

The Struggle of Adolescents with Physical and Sensorial Disabilities at Further and Higher Education Levels

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Abstract:

The Maltese anti-discrimination legislation stipulates that it is unlawful that an educational authority would discriminate against a person on the grounds of disability. The experience of young disabled persons with physical and sensorial disabilities attending further and higher educational institutions in Malta (and Gozo) was explored to understand the disabling barriers and enabling factors of inclusive education. The study stemmed from Dewey's theory of experience. Pragmatism was utilised as the main philosophical paradigm since lived experiences were considered essential for critical reflection on the experienced (the what) and the experiencing (the how) of experience. This paper focuses on the findings obtained from a narrative inquiry that was developed over two years with four female adolescents while attending a course at a further education institution and the University of Malta. The findings indicated that inclusive education is a social construct. The participants experienced an acceptable level of inclusive education. However, they unveiled an underlying struggle to overcome environmental, social and educational disabling barriers. It is recommended that in implementing quality inclusive education, the principles of democracy and social justice would stem from a rights-based rather than a charity-based approach.

Keywords: further education, higher education, inclusive education, disabled persons

Introduction

The experience of disabled persons with physical and sensorial disabilities attending further and higher educational institutions in Malta and Gozo was explored to understand the disabling barriers and enabling factors of inclusive education. This paper focuses on the findings obtained from a narrative inquiry that was developed with four female adolescents. This paper addresses the educational, social and environmental struggle that the participants experienced. It is envisaged that such consciousness would enable different stakeholders to reflect upon and transform personal and institutional current practices and policies that shape the politics of inclusive education.

Methodology

Based on a pragmatic approach to ontology deriving from Dewey's theory of experience (Dewey, 1938), the inquiry sought to understand the experienced (the what) and the experiencing (the how) in relation to the phenomenon of inclusive education as experienced by disabled young persons.

Narratology is a discipline "which takes as its central task the analysis of stories and narratives" (Plummer, 2001, p. 186). Cousin (2009) suggests that "narrative inquiry is particularly useful if you want to know something about how people make sense of their lives through the selective stories they tell about noteworthy episodes" (p. 93). Thus, the validity of the story should be valued more for the rich and insightful data that it provides rather than its representativeness. Narratology was implemented by conducting seven interviews with four adolescents who were given the pseudonyms of Alessia, Marie, Elena and Melanie, over a period of two years with an interval of approximately three months. In adopting Plummer's (2001) elements of narrative, the texts were analysed for key elements that shaped the lived stories to elicit meaning and interpretation of the experience of inclusive education of disabled young persons at further and higher education.

Theoretical Framework

The Maltese anti-discrimination legislation, the Equal Opportunities (Persons with Disability) Act (Laws of Malta, 2000, Chapter 413) specifies that it is unlawful that an educational authority would discriminate against a person on the grounds of disability. Moreover, as stipulated by the United Nations Convention on the Rights of Persons with Disabilities, state parties should create the measures to ensure that persons with disabilities are mobile and independent and that they experience non-discrimination and equal opportunities in education at all levels (United Nations, 2006, Articles 20, 24).

Adams and Brown (2006) argue that, "for most higher education institutions, the transition to inclusive education will require a significant cultural shift from seeing disabled students as 'outsiders coming in', to an institution which openly embraces 'all comers'" (p. 4). Thus, a pro-inclusion culture that enforces accessible and equitable quality learning and assessment practices for all students that respect student diversity and students' right of education are essential for the implementation of inclusive education.

Dewey (1930) sustains that, "not only does social life demand teaching and learning for its own permanence, but the very process of living together educates" (p. 7). However, students' diversity conveys the need for renewed commitment to teach all learners regardless of race, ethnicity, age, gender, socioeconomic status, ability or background to high standards (Gordon, 2009; Burgstahler, 2010). Florian

(2014) maintains that for teachers to sustain a commitment of inclusive pedagogy over time, they should adopt an approach that avoids marginalisation that is generated when students are treated differently, and a tactic that supports them to respond to learners' individual differences.

