Students Disclosing Disability and its Impact on their Educational Experiences in Higher Educational Institutions

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Abstract

This study attempts to understand the factors that influence Students With Disabilities (SWDs) to disclose their disabilities and special needs and strategies adopted by them to manage their higher educational experiences. The study is exploratory in nature. To answer the research questions posed in this study, the researcher has used mixed methods. Three universities were selected through purposive sampling, so as to gain maximum diverse variation. For this study, in-depth interviews were conducted with a hundred SWDs in the selected universities in Andhra Pradesh, India. These findings of the study also emphasised how students took responsibility, understood the term disability, developed support systems, and disclosed their special needs to seek out services to overcome academic, as well as physical, barriers. This, in turn, helped in improving their educational experiences in higher education institutions and to pursue higher education successfully.

Introduction

Students with Disabilities (SWDs) in higher education institutions are considered a vulnerable population because of the impact of intrinsic and extrinsic stressors associated with

their impairment. These students not only experience functional limitations, but also face many hindrances in attainment of academic and social achievements (Leavey, 2005). They also face problems

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with identity formation, developing social and intimacy relations and independence (Kroger, 2007). SWDs face various barriers in pursuing higher education. As reported in Eisenberg, Golberstein and Hunt, (2009), these students receive low grades as compared to their peer group. An attempt has been made in this paper to present some aspects of their academic life. Achieving success in higher education institutions for these students not only requires ability to manage academic challenges but also challenges faced due to their impairments. To manage the academic and social demands of higher education at the university level, students need to understand their disabilities, accept their strengths and limitations, and need to discuss their disabilities and special needs with teachers, university management for getting educational experiences (Hendriks, 2002). However, the review of studies indicates that majority of these students do not declare that they have an impairment and require special needs (Fuller et al., 2004). Adrianne, Johnson and NCC LAC (2006) noted that, if accommodation was needed within a college setting, a student was required to disclose the disability and related needs, but multiple dilemmas arose for the students as when to disclose, how to disclose, how much to disclose and to whom to disclose. This is especially a challenging situation for students from multicultural backgrounds who

face additional discrimination based on their minority status. Further, it was also found that there is a dearth of research studies in Indian context. Therefore, the researcher has attempted to understand how far disclosing the disability has contributed to a positive or negative social experience for SWDs within higher education institutions.

CONTEXT OF THE STUDY

The word 'Disclosure' means the process of making the self known (Jourard and Lasakow, Disclosure means different things to different people. With regard to persons with impairments, the disclosure of disability is the moment in which the persons communicate that they have a disability (Lynch and Gussel, 1996). Students with special needs in higher education institutions, given that there are various costs and benefits associated with disability disclosure (Corrigan Matthews, 2003). However, disclosing a disability/impairment is an individual decision, and there is no obligation on anybody to do so. Similarly, Jourard (1971) noted that disclosure is a process where the concerned individuals decide the degree of intimacy they want to achieve with other people in society. SWDs in higher education institutions are aware that the verbal or non-verbal transmission of knowledge about their disability status could improve their learning opportunities and also alter the

behaviour of others towards them (Olney and Brockelman, 2003).

Field and Hoffman (1999) state that family members' support helps people to develop self-worth and self-awareness from the childhood. Langer (1994) also found that persons who are not supported by their family members tend to develop insufficient social skills and low self-efficacy. Further, Hoehn's (1998) study also indicates that social stigma of SWDs also leads to lower self-worth and so much hesitation to discuss their special needs and seek for help (Hartman-Hall and Haaga, 2002). Swann (2005) states that disclosing of disability with others also influenced self-representation, i.e., process through which individuals come to agree with significant others concerning the role that each plays in the interaction.

Braithwaite (1991) found that the process of disclosing of disability for SWDs is based on a variety of factors. These include: (a) their relationship with other persons, (b) dependence on situation, (c) response of able-bodied persons, and (d) their own personal feelings about their disability. In addition to disclosing information about the special requirements, one also needs to understand the factors which might improve the educational and social experiences of SWDs in higher education institutions. Jacklin. Robinson O'Meara and (2007)Harris found the usefulness of the category of 'disabled

student'has helped the policy-makers introduce legislative changes, such as enactment of new polices, and provision of more support services to these students in higher education, and also brought about reasonable adjustments which could be enabling. Here, we should also recognise the fact that usage of a label was not always positive. Sometimes, it could lead to stigmatisation. Consequently, students would be reluctant to disclose their identity.

