Making Disabled People's Voices Vulnerable

Liliana Marić
liliana.maric@um.edu.mt

Abstract

This paper attempts to utilise creative writing to contribute to discourse in the fields of critical disability studies and inclusive education. Twelve semi-structured interviews were carried out with young disabled adults with different physical and/or sensorial disabilities who followed or were following courses at further and higher education levels. Research findings that show day-to-day experiences that disabled persons live are presented in short poems to reveal their presumed struggles. The evidence espoused that inclusive education is a process and a way of living. Support from parents, peers, administrators and lecturers are key to individual and community building. Self-help strategies are crucial in developing agency which, with a washback effect would transform society into a more democratic one. However, disabled persons need to be given the opportunity by eradicating the deficit mentality in society towards disability and disabled persons. The discussion unveils how society makes the voices of disabled persons disempowered and vulnerable. It is suggested that in Malta, wider opportunities for disabled persons to pursue their education at further and higher education levels and to enter the employment sector are needed to promulgate inclusive communities. Entities need to emulate a positive and proactive attitude towards social inclusion and cohesion. The contribution of this paper is to create awareness about the dire need for social praxis in fostering emancipation and social justice from a rights-based standpoint in favour of disabled people.

Keywords: *inclusive education, disability, further education, higher education.*

Introduction

As informed by Dewey (1930, p.89), education is fluid and continuous as "education is a constant reorganizing or reconstructing of experience." The journey of collecting data about the experience of inclusive education of disabled young people with physical and sensorial disability at further and higher education levels positioned me into another trajectory of reflexivity. Poetic creative writing was used as a medium for reflexivity which transformed my ideology of inclusive education and disability. This paper presents research findings that show the mundane challenges that disabled persons live and how society makes their voices vulnerable. The contribution of this

paper is to create awareness about the physical, social and educational factors that are experienced by disabled people. It unveils the struggle that disabled people face while hoping to achieve emancipation and social justice notwithstanding their rights being protected by anti-discrimination instruments (Laws of Malta, 2000; United Nations, 2006).

Theoretical framework

Critical disability theory was used to examine the politics that are entrenched within the experiences of dis/ablement of young adults in their attempt to attend post- and tertiary education and finding employment. Devlin and Pothier (2006) elucidate that "a primary concern of critical disability theory is an interrogation of the language used in the context of disability" (p.3) and that disability "is a question of politics and power (lessness), power over, and power to" (p.2). The application of critical disability theory for interpretation to promote emancipation and social inclusion from a rights-based perspective aligns to Meekosha and Shuttleworth's (2009) argument that, "emancipation is a cornerstone of critical theory, so it is inevitable that critical disability studies also encapsulate questions of human rights" (p.48).

In analysing how disabled persons are oppressed by society, the social model of disability was utilised as impairment is an attribute of the individual body or mind, whereas disability is a relationship between a person, an impairment and society (Oliver, 1990; Shakespeare, 2006; Barnes & Mercer, 2011). Finkelstein (2004) clarifies that the social model of disability is a tool of activism that provides an insight into the struggle of disabled persons towards emancipation.

Methodology

The findings presented in this paper are taken from one-time semi-structured interviews which were carried out with twelve young disabled adults with different physical and/or sensorial disabilities who followed or were following courses at further and higher education levels. Purposive sampling enabled me to obtain in-depth information to understand the research problem (Cohen et al., 2010). On average, they were an hour long and were audio-recorded. To conceal the identity of the participants, pseudonyms were given to all participants (Smith, Flowers & Larkin, 2010). The transcripts brought forward the issue of bilingualism in Malta. Thus some poems were written in Maltese and others in English depending on how the participants felt comfortable in expressing themselves. Camilleri Grima (2013) argues that the "language question" in Malta, which has been debated since the mid-nineteenth century, still resonates to this day (p.553). Interpretative phenomenological analysis (IPA) was used to analyse the transcripts for the

idiographic essence of the lived experiences of the participants (Smith et al., 2010). Selected excerpts of the interviews were transformed into poetic creative writing by putting together verbatim quotes to create a direct discourse that reflects political dynamics that occur between the self and society through experiences. To enhance the poetic element of the creative writing, few words that adhered to the message of the participants were also added.

