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# **Special Issue** *Inclusive Education: listening to disabled students' voices*

# Editorial

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Inclusive education is about making sure that schools, colleges and universities, and the education systems within which they operate, cater for the individual educational needs of each and every student. It is about asking the question 'what do we need to do to accommodate this student's needs?'. For this special issue of the Malta Review of Education Research, we have sought answers to this question in relation to the inclusion of disabled students. More specifically, we have sought these answers from research carried out with disabled students themselves.

The Convention on the Rights of Persons with Disabilities (CRPD) (United Nations 2006) determines the rights of disabled students in education. Article 24 sets out the details of these rights, establishing that non-discrimination and equal opportunity in the area of education requires 'an inclusive education system at all levels and lifelong learning' (Article 24.1) and the provision of a quality and holistic education that enables disabled students to develop their potential to the maximum. Furthermore, these rights require the provision of reasonable accommodation that attends to disabled students' impairment-related needs, including Braille, sign language, augmentative and alternative forms of communication, and individualized support. Crucially, Article 24 also emphasizes the function of education to enable disabled students to attain a 'sense of dignity and self-worth' (Article 24.1(a)) and 'to participate effectively in a free society' (Article 24.1(c)).

Listening to disabled students' voices is important for various reasons. First of all, it helps us gauge how effective education systems are being in including them in a way that truly suits their needs, and in line with the requirements of Article 24. Input from educators and from parents is of course very important. However, while the opinions of these and other adults are frequently sought and their advice and decisions acted upon, the voices of disabled students tend to remain hidden, and so do their perspectives which can sometimes be surprisingly different from those of the adults working with them. Very often disabled students, especially those who are still children, spend most of their time under adult surveillance, a situation which is not conducive to their being able to make their voice heard (Watson et al 1999). Secondly, enabling disabled students to talk about their experiences in education (as well as other aspects of life of course) should be seen as an integral part of that education. Having the opportunity to talk about one's life experiences and being able to reflect on them is essential to become adults who can participate effectively in a free society.

What then do disabled students have to tell us about their education? The papers included in this special issue provide us with some answers from various parts of the world – mostly from Malta itself, but also from Hungary, the United Kingdom, and Colombia. They also provide some answers about different levels of education – from primary school through to university; and answers about the inclusion of students with different impairments. These articles indicate that there is increased access to education at all levels for disabled students. But so much more needs to be done to achieve true inclusion, sometimes despite the efforts of well-intentioned educators and other adults. If these students were to write a report about their schools, colleges, universities, it would probably read 'Good effort, but needs to do much better'.

Pointers to how they can do better can be found in many ways including in what disabled students have to say. The article by Elvira Psaila shows us just how important it is to listen to their voices. Her research focuses on Alexander, a young boy with physical impairment in Malta. As Psaila herself remarks, the Alexander that his teacher and LSA describe seems to be a different boy from the image that Alexander projects of himself. Through her analysis, Psaila shows how the perspectives of the two educators on Alexander are embedded within notions of impairment as deficit and dependent on comparisons against pre-established norms, and why it is important to listen to and understand Alexander's own perspectives.

These norms are also the subject of analysis in the article by Pleven and Callus, which presents the perspectives of eight former students with intellectual disability on post-secondary vocational courses in Malta and their outcomes vis a vis employment. These students thrived in relatively sheltered educational settings that provided them with the support they needed, but found more open environments which do not have in-built support systems more challenging. The latter include most workplaces where needing support is seen as inimical to employability. But, as the authors argue, being a worker and needing support should not be seen as contradictory. Changes, therefore, need to be effected not only within education systems but at a wider societal level too.

Besides the support provided by educational institutions, disabled students also benefit greatly from supportive home environments and from being resilient themselves. The confluence of the various aspects of disabled students' 'ecosystems' is analysed in the article by Moreno-Angarita and Cárdenas-Jiménez. The authors present research carried out with four young disabled people in Colombia and focus not only on whether or not support was available at home and within educational systems, but also on the young people's own resilience. Highlighting this resilience foregrounds the agency that disabled students have over their own lives. In fact, evidence of resilience and agency can be found in the lives of all the disabled people who participated in the research presented in this special issue.

Resilience and agency need to be complemented by support of course. This support must be provided in many ways. Support in higher education is the subject of three articles in this special issue. Soorinen's research was carried out with thirty international disabled students in British universities. Much like Cárdenas-Jiménez and Moreno-Angarita's research participants, these students sometimes succeeded despite the system. Very often, these disabled students were expected to fit into already established systems, without those systems doing much to change in order to cater for their individual support needs. Soorinen comments that the difficulties encountered by her research participants are similar to those of British disabled university students. The fact that they had come over to study in Britain from different countries, and sometimes from very different cultures, compounded their difficulties.