Adrianne et al. (2006) found that disability of students increased the perception that they were devalued stigmatised, and sometimes they felt concerned about negative results of disclosing their disability. The researcher has suggested that, in order to resolve this problem, higher education institutions need to encourage the SWDs to disclose their disability. Similarly. institutions should ensure that these students are treated with respect and also work towards addressing and removing all the barriers to their learning within a positive culture. Thus, there are many reasons why disclosing a disability to a teacher, university administration and the peer groups is a positive action that will empower, assist and improve an individual's educational experiences higher education institutions (Pintrich, Anderman and Klobucar, 1992). However, the researcher could not find any research on this issue in the Indian context.

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OBJECTIVES

- 1. To understand the respondents' perception of the term disability.
- 2. To explore the impact of disclosing disability on their educational experiences in their respective higher education institutions.

RESEARCH METHODOLOGY

The present study is exploratory in nature and the researcher used a mixed method approach. For this study, the researcher collected data from three universities (one is a Central and the other two are State universities) in different parts of Andhra Pradesh, India. The Central and one of the State universities (a) have both a disability cell as well as a coordinator to look after the needs of SWDs in their respective universities, whereas the second State University (b) has neither a disability cell nor a disability coordinator. After selecting the universities, the researcher interviewed 100 SWDs, 48 from the Central University and 26 each from the two State Universities (a and b) by using snowball sampling. For this study, quantitative and qualitative data analyses were used and in most cases quotes of real text for each theme were recorded and used extensively.

RESULTS AND DISCUSSION

The findings of the study will be discussed under the three sections. The first section explains the brief profile of the respondents in the study. The second section deals with respondents' perception of the term

'disability'. The last section deals with the students who disclosed their disabilities and its impact on their educational experiences in their respective higher education institutions. They are as follows.

1. Brief Profile of the Respondents

For the study, data was collected from 100 SWDs (66 per cent males and 34 per cent females). Out of the total respondents, 72 per cent were orthopaedically impaired and 28 per cent were visually impaired. Representation of orthopaedically impaired students is nearly more than two times higher than that of visually impaired students. The researcher could not find students with other type of impairments during the study period. The fact was that some of the students actually did not want to disclose their disability. The researcher found that three students with hearing impairment [two from the Central University and one from the State University (b)] did not disclose the nature of their impairment at the time of admission. They wanted to be treated like any other student in the university. When the researcher asked them to be respondents in this study, they did not agree to do so and simply stated that they did not have any major problems related to their impairments at the university.

2. Understanding Disability from Students' Perspectives

Very limited research has been done on how SWDs understand the term

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Understanding Disability Percentage

Disability is a physical phenomenon 45

It is an impairment, but not a disabling condition 15

Extent of disability depends on the availability of support services 12

No response 28

Total 100

Table 1 Understanding Disability from Students' Perspective

'disability' and how it is actually construed by them. In this study, one of the research questions was to explore how the term 'disability' is construed by SWDs in higher education at the university level. Table 1 provides a brief description of the students' understanding of the term disability.

The above data indicates that all respondents had their own individual notions about how they perceived their disability.

2.1 Disability as a physical phenomenon

About 45 per cent of the respondents conceptualised the term 'disability' as a physical phenomenon. They perceived disability as predominantly physical, long term and something which affects all areas of life, including education, social life and economic and living conditions. The replies of the respondents reflect the view of medical model of disability, which is construed to mean a biological limitation or deficiency. Some of them stated that, they are facing a lot of problems such as spending time scanning, editing or

asking friends for material and also for recording the study material. They believe that all these problems are just because of their disability. Otherwise, they would have enjoyed studies along with other extra-curricular activities such as sports cultural programmes. The following statements represent how this group of the respondents perceived the term disability, based on their impairments which have been affecting their social and educational experiences and also day-to-day activities:

"I am a totally blind person. I cannot see anything, I cannot read by myself. I always need my friends' help or some assistive devices for my academic activities. I could not do all the activities which are considered as normal due to my visual impairment making me depend on others."

"Due to my disability (orthopaedically impaired student), I am not able to enjoy my social life. I miss many opportunities such as for going out with my friends. I cannot even play cricket with them, because I am a person with disability."

2.2 It is impairment but not a disabling condition

About 15 per cent of the respondents did not like to use the term 'disability'. They asserted, "We are not disabled". They believed that they are not less than anyone and can do as others are doing. These participants perceived the term disability from their own perspective.

"I have only mobility problem due to my impairment, which is not a disability. If you think it is disability, at one or the other stage of human life, everyone will face disabilities."

"People used to call us disabled. However, I do not like it because I am not disabled, I am a person with visual impairment."