Findings

The participants remarked that unless disabled persons' reflections about their experiences are listened to and a process of rumination is activated, emancipation of disabled persons is unlikely to be initiated. The participants put great effort to instil consciousness among non-disabled persons of their rights and reality.

Inclusive education

It can be corroborated that inclusive education is beneficial to all students, as it responds to student diversity (UNESCO, 2016). However, the participants' oral accounts showed that attitudes affect students' experience of inclusive education on a social, environmental and educational level. Democracy, social justice and human rights are the basis for sound inclusive education. Thus, our educational system should detach from a 'one size fits all' mentality (Portelli, 2010). Quality inclusive education also calls further and higher education institutions to be proactive rather than reactive in mainstreaming inclusive education. Our society needs to strive to eradicate the deficit mentality towards disability and disabled persons. This concept supports Ainscow's (1995) argument that, rather than emphasising on integration, there should be a shift towards inclusive education where schools are restructured to meet the needs of all. This is because integration merely entails that the schooling system will remain largely unchanged but would have additional arrangements to accommodate learners. This praxis would shift the culture towards more social inclusion and social cohesion as students would have the opportunity to live experiences together rather than being pulled out of the mainstream.

Disclosure

Riddell and Weedon (2014) explain that students with hidden impairments are the largest group of disabled students. The twelve participants acknowledged that disclosure was hard particularly when a person would be developing an impairment during adolescence or young adulthood, has not accepted the impairment fully, or

it is a hidden impairment. Some of the interviewees questioned the effectiveness of disclosure during employment interviews and on courses application forms as it was not a guarantee that the information was communicated to lecturers. Ongoing support from the staff and friends helped the participants to feel secure and to develop resilience and perseverance, especially during the first year of a course. Support was regarded crucial to come to terms with one's new identity and getting used to a new lifestyle.

Tneżżgħunix mid-dinjità! (A poem from Martin's narrative)

Niftakar...
Kemm kont insibha diffiċli
sabiex naċċetta u bla niftaħar
il-kundizzjoni li għandi b'perikli.
Aħseb u ara ngħid l-employer tiegħi
li bħal seqer fuqi
darba ġie miegħi
u sa anke qalli
il-vista hija don minn Alla,
għandek inkwiet serju.
Din mhix ċajta li wieħed falla
jew rakkont ta' xi misteru.

Għaddew bosta snin
u ddeċidejt nibda kors l-Università
u bħal ħobz bnin
rajt bibien miftuħa biex inwettaq xewqti b'dinjità.
Imma ma bdejtx bil-ward u żahar.
Attendejt għal-laqgħa ta' introduzzjoni
fejn f'ħin minnhom staqsejt imħeġġeġ bin-nar,
"X'faċilitajiet hemm għal nies b'nuqqas ta' dawl jew kumplikazzjoni?"
U dik ixxokkjat ruħha, nġibdet lura u instamtet,
u li kont tal-ewwel lili qaltli.
Le hija ma ffanfret
imma f'qalbi għedt din jonqos f'ħajti.

Do not undress me from my dignity! (Translation: A poem from Martin's narrative)

I remember...
How much I used to find it difficult
to accept without bluffing
my condition that I have with perils.
Let alone I would tell my employer
who as an eagle over me
once he came with me
and he even told me
vision is a virtue from God,
you have serious trouble.
This is not a joke that one missed
or a narrative of a mystery.

Many years passed
and I have decided to start at course at University
and like good bread
I saw open door for me to realise my wish with dignity.
But I did not start with roses and blossoms.
I have attended the introductory meeting
where at one moment filled with fire I have asked,
"What type of facilities are there for persons with visual impairment or a complication?"
And she was shocked, taken aback and perplexed,
and that I was the first one she told me.
No she did not boast about it
but in my heart I said this is what I need at the moment in my life.

