of students, they are able to receive suitable special education at school. This helps them to easily adjust to the higher education system. However, the study employs a small sample of participants and thus, the inferences do not lend themselves to

generalizations.

This study explores six students with autism studying in India from University of Delhi, Punjab technical university and one participant is from Oakland University's Center for Autism. They shared their experiences as college students and share education experiences. They were asked to describe experiences about how they cope in the environment and faces challenges, the experience of being a college student with Autism. The data for this study was collected from Interviews by phone conversations, email, online video conferences and face-to-face meetings.

All the students who participated in this study were asked to describe their feeling about autism and what they expect from their social circle. Most of the participants reported that they did not experience any major difficulties. They only wanted to change the negative attitude of people about autism. In fact, most of them believed that although autism has caused quite a few problems in their lives, at the same time, it had given them a lot of positive things as well. Being autistic gave them the freedom to be themselves and not to try to hide their mistakes, for example in reading or writing, from others. The awareness that they have autism gave them the confidence and determination to work extra hard at the things that they wanted to accomplish. All the participants reported that they had faced ups and downs, that they have to try harder and work more than others who do not have autism, but in the end, most of them could find something encouraging coming out of all this effort and felt proud of themselves.

The participants reported that they would not like to change this aspect of having autism. "In a way, it's not good to have autism but it gives a reason... if you feel you can't manage something, whereas if you were perfect, what reason would you have for not being able to do something?"

One participant shared her experiences about

autism. She does not mind being autistic. Instead, it is people's assumptions about being autistic that bother her. "I don't think being autistic is half as bad, it has some wonderful advantages, I can think things nobody else can even imagine thinking. I can do things that other people can't imagine doing. But people take for granted what is supposed to be easy and normal and straightforward, but I can't do it, and that to me is the side effect." She would like to get rid some of the negative effects that autism has on her and if she could change something in her life it would not be her autism but to be diagnosed when "she is 5 years old when she enrolled in a integrated school where she attended classes with children with other disabilities and she learnt there how to help and adjust with other different people."

Most of the participants were quite open to discussing about their difficulties and did not hesitate to talk about them or to tell other people that they were autistic. None of the participants denied the fact that autism has affected their lives, not only in terms of education but at a personal level too. Disappointment and frustration were some of the feelings that the participants reported, especially when they were younger, because of other people's expectations from them and from the way they treated them.

Participants agreed that autism has affected their lives but they both come to the point where they realise that this disability has made them stronger and more determined as they wanted to prove that they could accomplish their targets and their aims. Determination is a common theme among people with autism. Although people let them down and sometimes consider them unintelligent, people with autism do not give up! They persevere and succeed even though the odds might be against them. Students with autism are determined to prove to people that they are not quitters and can achieve and accomplish their dreams.

Participants who shares their experiences believe that life has been affected positively and negatively

by being autistic and because the spectrum disorder is not recognized. “Negatively because they came out of school with average marks and grades. But positively because it’s made them a stronger person and just to get with things and find ways of dealing with it.”

From the experience of the interviewees it appeared that one of the problems that people with autism face before being assessed is that they do not know how to cope with their difficulties and they feel incompetent. Simple things can be a struggle for them. One of the participants, for whom it appeared that her life is significantly affected due to autism, had a difficult childhood. Her problems have continued well into adulthood. She said, “My life has been affected by my autism a lot. Everywhere possible. Relationships, friendships, trusting people. For certain situations, I had to have a therapist when I was small because I was causing so many problems at home but they thought it was me and then they decided it wasn’t me, that I was clever and all sort of stupid things. Not getting proper treatment because people missed these certain things that you do and then they decide that you fall into this category and to treat you as being in this category and that carries on all the way through your life. I left school, I had terrible nightmares with jobs, dropped out of college. I had one job after another. I find it very difficult in a work situation because I don’t understand the politics, basically all that sort of stuff and it gets very confusing and I tend to get very isolated. I’ve had accidents all the time. I avoid going to very public places where a lot of people are there because you can’t understand what is going on. You get confused. You make mistakes; they say you’re stupid, everybody laughs at you and they talk about you behind your back and think you’re weird and all sort of stuff. You avoid going to new places because you’re going to get lost, you don’t know where to go, you don’t know how to get there. You miss appointments because you muddle up your time.”

It is not easy for people with disabilities to acknowledge the problems that they experience. On the other hand, it is vital for people with autism to inform their colleagues and friends about autism in order to avoid misunderstandings and awkward situations. Unfortunately, not all people with autism are willing to disclose their disorder.

In this study, a majority of the participants were willing to disclose their autism. The participants of this study accepted autism as an explanation to their problems. Some of the mature students noticed a big difference since the days they were at school and they were impressed with the help and support that nowadays-younger students, once they are diagnosed, receive at school and university. They have moments when they feel frustrated and they know that they have to work twice as hard as their peers but on the other hand autism makes them creative and makes their brain work differently and visualize things in a way that people without autism cannot do. They see and accept autism for the positive things it offers them. They perceive it more as a gift rather than a disability. The majority of the participants were also willing to disclose their autism to friends and colleagues. They believe that by letting people know, others are able to understand and accept them more. They also actively try to raise awareness about autism.