These statements show that, of members this group have confidence in themselves. This was reflected in their participation in extra-cultural activities and social life. They believed that they were bestowed with multi-tasking skills and it was noticed that they had much control over their problems, which could be the reason for their logical thinking process. It shows that, overall, these group members had positive attitudes and understanding about the terms 'disability' and 'impairment'.

2.3 Extent of disability depends on the availability of support services

About 12 per cent of the respondents did not consider that disability critically dominated their overall identity. They perceived that everyone is a disabled person, with a range of variations in their abilities

perform normal functions. to Furthermore. these respondents have begun to understand that the term 'disability' is not defined by solely personal and physical attributes. and that it was complex construct including person's physical environment and attitudes. Some respondents looked at disability in terms of psychological stress, because they are different from their peer group. They do not fit into educational physical. institutions without technical support services and thus these are perceived as problems imposed by the extant practices in the system. These responses reflect the view of social model which forces one to turn one's attention away from defining who is or is not disabled in identifying and addressing the barriers which in a given society restricts disabled people's participation in 'normal' 2001). life (Turner. Similarly. some of them described that their extent of disability depended on the availability of support services and role played by the university, which affect their day-to-day educational The experiences. following statements describe how this group feels on this issue.

"My visual impairment is making me lag behind my friends in case of my studies, or from the academic point of view. I am trying my level best to compete with them. But it is very hard to compete with them without sight. My severity of disability depends on

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the role of the university management in providing support services and adjustments as per my needs which would enable me to access all educational facilities, thus helping me to do well."

"I have a mobility problem, which does not give any major problems to me. So I prefer to be without a label if I can."

As seen from Table 1, 28 per cent of the respondents did not answer the question. These respondents simply declined to answer the question and stated that disability means disability only. They stated that they did not have any kind of problems because of their impairments. Some of them also asserted that they never consider themselves as persons disability or impairment. Interestingly, majority of these respondents, who did not define the term disability were having problem with slight mobility and partial eyesight. The statements of respondents in the first two themes reflect the perspective of a medical model which focused on individual perceived impairments, referring to functional norms of behaviours and performance (Turner, 2001). In contrast, narratives in the third section reflect the social model, which focuses identifying on addressing barriers and the which, in a given society, restrict disabled people's participation in 'normal' life.

3. Disclosing Disability

Disclosure is a process where the individual determines the degree of intimacy he wants to achieve with other people (Jourard, 1971). In the current study, disclosure as understood by the researcher is the communication of information about disability by students with the concerned authorities, staff and peer group in their particular university. The researcher found that disclosing students' disabilities was a critical issue for respondents in this study. Table 2 provides a brief description of the students disclosing disability by gender, nature of impairments and type of the university.

Table 2
Students disclosing Disability by Impairment and University

Variables		Disclosing		
		Yes (63)	No (37)	Total (100)
	Orthopaedic Impairment	43 (60)	29 (40)	72 (100)
Nature of impairment	Visual Impairment	20 (71)	8 (29)	28 (100)

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Type of the University	Central University	29 (60)	19 (40)	48 (100)
	State University (a)	15 (58)	11 (42)	26 (100)
	State University (b)	19 (73)	7 (27)	26 (100)

Note: The figures in the parenthesis are percentages

From Table 2, it can be understood that the majority (63) of students disclosed their disability during the admission process, while the rest 37 per cent of them did not. Similarly, when the students disclosing disability were looked at nature of impairment-wise, it was found that 71 per cent of students with visual impairments disclosed their disability, whereas only 60 per cent of orthopaedically impaired students their disabilities. disclosed data indicates that more number of students with visual impairments disclosed their disability, compared to the orthopaedically impaired students. This is perhaps due to the fact that the problems and requirements of students with visual impairments are diverse. For instance, at the time of the university entrance exam, these students have to inform the higher authorities regarding their scribe arrangement, extra time during the exam and for other support services. In order to complete the admission process, these students have to disclose their disability at one or the other time.

Further, the researcher compared students disclosing their disability type, university-wise, it was found that more number (73 per cent) of respondents from the State University (b) disclosed their disabilities, followed by 60 per cent and 58 per cent of the respondents from the Central University and the University (a) respectively. State These data show that more number of students from State University (b) disclosed their disability than those from Central and State University (a). The findings also reveal that, despite the variability in responses given, there was no significant difference between students disclosing their disability and type of the universities. Further, the researcher identified major factors which could two have influenced their decision as to whether or not to disclose their disability. It was found that 68 per cent disclosed their disability for securing/getting their rights and support services, while 32 per cent did not disclose their disability to maintain normalcy and avoid the stigma, which they perceived was attached with a disability.