Empowerment and community building

Shogren and Shaw (2016, p.58) argue that "higher levels of empowerment predicted lower levels of financial support and higher levels of employment, emotional wellbeing, and postsecondary education." The findings indicated that inclusive education is dependent upon positive relationships between the self, the family and the community at the educational or employment institution. The development of a social network that promotes community building is likely to propagate social inclusion and social cohesion. Nurturing and empowering young disabled people to develop agency contributes to the wellbeing of individuals and the community. These factors contribute to the development of maturity, resilience, and adaptability to cope with disabling barriers.

Issa l-waqt! (A poem from Clark's narrative)

Għandna defiċit.
Le mhix skuża biex tħossok skonfitt.
Irridu nħarsu 'l quddiem
jekk nemmnu f'dak li ngħidu bis-sliem
li kulħadd għandu dritt għall-edukazzjoni,
u qegħdin f'soċjetà inklussiva u ta' emanċipazzjoni.

Irrid ngħid li rrid inkompli nistudja,
ma nafx fejn se nasal avolja mimli fiduċja.
Qegħdin jgħiduli ieqaf,
avolja kontra l-prinċipju wieqaf.
Il-kelma diżabilità aħna s-soċjetà kkrejajna,
għax kull persuna għandu diżabilità aħna smajna.

Il-limitazzjoni ma qiegħda fuq l-individwu qatt.
Is-soċjetà, l-umanità tisħaq dak fil-fatt.
Meta ma nkunux kapaċi nilbsu n-nuċċali biex niffukaw
il-vista tagħna u naraw u naċċettaw
lil kulħadd kif inhu,
hu min hu
bil-limitazzjonijiet
u d-diffikultajiet,
mingħajr kritika,
u tabella satirika.
Din hija xewka, pjaga, stallett
li jinfed sa ġewwa nett.

Now it's the time! (Translation: A poem from Clark's narrative)

We have a deficit.
No it's not an excuse to feel defeated.
We have to look forward
if we believe in what we say peacefully
that everyone has the right of education,
and we are in an inclusive society and of emancipation.

I want to say that I want to continue studying,
I don't know where I'll arrive even though I'm full of trust.
They are telling me to stop,

even though it's against the standing principle.
The word disability we the society have created it,
as every person has a disability we heard.

The limitation is never on the individual.
Society, humanity stressed on that fact.
When we're not able to wear the glasses to focus
our vision and we see and accept
everyone how he is,
whoever he is
with the limitations
and difficulties,
without criticism,
and a satirical label.
This is a fish bone, a wound, a dagger
that pierces profoundly.

Parental support

The participants suggested that at further education, it is essential that like any other adolescent, disabled people develop self-advocacy and learn how to fend for themselves. This implies that with support, parents become sensitive to their children's age and adopt an advisory role. Sanders (2006) argues that when parents overprotect their children, they cause their child to become powerless, be limited in developing advocacy skills and during their transition to adulthood, they become dependent on others. The analysis of the interviews revealed that parental and other adult overprotection has a negative impact on the development of identity, independence and disempowers adolescents.

Peer support

Evidence revealed that friendship with staff and peers of good-will 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 being a second-class citizen. Høybråten Sigstad (2016) explains that friendship is an important relationship that may include practical support and may act as a protective factor for physical and mental wellbeing.

Administrators' and lecturers' support

Administrators ended up having a salient role in promoting inclusive education. Riehl (2008, p.184) explains that "Principals occupy positions that carry unique responsibilities and opportunities." Participants claimed that the Principals' attitude in empowering disabled adolescents to speak up and to seek strategies on how to implement inclusive education was salient in reducing disabling barriers. In developing self-advocacy among adolescents, the participants asserted that people in authority need to be sensible enough to empower and give the opportunity for disabled students to voice themselves.

Lecturers were believed to be main stakeholders in the implementation of inclusive education both in the teaching and assessment components (Shek & Wu, 2014). Lack of standardisation regarding information accessibility disables students. Lack of infrastructure limits the possibility where distance learning could be implemented. The participants remarked that in supporting the lecturers' input, dissemination of any relevant information must be done as early as possible. As indicated in the excerpts of the interviewees, synergy across stakeholders affects the quality of inclusive education students would experience.