As Maric argues in her article about inclusion in further and higher education (FHE), the values of inclusion need to be at the heart of education policy making and educational practice. This is true of education at all levels. In her discussion of narrative research she carried out with four young disabled people in Malta regarding their experiences in FHE, Maric makes the important point that listening to what students have to say about their individual educational experiences is crucial for policy-makers and practitioners alike. She argues that no two educational institutions will implement inclusive education in the same way and that various factors need to be considered, among them the school ethos and infrastructure. As Maric says, disabled students' own experiences is a very important factor that needs to be considered.

Listening to disabled students' voices need not always entail the formal process of conducting research with them but can also be done by finding out the issues that they discuss on a daily basis. This was the approach adopted by Flamisch and Hoffman who found out about the experiences of blind students in higher education in Hungary through an already-existing Facebook group. The perspectives of disabled students need to be trusted, as these authors say. It was the feeling of not being trusted and listened to that motivated the creation of this group which, although it is closed to members, can be joined by anyone interested in the inclusion of people with visual impairment in Hungary. Listening to disabled students' voices can therefore help bring down barriers not only through identifying obstacles to effective inclusion in education but also by challenging the stereotype of disabled people as being incapable of speaking about their needs.

Listening to disabled students' voices and giving them their due importance does not mean that the voices of parents, educators, and academics are discounted. Our special issue in fact starts with an interview that Elena Tanti Burlò, from the University of Malta, carried out with Salvatore Soresi and Laura Nota from the University of Padova in Italy. Inclusion, as Soresi and Nota tell us, is for all students, and all educators should strive to achieve it without any 'ifs and buts'. Achieving inclusion can present difficulties but these should be seen not so much as obstacles but as challenges that, once overcome, will create better educational systems for one and all. The creation of such systems is not achieved once and for all, but is an ongoing process of adaptation and change. And knowing what needs to be adapted and changed depends, among other things, on listening to what disabled students have to say about their experiences of education.

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# 'Working toward inclusion without ifs and without buts.'

An interview with Profs Salvatore Soresi and Laura Nota, University of Padova conducted by Dr Elena Tanti Burlo', University of Malta

ETB: Thank you for accepting to give us your time for this interview.

Prof Soresi we met many years ago when you presented a paper on the effects of a peer preparation programme on the inclusion of a young child with autism. Your paper emphasised the statement I have always heard you make, that : the success for inclusive education depends on many stakeholders: the teachers, the support staff, the school management team, parents, other professionals, the Union, policy makers and above all, ALL the students . I would like you and Prof Laura Nota to share with us your thoughts on the space allocated to "students' voices" in inclusive education.

Prof Soresi: Inclusion, as against mainstreaming and integration, is no longer concerned about this or that category of people....it makes no sense to talk about the inclusion of certain categories of people, for example, those with disabilities, with mental health problems, of immigrants and so on....this would have been valid when we used to speak of mainstreaming and of integration. This could have made some sense in the previous century when the movements in favour of mainstreaming and integration were in their infancy. Today, to ensure that these important achievements would not be challenged, it is preferable to reassert that inclusion inherently implies a series of important conditions which characterise the lived contexts of everyone. This will safeguard everyone's rights and carefully consider everyone's expectations, necessities and demands.

In other words, if a particular context is welcoming, tolerant or shows solidarity towards only certain individuals, it could, in effect show little respect towards differences, and because of this, the context cannot be defined as being inclusive. A context, in our opinion, either is or is not inclusive and it cannot demand any conditions for membership. (We like to say...inclusion with no ifs and no buts). As Asante (2002), one of the leaders of New African Voices, affirmed, inclusion needs and expects acknowledgement of interdependency and the understanding of the universality of the human condition. In fact, inclusion consists in 'acknowledging that we are "one thing" even if we are not all the same thing' (p1).

Prof Nota: Inclusive scenarios are possible as long as systematic and early intervention work is focused on the facilitation of:

a) The engagement of all who work at school (directors, teachers, administrative personnel, and those who organise and run the school) as they, independently from their roles, their qualifications and specialities, are the most responsible for the 'inclusive culture' which one would breath in a particular scholastic reality.

b) *The engagement of parents, of all the parents,* so that they collaborate to eliminate bias and stereotypes and promote the adoption of 'school rules' and programmes that foster the principles of inclusion and solidarity.