Discussions with participant help to understand about how school education was helpful for students with autism in coping with the university processes. Self-awareness, proactivity, goal-setting, the presence and use of effective support systems, and emotional coping strategies help lead student with autism to success. However schooling considered to be in fostering success attributes in children with autism. Child explores more about individual strengths, weaknesses, and special talents or interests. Schooling with required support help child to choose potential jobs and careers that best match his or her abilities

and relevant choices. Students with autism need support in a number of areas including: education, employment, social relationships, psychological health, independent living, family relationships, and recreational activities. All participants accepted that initial special education helps them to know how to access and utilize, support services in each of these areas. Particular attention directed at helping children with autism in school whether it was special or inclusive school they understand the benefits of using support systems and learn to use technological help.

University life is a start of a new life and a brighter future. Students stop being dependent on their families and they have to face everyday life on their own. Universities expect their students to be independent and work on their own in order to complete their assignments and pass their exams. For students with autism, achieving independence is not easy as they have to cope with their course demands and at the same time they have to find ways to manage the difficulties that they face due to autism.

Going to university for students with autism can be a struggle in the beginning or in some cases, throughout the duration of the course. The workload is much more compared to their schoolwork. Everybody expects them to submit everything on time and manage the given deadlines. Sometime they do not want even have extra time in exams because they do not want to be treated differently. Another problem a lot of the participants in this study faced during university is their inability to express their thoughts. One participant shared her experience-

“I have all the information, I’ve done all the research and then it’s how to put it on the paper?” The inability to express thoughts on paper is difficult. Sometime they write but writing does not match what they speak. Exams also seem to be another major problem for the majority of the students;

examinations are influenced by the students’ lack of ability to express their thoughts on paper and by their difficulties.

Note taking is another difficulty, which all the participants in this study face. It is a very complex skill for autistic people. It is affected by a significant number of factors including listening comprehension, processing information, and organising and recording notes in a legible and fluent fashion they have a great difficulty reading their notes because they cannot understand what they have written during the lecture. They find it difficult to concentrate in order to write something during their lectures and listen to the teacher at the same time. Because of the structure of the university courses, a lot of lectures may be given at a pace that is difficult for students with autism to follow. So students have to be quick and write down their notes if they want to keep up with the information given. Rapid reading and writing can tire the eyes and the brain. Autistic students often can do that for only a short period of time. As a consequence they end up with messy notes, or because of the speed at which they are writing, they are unable to read their own handwriting later and they end up very stressed and frustrated. A recorder that might seem a solution is not always easy to be used as the person who handles the recorder has to be very close to the teacher in order to have a clear recording of the lecture. Besides, sometimes the number of students in lecture theatres is quite big and the background noise affects the quality of recording and makes transcription difficult.

Another difficulty that students with autism face in the university is finding books in the library. Sometimes, finding their way around the campus is also difficult. At the university, participants shared their experiences having problems with orientation and finding their way around campus.

All the students who participated in this study pointed out that computers are the most useful

devices that help them to cope with their difficulties arising out of autism. Computers can help them with their spelling and correct most of the mistakes that they make while they are writing their essays and assignments. It has to be mentioned that sometimes word processors do not correct all the mistakes people make while they are writing, as they cannot spot words that are spelt correctly but are used in the wrong sense.

Almost all the participants, agreed that they now could cope with the problems caused by being autistic much better than they did in the past. There is more help available to them and more awareness about autism and that has made them more confident and more relaxed to ask for help from other people and not to try and hide their problems. All the students overall were content with the support that they were receiving from their universities but they felt, that lack of awareness about autism and its symptoms in the past prevented them from doing better in life. Now they are quite pleased with the support that they receive.

For Students with autism, trying to navigate our 'normal' world is very draining and often overwhelming. The amount of physical, mental and emotional energy it takes to navigate our complex social world for them is tremendous. It is no wonder why they frequently shows tantrums of exhaustion and frustration. As the years roll on mental stress sets in from the ongoing mental and emotional strain.

The participants of this study took advantage of opportunities given by universities to interact socially with peers, professors, and others by participating in social interactions such as group work, clubs and organizations, and class discussions. These opportunities gave the students a chance to explore more and make interactions and make adjustments as needed. Universities and higher education institutes can help students with autism creating new ways to become more

independent to foster growth they can help the students with autism to learn about transition to the college atmosphere while creating networks with faculty, staff, and peers to maintain throughout the students college experience meaningful. Colleges, institutes and universities can provide development opportunities, vocational guidance and organize placement and internship opportunities for these children. They need a support system to be independent and to contribute to the society.

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