Consultation with disabled persons

Consultation embeds democratic practices within the nuclei of classrooms and institutions that are basic in an inclusive agenda (Shevlin, 2010). The participants argued that unless disabled persons and other minority groups are considered as knowledgeable in their own field and are represented and involved during the consultation process and decision-making, an improvement in inclusive education and employment looks bleak. Consultation reduces pressures arising from power tensions between students, lecturers and administrators, but enhances empowerment between stakeholders.

L-effett tal-mentalità (A poem from Rose's narrative)

Il-barrieri soċjali huma bla qies
sforz l-injoranza tan-nies.
Jekk ma jkollokx ġenituri li jkunu sodi
u ma joqogħdux jitħassruk bl-ebda modi
għax miskina għax ħa tweġġa',
jaqtgħulek qalbek, tispiċċa bla ħeġġa
għax id-dinja fit-tarf iġibulek.
Ikun hemm il-biża' għal ruħek,

imma b'xewqa ta' faraġ,
il-ġenituri jgħinuk titla' t-taraġ
biex issiefer, titgħallem il-karozza b'kunfidenza
u b'għożża takkwista l-indipendenza.

L-iktar li ddejjaqni l-mentalità antikwata,
mhux għax forsi joqgħod iħares qisni blata
għax illum il-ġurnata ma nagħtix kas,
imma meta kont iżgħar, meqjusa bħala każ
naf minn xiex għaddejt
sakemm qoxra rabbejt.
Issib Kapijiet li jagħmlulek il-bsaten fir-roti.
Għalliema, dejjem sibt l-għajnuna għan-noti.
Il-ħbieb importanti għax tkun adoloxxenti.
Kieku l-klassi lili le m'aċċettatni għax kompromettenti,
emozzjonalment kienet lili tkissirni,
għax tħossok wisq maqtugħa mis-soċjetà li tifnini.

The effect of mentality (Translation: A poem from Rose's narrative)

Social barriers are endless
due to people's ignorance.
If you won't have parents who are firm
and they won't pity you in any way
as poor thing, as she's going to hurt,
and enable you to give up, ending without any zeal
as they would bring up endless difficulties.
There would be fear for your soul,
but with a wish of consolation,
parents would help you to go up the stairs
and go abroad, learn how to drive confidently
and with great affection you'll acquire independence.

The most that bothers me is the old fashioned mentality,
not maybe because he keeps on staring as if I'm a stone
as today I don't pay attention,
but when I was younger, considered as a case
I know what I have been through
until I grew a thick skin.
You'll find Heads who would create many difficulties.
Teachers, I always found help for notes,

Friends are important as you'll be an adolescent.
If the class did not accept me because I'm challenging,
I would have been broken emotionally,
as you'll feel cut too much from society that wears me out.

Self-help strategies

All participants emphasised that disabled people need to learn how to empower themselves and participate in activities with peers and in society. Developing skills of persuasion and reassurance were essential into overcoming personal moments of apprehension. Being brought up in an inclusive culture influenced their self-determination. Self-determination entailed developing psychological strength towards social and educational disabling barriers that are permeated in language, environmental inaccessibility, lack of distance learning opportunities and elements of paternalism expressed by others.

Disabled people's activism

The participants indicated that active participation of disabled persons creates a social capital of disability activists. By means of dialogue and collaboration they enabled staff within educational and employment institutions to became familiar with a typology of a student/ employee that exposed some form of otherness from the traditional student/employee. Their activism created consciousness and had an emancipatory effect on improving accessibility in the building, accessibility in learning and the working environments. The adaptations had a beneficial effect for all students and staff (Chanock, Stevens & Freeman, 2011). They also became conscious of the power they shared stemming from their experiential knowledge. The participants recognised that 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.