*c) The engagement of class-mates,* so that as they may learn how to manifest pro-social behaviour of acceptance support, help and solidarity in their relationships, (Soresi and Nota, 2001; Soresi 2007; Soresi, 2016; Soresi, Nota and Ferrari, 2006; Nota, Soresi and Ferrari, 2014).

All this requires 'capacity building'. In other words, that internal process in an organization that facilitates continuous improvements, aiming at valourising the existing capabilities and stimulating new ones, that instil processes for cultural growth and continuous improvement (Banks, 2009). The processes of co-construction of new knowledge, capabilities, innovative ways of understanding inclusive processes, stress on the resources of individuals and contexts, the involvement of the administrative and organizational structure are therefore necessary.

ETB: How have the peer preparation programmes evolved in the past 20 years especially in the light of research on self-determination and quality of life? (Are you still talking about peers of disabled students or are all students involved in the programme?)

Prof Soresi: The current school reality is characterized by a high level of heterogeneity and plurality of situations so much so that in one class there are children and adolescents who have different experiences, living conditions, diverse languages and culture, abilities and functionalities. The opportunity to belong to such classrooms seems to benefit all students, be they able or disabled persons, children of Italian parents or those who have immigrated, and those with low or high socio-economic status.

If one wants to aim towards inclusion, to an inclusion 'without ifs and without buts', one must seriously consider the fact that there are a series of barriers and obstacles that still present risks of exclusion and discrimination, especially for persons who are particularly vulnerable notwithstanding the existence of policy declarations and current legislation. These negative and penalizing phenomena are by now well known. Counter-measures have to be put in place that have to take on the characteristics of permanent and affirmative educational actions. Such actions will deal with the teaching and the education of all involved, on how to act respecting diversity, inclusivity and solidarity as to combat injustices in a way that 'the groups one finds oneself' in will grow and mature in respect of the individualities which characterises them.

Moving towards inclusive classrooms is the cornerstone which facilitates the creation of a micro-reality and a laboratory of solidarity, pluralism, and compassion.

Prof Nota: From this point of view, inclusive schools act, teach, educate, prevent and do not let 'natural tendencies' of the human race take over. The children and youngsters in class must, from the very first day of school, breath the air of inclusion, high demands, gratifications and special attention in respect of inclusive behaviour and attitudes. It is necessary to educate and teach, divulge knowledge and skills, act as role models and all this with high frequency in the awareness that inclusion requires intentionality, investment in human resources and continuous care.

To promote inclusion it becomes important to:

a) augment awareness on the existence of diversity; work on the reduction of negative stereotyped attitudes and the acquisition of skills promoting and maintaining positive and diverse relations with different peers in their school environment;

b) promote pro-social and social skills towards others, in spite of their having any difficulties, disabilities, hardships, vulnerabilities, etc.;

c) favour positive and hopeful attitudes when faced with problems and difficulties.

ETB: Italy has a system of school democracy where students form part of the school council as well as class councils. I was always interested in the amount of energy you have dedicated to programmes that motivate, engage and empower peers. What are your latest programmes?

Prof Nota: In the wake of what has been proposed in the literature on how to motivate the engagement and participation of peers; considering the present composition of Italian classrooms and the necessity of helping the younger generations to cope with living, in a satisfactory way, in super-diverse contexts, we present two of our most recent proposals: a) '*Positive Actions'* (*Le Belle Azioni*). A training programme, based on ten encounters of 35-45 minutes each held in *kindergarten classes* to promote positive attitudes, like the propensity of working and helping various classmates, to highlight the strong points of others, to create positive relationships and to be attentive towards differences. (Nota, Santilli, Soresi & Ginevra, 2014; Nota, Soresi & Ferrari, 2014; Soresi, Nota, Ferrari, Sgaramella, Ginevra & Santilli, 2013).

b) 'Hurray to Differences, Hurray to Participation'. This programme is based on ten meetings each of two-hour duration. It aims at creating awareness, amongst compulsory school aged children, to highlight the *differences* that are present in the classroom; to describe *their peers' strengths* and their repertoire of abilities in the engagement of numerous activities in everyday life; and to create support and help so that the participation of everyone in school activities is increased.

ETB: You have been involved in some pioneering work on positive psychology for the past few years. How do you link this work with the development of students' positive outlook toward their future, resilience and the ability to adapt to stressful environments and situations? How do you see this work help students face the world with optimism, hope and courage - courage to air their views and hope that their voices are heard?

Prof Nota: The recent models of development view positive aspects, such as hope and optimism, as having increasing importance. As already mentioned in our writings, when faced with diversity and caring behaviour towards others positive attitudes are involved.