Findings

The findings indicated that inclusive education is a social construct. The participants experienced an acceptable level of inclusive education. However, they unveiled an underlying struggle to overcome environmental, social and educational disabling barriers on three levels, namely in relation to the self, in relation to others, and in relation to educational, assessment and employment entities.

The politics between the self and one's identity

Self-consciousness of one's limitations and abilities was associated to identity development as a person who can contribute to society. Participants learned how to adapt to their impairment, a system or persons, and be immersed into a culture of a majority of non-disabled persons. They recognised that they had to be nurtured to learn how to fend for themselves. This entailed developing self-help strategies, and a positive as well as a realistic approach towards life:

I'm lucky enough that I see both worlds and I'm part of both. ... You could have a student who can cope alone, but if he doesn't have accessibility, you've stopped everything. (Marie)

Society makes you disabled as it won't see you in the same way as someone else. ... I focus on my abilities. You need to think about what you can't do too, but you'll find another road to succeed. (Melanie)

The participants expressed that disabled people are faced with two problems, in adapting to the embedded limitations caused by the natural aspect of their impairment and coping with the disabling barriers that are socially constructed. Struggling against other people's perceptions of one's disability and disempowering attitudes was frustrating. Nurturing a rights-based approach from childhood empowered the participants to take up their responsibilities, develop self-advocacy and agency:

You are not judging yourself as a normal person is supposed to do. You are finding someone else judging you instead. (Alessia)

To make my voice heard, apart from being a right, I think that it's my duty as even if I'm not going to use it myself, someone else is going to use it. (Melanie)

Disabled persons should inform the school administration of their needs and that the information should be disseminated to lecturers as this could improve the quality of their learning experience. However, disclosure of needs should not imply a different treatment or a negative disability identity. Communication, collaboration, ongoing planning and training, enable stakeholders to be sensitive of the needs of diverse individuals:

I think you always need to tell as if you'll need something different, at the middle of the year, maybe it will be more difficult for someone to help you. But then it shouldn't define you. (Elena)

I should tell them that I am visually impaired. They'll be alerted so that they'll be able to prepare from beforehand. (Marie)

Conforming and experiencing life as their peers were salient factors in their education and in their identity development as an adolescent. It increased their chances of social inclusion and social cohesion. Portraying an identity of a dependent person was considered as deviating from the socially expected norm of adolescents. They tried to be independent as much as possible:

I don't want that someone treats me as if I am of a lower value than others because I'm normal like anyone else. (Alessia)

I wished to be independent. I wished to be like others. No one has an LSA (Learning Support Assistant) and why should I be different, not having my liberty, independence and privacy. (Melanie)

The hardships in overcoming the natural limitations caused by the impairment and socially constructed disabling barriers that limited the participants' academic development enabled them to develop perseverance and courage to face perils. Attending mainstream education was a learning process in developing resilience to obstacles and reflexivity in being aware that there are always persons of good-will and those who are ready to be spiteful. Past friendships increased their self-confidence and resilience to new situations:

There are youths who speak with arrogance. Although you try not to pay attention, it's not easy. Now either you're going to let it to break you or you're going to adopt a positive approach towards others. (Melanie)

Last year I made friends quicker for the fact that I had lectures with my friends. (Marie)

The politics between the self and others in experiencing inclusive education

Sensitivity towards the needs of different individuals and positive attitudes towards disabled people from family, friends, lecturers, non-academic staff, administrators and professionals affected the participants' physical and mental wellbeing. It also affected the extent environmental, social and educational disabling barriers were removed and the extent social inclusion was promoted. Friendship created a support network that promoted the development of individual and group resilience to stressors. Friendship inculcates the development of values that foster social inclusion and cohesion such as reciprocity, interdependence, altruism and solidarity without making a person feel as a second-class citizen:

We have a presentation. The place where we hold the lectures is like a theatre and with steps. ... When I told them and they made accommodations for me, I felt included. ... If you're going to place a person in a school, the students around her are going to be different. That's how you'll become included and their values would be strengthened. (Melanie)

We had spoken to the Principal because I don't see from far away. If I'll need assistance, I can go to room 103. He told us that he was going to tell the teachers, but no one knew that I had to stay at the front row. (Elena)