Provision of assistance

Deaf participants and those with hearing impairment indicated that lack of support from lecturers, peers and people while conducting research was detrimental on a social and educational level. These participants recognised that to prevent receiving a different treatment and avoiding humiliation and embarrassment in exposing their vulnerability (Roberts, Georgeson & Kelly, 2009), they used the strategy of "passing" by pretending that they were coping with academic needs (Michalko, 2002, p.21).

Rejection from employers led to poverty, solitude and disillusion. Lack of assistive technology in labs, and lack of audio and tactile resources in public places reduces the confidence of persons with visual impairment to move freely and securely. Such educational and environmental disabling barriers put additional pressure for students to finish assignments and research on time.

All is fine! (A poem from Ann's narrative)

The transition to university
instilled hope and curiosity.
It made me aware that I needed help
with a voiceless yelp.
Since I was a teenager I had repents
to ask for help from friends
as it was very embarrassing
to do the act of incessant pretending.
I am deaf and depend on lip reading,
so I can't listen and write as if I'm weaving.
I had to copy or borrow notes from friends
as electronic note takers are recent trends.
My parents encouraged me to continue with my studies,
and my teachers let me sit in the front of their settees.
They ensured that I was following
what they were saying or bellowing.

Finding employment
was one of the most difficult torment
and heart-breaking experience
for which I had to develop resilience.
Being deaf, employers were not interested
in giving me a chance, even if so far I persisted.
Although I had the qualifications as requested,
since I was without experience I was still rejected.

Discussion

This paper contributes methodologically by demonstrating how, within the Maltese context, findings at grassroots level could be transformed into creative writing. In creating community building, a socio-cultural praxis pro-inclusion can create a collective commitment to promote social justice and celebrate diversity in a

way that empowers individuals irrelevant of their differences (Adams & Brown, 2006; Gordon, 2009; Burgstahler, 2010). This statement adheres to Dewey's (1930) assertion that the process of living together reaps educational benefits. As suggested by Portelli (2010), there is the need for more open fora that critically deconstruct and reconstruct the 'learning landscape' by different stakeholders. This open discussion on inclusive education could be regarded as a process of growth to reach out to different learners (Ainscow, 2008). An inclusive culture necessitates creative and flexible systems of inclusion to suite different learners rather than having a fixed interpretation of inclusive education. This approach would recognise that each student is unique, has strengths and difficulties and a right for quality education (Corbett, 2001). Wider opportunities for disabled persons to enter further and higher education academic and vocational institutions are recommended, as these are a niche to create inclusive communities that respect the dignity of disabled persons.

References

Adams, M. and Brown, S. (2006) Introduction. In M. Adams, and S. Brown Eds., *Towards inclusive learning in Higher education – developing curricula for disabled students,* (10-22). London: Routledge.

Ainscow, M. (1995) *Education for all: Making it happen.* University of Cambridge: Institute of Education. Keynote address presented at the International Special Education Congress, Birmingham, England, April 1995. [Online] Available from: http://www.eenet.org.uk/resources/docs/making_it_happen.doc [Accessed 23rd July 2019].

Ainscow, M. (2008) Profile. In P. Clough, & J. Corbett Eds., *Theories of inclusive education – a student's guide*, (39-42). London: Paul Chapman Publishing.

Barnes, C. and Mercer, G. (2011) Exploring disability. 2nd ed. Cambridge: Polity.

Burgstahler, S. E. (2010) Universal design in higher education. In S. E. Burgstahler, and R. C. Cory Eds., *Universal design in Higher education – from principles to practice,* (1-20). Cambridge: Harvard Education Press.

Camilleri Grima, A. (2013) A select review of bilingualism in education in Malta. *International Journal of Bilingual Education and Bilingualism,* 16(5), 553-569.

Cohen, L., Manion, L. and Morrison, K. (2010). Research methods in education (6th ed.). London, UK: Routledge.

Corbett, J. (2001) *Supporting inclusive education – a connective pedagogy*. London: Routledge Falmer.

Devlin, R. and Pothier, D. (2006) Introduction: Toward a critical theory of dis-citizenship. In D. Pothier, and R. Devlin Eds., *Critical disability theory: Essays in philosophy, politics, policy, and law*, (1-22). Vancouver: UBC Press.