We would also like to share with you the workshop *Jujube of Optimism and Hope at school"* "Giuggiole di Ottimismo e Speranze a scuola" (Nota, Di Maggio, Santilli, & Ginevra, 2014) which was designed by La R.I.O.S Laboratory and the International Hope Research Team (IHRT) of the University of Padova. This workshop proposes to analyse, together with the children, the idea of optimism and hope, stressing the importance of certain strategies and ways of thinking and developing children who are optimistic and hopeful.

In the course of the workshop, the children were trained to identify positive thoughts and to distinguish them from pessimistic ones, to identify the positive characteristics associated with optimism and hope, and to formulate positive objectives for their own future, showing also the strategies they need to achieve them. To check on the efficacy of the workshop a pre and post programme assessment was carried out. The children were asked to finish the following statements "the optimistic person is.....", "the person who is hopeful is....". This has allowed us to verify that at the end of the workshop the participants were fully aware of the essential points of the arguments

discussed and they also added more elements and characteristics to the definitions initially presented to them.

ETB "Jujube of Optimism and Hope at school" (Giuggiole di Ottimismo e Speranze a scuola). What an interesting title. "Giuggiole" - "Jujube" can you explain the meaning behind this word? It reminds me of the Maltese word "Guġu" which are coloured gummy sweets covered in sugar.

Prof Nota: Yes, in fact, "Giuggiole" are the same as your "*Gugu*": they are coloured, fruity, gummy sweets which children generally love. It's a fun word, full of hope, joy and optimism. That's why we called this programme Giuggiole di Ottimismo e Speranze a scuola.

ETB: It is a fun word. I can almost see the shopkeeper picking up the multicoloured sweets from a big transparent glass jar and us, as children, joyfully choosing our favourite coloured "Guġu" first from our 6 pence worth of paper bag and licking our fingers from the lingering sugar.

### ETB: Your work has really developed from your initial peer preparation programme

Prof Soresi: Yes it has, and we have continued to stress on the skills needed to identify diversity, to respect and celebrate it. Diversity is part and parcel of life and the skills needed to identify, respect and celebrate it may be learnt and developed. Inclusion just does not happen on its own. It is up to us to create the right contexts, which facilitate inclusion. We know that you like to say that all those working within the educational system have to stop cutting corners and quickly loose hope when faced with challenges which leads them to create segregating environments. There is no easy and quick path to inclusion.

ETB: Yes indeed, there are no easy and quick paths to inclusion. These would only lead to segregating practices and environments, as we have been, unfortunately increasingly, witnessing over the years.

Thank you Professor Salvatore Soresi and Professor Laura Nota for your time and for sharing your innovative insights on how children may be prepared to become empowered and self-determined to make their voices heard. We need a lot of elbow grease.

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# Voices in the Classroom – Exploring how the Voice of the Disabled Child and the Educational Professionals are Manifested in the Classroom

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Abstract: Children are often presented as vulnerable and in need of guidance (Priestley, 2007), thus, as adults and professionals we tend to assume that we know what is best for them, particularly if the child has some form of impairment. This may therefore cause children's voices to be silenced, unacknowledged and unheard. Drawing on the findings of a project I embarked on through the use of the Mosaic Approach, this paper presents the voices of a seven year-old boy, Alexander, having Spina Bifida, and that of his teacher and LSA. A brief overview of the importance of voice is given, and the paper then proceeds to explain why the Mosaic Approach is an appropriate tool in making children's voices heard in research and everyday life. By presenting the voices of Alexander and the education professionals simultaneously, the messages they are attempting to convey, namely themes focusing on identity, normalization of the body, academic excellence and accessibility, are then discussed. The voices brought forward highlight the different discourses presented by the child and the professionals. Whereas the child projects a message of normalcy and equality with peers, the education professionals still place emphasis on disabling discourse. Possible ways in which the disabled child's voice is promoted and acknowledged at a level at par to that of the education professionals conclude the discussion brought forward in the paper.

Keywords: Disability, Voice, Listening to children, Child

'We are going to do some classwork and for homework we are going to have the same as classwork. And you only have 29 minutes to finish it! OK? So you better get to work!' (Alexander, age 7)

'He is very laid back. He is dependent on having an adult prompt him all the time, and in group work, he allows others to take control.' (Teacher & LSA)

Reading through the excerpts above, it is rather hard to believe that the teacher and learning support assistant (LSA) are referring to Alexander. The contrasting messages being conveyed reinforce patterns and behaviours I observe daily working with disabled children myself. As adults and professionals, it seems natural to assume that we know what is best for the children we work with, particularly when these children have some form of impairment. Thus, although the children in our lives may be attempting to make their voice heard, this is often, at times unconsciously, silenced, unacknowledged and unheard. These observations led me to question how ready we adults really are to listen, respect and give power and value to the voice of the children in our lives. Furthermore, I was intrigued by how ready the children really are to make their voice heard, and whether they are given enough space to make their voice heard in the various environments of their day-to-day lives.