3.1 Getting their own rights and support services

A study by Corrigan and Matthews (2003) indicated that disclosure means different things to different people, especially among university

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SWDs, given that there are various costs and benefits associated with disability disclosure. In the current study, it has been observed that 68 per cent of the respondents reported that they disclosed their disability during the admission process in order to utilise support services, including reservations, rights and special provisions which are provided by the Government of India under Persons with Disability Act 1995, through the Ministry of Social Justice and Empowerment and University Grants Commission. They perceived that they need to get this support in order to achieve what they want to get. Without this support, they would have found it difficult to reach their educational majority The of reported that they had disclosed their disabilities to get reservations in their respective universities. The following statements reflect their thinking on this issue:

"If I want to utilise my three per cent reservations in university admissions, I have to disclose my disability. That is my right."

"I disclosed my disability in the admission application; that is why now I am exempted from payment of tuition fees."

"Initially, they provided me a hostel room on the second floor, but when I went and disclosed my disability and submitted a request letter, they allotted me a room on the ground floor."

The positive side of having disclosed their disability was that

this facilitated access to support services and reasonable adjustments to enable these students to succeed in their studies in higher education institutions. These findings support those of the study by Braithwaite (1991) in which participants made choices about disclosing disability in a variety of settings, but the most common setting for disclosure was to get good support, to various facilities academic life which could enhance their learning experiences.

3.2 Desire to maintain normalcy and avoid stigma

About 32 per cent of the respondents desired to maintain normalcy. Unlike other disabilities, certain physical disabilities, such as slight mobility impairments partial and visual impairment, were not obvious to others. Here, the students could make a choice about disclosing their disability and maintain some degree of control over its impact. Some respondents reported that disclosing their disability may make it appear that they were soliciting pity or making an excuse for themselves. It also appears from the students' narratives that they wanted to be treated like other students. They know that there were many benefits if they disclosed their disability, but they did not feel comfortable to do. That was why they had not disclosed their disability. However, respondents in the study faced some difficult situations about disclosure on a regular basis. Some of the views are as follows.

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"I didn't disclose my disability in my application form when applying. I got admission here in the open category only. I did not want to use any reservations to gain admission. I have belief in myself and that is why I didn't disclose my disability."

"I wouldn't like to disclose my disability because I will be perceived as doing this to get some leverage."

From the above descriptions, it can be concluded that SWDs, at selected higher education institutions, minimise or downplay their own disability status which they perceive devalues or stigmatises them. These findings have been supported by the study of Barnard (2010) which indicates that SWDs prefer not to disclose their disability status to minimise their disability in order to pass as able-bodied. It is

also understood that disclosing their disability seems to revolve around their own perceptions about how others would treat them. As pointed out in the study by Olney and Brockelman (2003), it is also obvious that disclosing disability depends on the severity of students' impairment and their diverse needs.

4. Students Informing Concerned Authority and Teachers

SWDs are struggling to receive ad hoc support in higher education institutions. In this context, the researcher was interested to find out whether SWDs informed the concerned authorities and the teachers about their needs and Table problems. 3 shows the responses of the respondents on this issue.

Table 3
Percentage of Students who Informed the Concerned Authority and Teachers,
by Impairment & University

Variables		Informing Course Authority		Total	Informing Course Teacher		Teta1
		Yes (15)	No (85)	(100)	Yes (16)	No (84)	Total (100)
Nature of Impairment	Orthopaedic impairments	4 (6)	68 (94)	72 (100)	ı	72 (100)	72 (100)
	Visual impairments	11 (39)	17 (61)	28 (100)	16 (57)	12 (43)	28 (100)
Type of the University	Central University	14 (29)	34 (71)	48 (100)	12 (25)	36 (75)	48 (100)
	State University (a)	1 (4)	25 (96)	26 (100)	1 (4)	25 (96)	26 (100)
	State University (b)	_	26 (100)	26 (100)	4 (12)	22 (88)	26 (100)

Note: The figures in the parenthesis are percentages

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It can be seen from Table 3 that only 15 per cent of students informed the concerned authority and 16 per cent informed their course teacher about their problems and needs their respective universities. Similarly, when we look at students informing the concerned authorities by the nature of impairments, it is clear that more number of students with visual impairments informed the concerned authorities compared to orthopaedically impaired students. Similarly, it was also found that only students with visual impairments informed the course teachers about their problems and needs at their universities. It can be concluded from Table 3 that significantly more visually impaired students informed the course teachers regarding their problems and needs in the classroom. This is perhaps due to the fact that needs of students with visual impairments are entirely different from those orthopaedically of impaired students. Thus, they require more support services as compared to orthopaedically impaired students in higher education institutions. Thev have unique educational needs. In order meet their to unique needs, these students must have specialised equipment technology and services, books and get materials in Braille to get equal access to the curriculum and enable them to participate equally along with their peer groups in higher Thus, these students education. have to meet the concerned higher authorities, teachers and frequently discuss the requirements including study material, extra time during examinations, reader and scribe allowances, fees refund, arranging scribes and also for technical assistive devices. Similarly, when students informed the concerned authorities and teachers, it was found that female students were more informed about their needs compared to their male counterparts.