Dewey, J. (1930) *Democracy and education – An introduction to the philosophy of education*. New York: The Macmillan Company.

Finkelstein, V. (2004) Representing Disability. In J. Swain, S. French, C. Barnes, and C. Thomas Eds., *Disabling barriers – enabling environments*. 2nd ed., (13-20). London: SAGE Publications.

Gordon, D. T. (2009) School reform: are we just getting started? In D. T. Gordon, J. W. Gravel, and L. A. Schifter Eds., *A policy reader in Universal design for learning*, (19-33). Cambridge: Harvard Education Press.

Høybråten Sigstad, H. M. (2016) Qualities in friendship – Within an outside perspective – Definitions expressed by adolescents with mild intellectual disabilities. *Journal of Intellectual Disabilities*, 21(1), 20-39.

Laws of Malta. (2000) Equal Opportunities (Persons with Disability) Act (CAP. 413). [Online] Available from: http://docs.justice.gov.mt/lom/legislation/english/leg/vol_13 [Accessed 23rd July 2019].

Meekosha, H. and Shuttleworth, R. (2009) What's so 'critical' about critical disability studies? *Australian Journal of Human Rights*, 15(1), 47-75.

Michalko, R. (2002) *The difference that disability makes*. Philadelphia: Temple University Press.

Oliver, M. (1990) *The individual and social models of disability*. [Online] Available from: http://www.leeds.ac.uk/disability-studies/archiveuk/arc [Accessed 23rd July 2019].

Portelli, J. P. (2010) *Inclusive education*. [Online] Available from: http://www.academia.edu/397579/Inclusive_Education [Accessed 23rd July 2019].

Riddell, S. and Weedon, E. (2014) Disabled students in higher education: Discourses of disability and the negotiation of identity. *International Journal of Educational Research*, 63, 38-46.

Riehl, C. J. (2008) The Principal's role in creating inclusive schools for diverse students: A review of normative, empirical, and critical literature on the practice of educational administration. *Journal of Education*, 189(1/2), 183-197.

Roberts, H., Georgeson, J. and Kelly, K. (2009) Identity work – ways of being a disabled student in higher education. In M. Fuller, J. Georgeson, M. Healey, A. Hurst, K. Kelly, S. Riddell, H. Roberts, and E. Weedon Eds., *Improving disabled students' learning – experiences and outcomes,* (96-113). London: Routledge.

United Nations Educational, Scientific and Cultural Organisation (UNESCO). (2016) *Education 2030 - Incheon Declaration and Framework for Action Towards inclusive and equitable quality education and lifelong learning for all*. [Online] Available from: http://www.uis.unesco.org/Education/Documents/incheon-framework-for-action-en.pdf [Accessed 23rd July 2019].

Sanders, K. Y. (2006) Overprotection and lowered expectations of persons with disabilities: The unforeseen consequences. *Work*, 27(2), 181-188.

Shakespeare, T. (2006) *Disability rights and wrongs*. London: Routledge.

Shakespeare, T. (2013) The social model of disability. In L. J. Davis Ed., *The disability studies reader*. 4th ed., (214-221). London: Routledge.

Shek, D. T. L. and Wu, F. K. Y. (2014) The role of teachers in youth development: Reflections of students. *International Journal on Disability and Human Development*, 13(4), 473-480.

Shevlin, M. (2010) Valuing and learning from young people. In R. Rose Ed., *Confronting obstacles to inclusion – international responses to developing inclusive education,* (103-121). New York: Routledge.

Shogren, K. A. and Shaw, L. A. (2016) The role of autonomy, self-realization, and psychological empowerment in predicting outcomes for youth with disabilities. *Remedial and Special Education*, 37(1) 55-62.

Smith, J. A., Flowers, P. and Larkin, M. (2010) *Interpretative phenomenological analysis – Theory, method and research*. London: SAGE Publications.

Bio-note

Dr Liliana Marić has taught at secondary, post-secondary and tertiary levels. 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. Marić's Ph.D. thesis 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.