Drawing on the findings of a project I embarked on through the use of the Mosaic Approach, this paper presents the voices of a seven year-old boy, Alexander, having Spina Bifida, and that of his teacher and LSA. The paper starts by giving a brief overview of the importance of voice, particularly in the life of a disabled child. It then proceeds to explain why the Mosaic Approach is an appropriate tool in facilitating the projection and promotion of child voice in research and everyday life. The paper then moves on to simultaneously present the voices of Alexander and the education professionals involved in his life. The voices and the messages they convey are then discussed and analyzed to determine whether all the voices are heard, acknowledged and respected equally. The paper then concludes by suggesting possible ways in which the disabled child's voice can be promoted and acknowledged at a level at par to that of the education professionals.

For the purpose of this paper, the term 'disabled child' will be used in preference to 'child / children with disability', as I feel it is more in keeping with the principles of the social model of disability, whereby it is society that imposes the disability on the individual (UPIAS, 1975). Also throughout the paper, I acknowledge the child's voice as more powerful than mine as a researcher, as a professional, or as an adult. My role is therefore that of bringing to light the participating child's voice and his experience of what it is to be a child with a physical disability in Malta. In my reflections and writing of this paper, I aim to be 'true' to the stories, feelings and emotions being conveyed by all those involved, whilst I also embrace the role of advocate for the child's rights and needs and the importance of equal opportunities for all. I also acknowledge that as a researcher I still hold a degree of power within the writing of this paper. This arises from the fact that although the data will be generated by the child, the interpretation is still my own. This interpretation is therefore subject to my own personal perspectives, shaped

my own reflections and experiences (Foucault, 1980, as cited in Gore, 2005). Given that the participating child was a boy, throughout the paper the term 'him' / 'his' will be used to refer to the child.

# Voice and the Disabled Child

The power of voice is a concept that often we, as adults, parents and professionals, take as a given. Our position in society gives us a privileged platform that allows our voice to be heard, acknowledged and, to an extent, affect the lives of others. The same, however, cannot be said for all members of society, particularly those belonging to minority groups and children. From personal experience working with disabled children, I feel that the importance of voice, and its absence, holds particular relevance in their lives (Lewis, 2008). The voice of disabled children is often silenced by that of the adults around them in every environment of their day-to-day life. The implications of this silencing means that disabled children have little or no control on various aspects of their day-to-day lives.

The most influential agency in cultivating independence and autonomy is the family (Cardona, 2013; Devenney, 2004). At home, however, it is the parents that decide what is best for their children, and whilst it can be argued that this holds true for all children, it must be kept in mind that the presence of impairment adds factors that would otherwise not be in play. The parents of disabled children decide the type and frequency of therapies their children attend. They decide on whether their child attends mainstream or special schooling systems, and how much schooling is missed in order to attend therapy services available only in the mornings. The time dedicated to therapies, in order to minimize the impairment present, also determines the quality and quantity of time dedicated to other crucial childhood activities such as play and involvement in extracurricular activities (Blum, Resnick, Nelson & St Germaine, 1991). Disabled children are rarely consulted on whether they are happy with their home routine as is, and thus the parents construct the child's life based on guidelines given by medical and education professionals or by their own research on how to provide the best for their disabled child.

At school, the voice of the child is silenced by the need to conform to schooling practices that need to meet a vast curriculum. For disabled children this may be further hindered by the constant presence of a supervising adult (DeSchauwer, Van Hove, Mortier & Loots, 2008), especially the LSA, which may affect the freedom the child has to express himself, both with his peers and the class teacher. Furthermore, disabled children, as mentioned previously, may be made to miss school to attend medical appointments and other services. This may create feelings of 'visitorship' rather than

'membership' within the classroom (Anita et al, 2002), further diminishing the importance and space given to make the disabled child's voice heard.