The importance of being courageous to try new things and face challenges was recognised by all the participants. However, lack of human resources, training and matching of human resources to the services that need to be given to students create great limitations for students to succeed. The participants indicated that time is needed for any person to become empowered and habituated to fend for oneself, but disabled persons need a bit more time due to personal limitations:

If the LSA (Learning Support Assistant) is sick, I am not able to come to school as there isn't a pool of LSAs. I'll be absent. (Alessia)

I didn't have an orientation visit. It would have been much easier. Last year, they provided me with an LSA (Learning Support Assistant). Her first experience as an LSA! She used to ask me what she had to do and I got confused. (Marie)

All participants agreed that lecturers are main stakeholders in creating a successful story of inclusive education. The rapport lecturers build with students, the group dynamics they create in class and inclusive pedagogies they use are crucial factors. Effective two-way communication and partnership between them and the lecturers were effective in identifying the plan of action to be implemented:

If you'll have a good relationship, it will be the most beautiful thing in the world, but if you won't have a good relationship, it's better that for each subject there will be more than one lecturer. (Elena)

Communication amongst the students and the lecturer I think that it's very important. (Marie)

The participants were afraid of being embarrassed in front of their peers as embarrassment disempowers a student and affects the type of relationship that is developed between the student and the lecturer. Causing embarrassment reflects lack of sensitivity and empathy towards others and that the lecturer went to class with stereotypical assumptions about who the students could be. The participants indicated that most of the lecturers were supportive, but there is room for improvement:

Power Points, some of them they'll be in a small font, the diagrams, the labelling will be small, notes incomplete ... You'll get annoyed telling them to write bigger. ... The first time I went, she told me, "Why are you with the fringe, are you blind? In front of the class I could not tell her "Yes." I didn't speak. (Elena)

Certain teachers don't expect to see a person with disability. ... There are ones who don't provide slides or leave the slides flipping and he talks on something else. (Melanie)

The politics between the self and entities of education, assessment and employment

Access is a key factor that improves the quality of inclusive education. In creating environmental, social and educational access, the participants indicated that stakeholders need to work in synergy. The participants put pressure on the administration to comply to their rights. They also showed an inner mission statement to contribute for the common good of disabled people and the student cohort in general:

I won't be able to go most of the outings as they are not held in accessible places. (Alessia)

Previous students with disability sort of pave the way for someone else. Inclusivity is a culture, sort of the habits of people. I still feel, that because I am asking for help, I am at a lesser level than someone else as the others just cope with what they have to do. (Elena)

There's the need for much more awareness even in schools. We are different, but our differences should not result into discrimination. (Marie)

The participants showed that information accessibility was an enabling factor to academic development. The availability of accessible tools on the market and in schools would give more freedom for disabled students to choose certain subjects and be able to complete tasks at par with non-disabled others:

I went to the library of here and the university. They neither have audio books nor eBooks. ... As I'm First Year repeater, I changed Maltese since a screen reader that reads in Maltese was issued at the end of last year. (Marie)

The participants recognised the importance that they are involved in decision-making as they would experience the consequences. They called for justice so that disabled persons do not have to struggle over and above other students. They experience a struggle in completing the statement of needs to prove that they are able to perform in exams or to verify that they are eligible for access arrangements:

The psychologist didn't ask me, he asked my mother and the school that I used to attend about what access arrangements I had. What I take at school, I take at MATSEC. ... I believe I don't have to pass through this board. (Melanie)

The board decides upon the report of the doctors. I won't tell what I need. The doctors should state that I need certain things. I won't have a choice. A normal girl won't have these papers and certificates that you need to do. (Alessia)

The process of interrogation bothered the participants. It created stress over and above the stress students experience in preparation for their exams. It made them feel as second-class citizens, humiliated and submissive to a hegemonic entity that judged their entitlement for access arrangements according to their medical portfolio. The participants recognised that this is done to curb abuse, but the approach needs to be evaluated:

The pressure that you'll start feeling while she's testing you, it's like you are doing the exam that you have to sit for. I don't think that it's fair. ... You have to study for the A-levels. (Alessia)