Finally, it is clear from Table 3 that a significant number of Central University students informed the concerned authorities and teachers about their problems and needs, as compared to State University students. It also shows that none of the students from State University (b) informed the concerned authorities about their needs and problems at their university. The fact is that students from State University (b) neither had a disability cell/unit nor disability coordinator to discuss their issues at their university. Therefore, it can be concluded that students who had a disability cell/unit, and a coordinator, have an opportunity to discuss their needs in order to get support services that facilitate them to pursue their studies successfully. It can also be concluded that more number of students from Central University informed the concerned authorities and teachers their special needs and problems. Similarly, it is obvious that visually impaired students (mostly females)

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were more in frequent contact with the administrative authorities and teachers to discuss their unique needs. Similarly, the research study conducted by Braithwaite (1991)also brought students disclosed their disabilities to the teachers in order to receive necessary facilities such as extra time during examination, teaching aids and learning resources. But all these factors are based on the assumption that the disclosure is purely voluntary in nature.

5. Classroom Teaching Experiences for Students with Visual Impairments

Respondents were asked to reflect on teaching experiences they received at the university level. Keeping in view the variety of teaching contexts, they were asked about learning in lectures and support from the teachers. In this study, majority of the respondents emphasised that there were difference in teaching strategies. They followed usual teaching strategies, treated them the same way as the rest of the students and that they had the same demands from them. It also appeared from the students' comments that they also never expected their teachers to treat them differently in class. Interestingly, it was found that 57 per cent of students informed the course teachers about their impairments and also disclosed their requirements such as teaching material, adjustments in exam timing and arranging scribes. But none of them requested their concerned regarding teachers changes teaching strategies, including asking the teacher to read whatever she/ he wrote on the blackboard. They also stated that they never had any problems with classroom discussions, attending and participating in classroom seminars and presentations. All the three universities had set up procedures for granting alternative exam arrangements to students who need them. Most of the respondents had no problem in getting appropriate arrangements made for their exam time and separate rooms for writing exams. Almost all the respondents stated that whenever they approached their teachers regarding arrangement of scribes and for allotting extra time during examinations, they received it. Some of them noted:

"Before the exam day, I go to my teachers and get permission to take the help of a scribe for exams. They are always positive. Once I get it signed from my teacher, I submit that letter in the academic section. Later I get the scribe allowance to pay the person who helps me in writing exams."

Some teachers were also identified as being particularly approachable and helpful to students who had missed some classes, or who would like to need special classes to clear doubts. Some respondents considered their teachers to be very helpful. They noted:

"Our teachers call us to his/her office, suggest the reading material

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and give whatever material he/she is having with him/her."

"My teacher is very friendly to all of us. If I need to clarify some doubts I go and ask him. He gives the reading list and suggests the source from where I would get the material for the entire syllabus."

"I informed my entire course teachers and requested them to allow me to use voice recorder in their class. They didn't object to it."

Some respondents are proactive about negotiating their needs and problems in the class. They are very clear about their needs and have no hesitation in asking for it. They stay back in the classrooms or personally meet the teachers in their cabins, after the lectures in each course. They believe that informing the course teacher about their needs helps them to get some of the material, soft copies and follow their studies better in time like other students in their class.

Conclusion

This study examined the factors that influence disabled students to disclose their special needs and strategies adopted by them to manage their higher education experiences. The effect of understanding and labeling as a disabled person is likely to be responsible for altering their world, the way others perceive them to be as well as how they perceive themselves. The findings of the study also emphasised on how students took responsibility, understood the disability, developed term support systems and disclosed their special needs to seek out services to overcome academic as well as physical barriers. Similarly, those students who informed/ or disclosed their disabilities and special needs to their teachers and higher authorities, benefited more by getting their requirements, reservations, such as and special provisions, support services, extra time during exams, reader and scribe allowances and also various support services. This, in turn, helped in improving their educational experiences in higher education institutions and to pursue higher education successfully.

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