Classical portrayals of the role of children, including those having impairment, are another contributing factor in the lack of value given to the child's voice. Children have often been depicted as naïve, innocent, mischievous, anecdotal, and unable to fully understand the nature of ongoing events (Priestley, 2003). The presence of an impairment tends to locate the cause of disability and social disadvantage within the child, promoting a personal tragedy and medical model view (Bult, Verschuren, Jongmans, Lindeman & Ketelaar, 2011) further distracting professionals from engaging and listening directly and actively to what the child himself has to say (Curran & Runswick-Cole, 2014). Besides these preconceived misconceptions, hearing the disabled child may be further hindered by the presence of impairments that hinder speech and the ability to utilise the spoken and/or written word as a means of communication.

### The Mosaic Approach

Historically, the dominant societal view that children were incomplete adults signified that children were deemed incapable of participating in meaningful research (Aries, 1986). Thus, the study of childhood was based on retrospective views of adults or on the views of the parents and professionals involved in the children's lives (Watson, 2012, Disability Rights Commission, 2006). This was also true for studies focusing on disabled children and disabled childhoods were the experience of disabled children is largely invisible (Curran & Runswick-Cole, 2014, Sylvester, Donnell, Gray, Higgins & Stalker, 2014) and when researched through classical approaches disabled childhoods have been mainly associated with a negative, medicalized and personal tragedy view (McColl & Adair, 2013). Hence, until recently, the main themes emerging from research on disabled childhoods were centred on the economic and social effects on the family and on service provision (Watson, 2012). This failure in exploring disability in childhood within its entirety, by excluding cultural contexts and children's first-hand experiences, resulted in the objectification and silencing of disabled children (Watson, 2012).

The Mosaic Approach was designed by Clark and Moss (2005) in view of this need to finally place the child's voice at the forefront of research. This is achieved by specifically acknowledging children as experts in their own lives and by giving priority to the importance of children's voice through the use of a combination of both traditional and participatory tools (Clark & Moss, 2011). Hence, it is the child himself who directs the course of the research project, and therefore only situations, both positive and negative, and barriers that the child feels are important in his day-to-day life are explored. The issues raised by the child are then used in interviews with the key adults in

the child's life. This helps create a more holistic picture of the child's life experiences, and explores how the child identifies himself and transgresses the barriers created by society (Clark & Moss, 2005).

Using the above principles, I worked with Alexander both in the home and school setting (Psaila, 2015). For the purpose of this paper, however, only the school setting is being explored. Alexander was given space to make his voice heard through child-conferencing (verbal discussions with the child), drawings, role-plays and photographs. The teacher and LSA were then interviewed, so as to add weight to Alexander's voice and issues he raised, as well as present a more holistic picture of Alexander's school life. I observed Alexander in his classroom on three separate instances during our time working together.

# Setting the Scene

Alexander is a seven year-old boy. He lives with his parents and two younger brothers. Alexander also has spina bifida and is a wheelchair user, although he is able to walk very short distances with the use of mobility aids. He attends a mainstream, state school and has a one-to-one LSA at school. There are 19 other pupils in his class and, while the majority of students come from a diverse mix of cultural and ethnic backgrounds, he is the only disabled child in his class, albeit not the only disabled student within the entire school.

In class, the teacher sits on the side at the front of the classroom, with the interactive board and a white board filling up the rest of the front of class. Some of the students are seated in groups of fours at the centre of the room, with the rest of the students sitting side by side forming a U-shape around the group in the centre. Alexander sits on the outermost side of the U shape, with the LSA on another desk by his side. He sits on a cushioned, classroom chair, with his wheelchair parked at the side of the classroom. Alexander's classroom is on the first floor of the school, and he can reach it by using a lift. The playground and entrance to the school are both accessible via a ramp.

This setting suggests that Alexander is completely included within his classroom environment. Still, it does not necessarily mean that his voice is being heard by the education professionals. In the following section, Alexander's voice, as expressed when working with me on an individual basis, is presented concurrently with that of his teacher and LSA, so as to question whether all those involved in the classroom are actually hearing what the other parties are trying to say.

### What is being said? Alexander

• I would like to stay in the wheelchair in class. It is more comfortable and I can get around on my own.

• Me: And are we going to the playground? Alexander: Of course we are!! Me: And how are we going to the playground? Alexander: (Thinks and rolls his eyes) Let's see... With the big lift! Me: With the lift? OK. Alexander: With the lift and all the children!

• Me: And what will we do in the playground? Alexander: Play too much! Me: And what are we going to play? Alexander: What I told you... hide and

seek, doctors and dentists Me: Doctors and dentists? Alexander: Yes, and of firemen, and we are going to do some activities.

• At school I am happy when I am playing with the children

• We are going to do some classwork and for homework we are going to have the same as classwork. And you only have 29 minutes to finish it! OK? So you better get to work!