For the statement of needs, I did tests. You shouldn't need to redo this process every two years! (Melanie)

The stories indicated that they were generally satisfied with the access arrangements that the respective school and MATSEC board provided. However, they criticised the MATSEC system in the way students obtain access arrangements and their effectiveness. During exams the participants experienced frustration and they noted that the access arrangements disabled them rather than created an equitable situation:

At times, I take half an hour trying to explain. ... If you have Italian, at least the person who is going to be with you would know the basics of that subject. Not to help you, but to understand you! (Alessia)

I just needed extra time and a computer that reads for me the paper. Then a technician comes, he saves it on a pen drive and prints the paper as it is. ... The system that I am following now beats a scribe. (Marie)

All participants, albeit different challenges in terms of access and attitudes of non-disabled persons, recognised the benefits of attending mainstream schooling. Inclusive education was regarded useful for the school's community as by living together, a culture of inclusion from a rights-based standpoint is likely to develop over time:

Even the students amongst themselves as it's one thing seeing the person and the wheelchair only and another seeing the abilities of the person. (Alessia)

The fact that I'm in a class with my friends, it's better than if they locked me up in another room with three others. ... People who know me sort of they'll start thinking a bit before they speak. (Elena)

There is a nexus between further/higher education institutions and employment entities, but the transition from one sector to another is not as smooth as one would expect. They remarked that there is the need for more career guidance and transparency on the type of assistance that disabled students could get while reading a course at further and higher education and what activities will they be asked to do. Lack of job opportunities suitable for different disabled persons defeats the purpose for attending mainstream education and striving during the schooling years:

I don't know what I'm going to choose at university. There has to be more information. ... I think companies need to open more, rather than closing their doors for you immediately. (Elena)

Discussion

The participants shared a common belief that adolescence is a unique developmental

stage, and limiting disabled adolescents to experience it to the full due to environmental disabling barriers was oppressive and discriminating (Shakespeare, 2006; Laws of Malta, 2000). The participants through their activism tried to challenge forms of internalised oppression that society imposes in a subtle way. According to Watermeyer (2012, p. 170) in the disability sector, internalised oppression implies “maintaining marginality, material deprivation, dependency of all sorts, ostracism and struggle as the province of those designated disabled, in order that the business of othering may continue successfully.”

The research reinforced that inclusive education is essentially the onset of a social process “which engages people in trying to make sense of their experience and helping one another to question their experiences and their context to see how things can be moved forward” (Ainscow, 2008, p. 41). Dewey (1930) explains that, “communication is a process of sharing experience till it becomes a common possession. It modifies the disposition of both the parties who partake in it” in order to improve the quality of experience of those involved (p. 11). Consultation embeds democratic practices within the nuclei of classrooms and institutions that are basic in an inclusive agenda (Shevlin, 2010).

Conclusion

Inclusive education is dependent upon positive relationships between the self, the family and the community at the educational institution. It is recommended that in implementing quality inclusive education, the principles of democracy and social justice would stem from a rights-based rather than a charity-based approach. The development of a social network that promotes community building is likely to propagate social inclusion and social cohesion. Nurturing self-help strategies among disabled people and continuous planning to assist and guide diverse students across the educational sectors helps students to experience positive transitional periods between one educational institution and another. Training in implementing inclusive pedagogies such as the framework of Universal Design For Learning would increase the likelihood that the struggle of disabled persons and other minority groups would be dissipated and more students are supported to reach their full learning potential.

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Bio-note:

Dr Liliana Marić has taught at secondary, post-secondary and tertiary levels over the past twenty-two years. She teaches Home Economics at the University of Malta, Junior College. At University, she delivered lectures about inclusive education, teaching strategies and narrative inquiry. She was a tutor in practice placement of Learning Support Assistants as well as being a member on dissertation examining boards related to disability, Home Economics and inclusive education. Liliana has recently submitted her Ph.D. thesis which focused on the experience of inclusive education of disabled persons with physical and sensory impairment at further and higher education levels. Her interests lie in researching and contributing to the field of inclusive education.