• I am angry when the teacher tells me to be fast. Every time fast, fast, fast!!

• I'm happy when I do my class work

### Teacher & LSA

• Teacher: I think he needs to speak to a counsellor. He's growing and he's realizing. Right now he is becoming more aware he's different.

LSA: In fact, he's stressed all the time. He's constantly throwing up

• Students have a schedule on who can accompany Alexander in the lift.

• Me: Is there anything else you want to add?

Teacher: Yes, maybe, I don't know if it's the point, but is he doing physio? Me: No

Teacher: That's something that really bothers me – that he says that they can't take him because of his siblings. LSA: I would take him to physiotherapy myself if transport was available from school.

• He needs to walk daily. That's why we spend break time walking in the corridor, as walking in the playground is unsafe.

• In reality the girls take more care of him, they think of him, they want to go in the lift with him. But he is more attached to the boys.

• And when we were talking about their special friends, he didn't mention Anne. And Anne was the one that when we were doing the dancing of the concert offered – she told me "I want to stay with Alexander", and I mean at that age, it's remarkable.

• My aspiration for Alexander is, is for him to be very good at school. Because he needs to work, I want him to. I don't want him to end up in a home with people doing nothing all his life. Because he can do a lot of things.

• I think that his future lies in his brains. There's nothing much that can be done other than that. I mean, his physical impairment is quite big. You can't overcome it. There's nothing we can do. That's why I want his parents to understand how important it is for him to work hard now.

# What is being heard?

From the above, my observations and from working individually with Alexander on a one-to-one basis, I felt that the most predominant message was that Alexander is happy as is, and would like to be known for who he is as a person, and not be defined by his physical impairment and what he is physically able to do (Wickendon, 2011). Alexander wants us to acknowledge him as a seven-year-old boy, equal to and same as his peers. He isn't angry at the fact that he cannot use the stairs, he is bothered by the fact that not all of his friends can join him. The use of a wheelchair does not define him, but is rather just an extension of who he is (Egilson, 2014), so much so that attempting to walk is not a priority for him, playing with his friends during break time is.

What I heard Alexander saying helped me create a powerful, positive image of an assertive, happy child. However, this image was shattered as I progressed with interviewing his teacher and LSA. All of a sudden, I was hearing the voice of the education professionals describing a stressed out, laid-back, quasi-pitiful boy with a severe impairment that is moulding the entirety of his school life. I was shocked. Where was the Alexander I knew? Had I incorrectly heard and interpreted everything he had told me? So I decided to embark on a quest to re-evaluate my reflections and the knowledge generated by Alexander, and delve deeper in the voices present within the classroom and question whether listening is actually occurring between the different parties involved. Using direct quotes from both Alexander and the education professionals, the power of voice is discussed in terms of identity and normalization of the body, academic performance and accessibility – the main themes emerging throughout the research project.

# 'I'm comfortable in my wheelchair' - 'I would take him to physiotherapy myself'

Working with Alexander I was struck by the fact that words such as 'different' and 'disabled' never came up. When drawing himself, both in his family portrait and when with his peers, Alexander draws himself, a boy without the wheelchair, in the exact same manner as his non-disabled, family and friends, something he did by choice and not by lack of ability to do so. Alexander never voiced negative emotions, such as frustration and anger caused by the presence of the physical impairment and the necessity of using a wheelchair, although reference was made to the need of accessible environments. The data generated does not hint at the presence of an impairment, however, I did not feel that Alexander's silence on his bodily appearance and use of the wheelchair, reflected a denial of the impairment's presence. Rather, for him, it is just a normal, everyday part of who he is (DeSchauwer et al, 2009), a necessary extension of one's self that allows for independence rather than difference (Egilson, 2014). Thus, I feel that Alexander is conveying the message that 'disabled children are just regular persons with everyday interests, desires, activities, worries, and choices' (De Schauwer et al, 2009, p.104). Walking and 'normalizing' the body is a preoccupation of the professionals, not his (Hall & Hill, 1996).

And yet, the teacher and LSA imply that he needs to seek help as he is realising he is different. The 'altered' body is powerful enough to silence the child's voice, hindering the professional's ability to acknowledge and understand what Alexander is saying. Alexander clearly says that he would rather spend his day in his wheelchair, both in class and during break time. But instead, he is transferred onto a school chair during lessons and made to walk in a corridor during break time. Furthermore, both the teacher and LSA voiced the need for Alexander to resume physiotherapy sessions, a concern which was clearly voiced in Alexander's presence. This has two notable implications, in my opinion.

First, the stress being placed on the need to walk and to 'fix' the physical body implies that the education professionals still view disability from a medical model stance. Missing school, so as to be able to attend physiotherapy sessions, seems perfectly justifiable. So much so, that if possible, the LSA offered to take him to physiotherapy herself, in view of the fact that the mother could not take Alexander. The opinion being voiced is that only through minimizing the individual's physical impairment can the degree of disability be decreased (Mitra, 2006). This brings to the forefront the belief that non-disabled adults and professionals still define, interpret and construct independence in terms of the ability to be physically able to walk (Oliver, 1993). The education professionals felt that by allowing Alexander to enjoy everyday childhood experiences (Heywood, 2010), without the burden of regular physiotherapy intervention, the parents were unable to prioritize the needs of their physically impaired child.

Secondly, all of this was said in the presence of Alexander. This not only helps project a disabled identity and a need to identify as different from peers onto Alexander, but also reinforces the societal belief that disabled children are passive beings (Priestley, 2007). Talking over the child's head is not seen as an issue, and the effects of the spoken words on the child himself go unnoticed and unacknowledged. Thus, if the disabled child is still seen as being so passive that it is assumed that the power of our own voice as adults, talking about the child's own needs, goes unnoticed by the child himself, is it really a surprise that the disabled child's voice goes unheard? The effect that the physical impairment will have on the disabled child's ability to develop into an independent, autonomous adult was another constant undercurrent in my interview with the teacher and LSA. The need for Alexander to compensate academically for his physical impairment was voiced so loudly that it drowned all the other messages Alexander was trying to voice.

# 'So you better get to work!' - 'His future lies in his brains'

It is often presumed that if one has a physical impairment, then one is also dependent and incapable of learning at the same rate as peers (Nario-Redmond, 2010). In Alexander's narrative, however, he is expected to overachieve academically so as to compensate for his physical limitations. This is voiced repeatedly to Alexander on a daily basis. He is expected to obtain a perfect score in classroom tests and he is expected to be fast in his work. From my observations in class, whereas his classmates are allowed to make mistakes, and ask Alexander's LSA for assistance, when Alexander asks for help it is interpreted as over-reliance on adult input.

What is interesting is that although the education professionals seem too wrapped up in their own agendas to hear Alexander's voice, Alexander is extremely aware of what his teacher and LSA are saying. In our work together on an individual basis, he expressed his frustration at constantly being made to work quickly at school – 'I am angry when the teacher tells me to be fast. Every time fast, fast, fast!!' In our role play, where he was embracing the role of a teacher, he also brought this up by being extremely assertive with me (as his student) and by ordering me to be fast in my work – '*And you only have 29 minutes to finish it! OK? So you better get to work!'* He also sent me home with a list of sums to work out, which he then corrected in our subsequent session.

The power of the educational professional's voice in expecting excellent academic achievement has also translated into Alexander's behaviour at home. His parents have noted that he is increasingly more stressed after school, and that he is at times physically sick with the stress being placed on him. The difference, though, is that the parents are ready to listen to Alexander. They have heard what he has to say and acknowledge him as a seven-year-old boy who is being asked to constantly excel at school. For the education professionals, however, the root of Alexander's stress does not lie in their practice and their expectations of him. The cause of stress, they believe (and have voiced this to both myself and the parents) is that Alexander has a physical impairment that makes him look and feel different to his peers.

# 'With the lift and all the children!' – 'The children have a schedule on who can use the lift'

Accessibility was a theme Alexander brought up in all the tools used both in the home and school environment. He clearly and determinedly expresses the need for an environment designed with access for all (Imrie, 2004). Despite his young age, he does not speak in terms of wanting to walk so as to be able to access places easily. Instead, he views accessibility as an inherent right that should be made available to all. What irks Alexander is that although the school is accessible, his friends are not allowed to use the lift with him. Thus, what makes the school accessible, with particular reference to the lift, is also a source of marginalization. Alexander voices the wish that all his friends should be allowed to use the lift with him, not that he would like to use the stairs like the rest of his peers. But again, this wish has gone unnoticed, with the teacher and LSA making no mention of any problems with the schedule system they put in place. The idea that it may be more inclusive to keep Alexander's class at ground floor level, so as no one needs to use the lift to get to class was easily dismissed by the school staff.

Another important issue pertaining to voice and accessibility in the classroom is the fact that Alexander says that he would rather spend the day in his wheelchair so he can get around in class and participate in activities that involve the children to move to the front of class. But once again Alexander's voice goes unheard. This time, the cause is the advice given to Alexander's previous teacher and LSA by health professionals a few years earlier. At the time, Alexander was still being taken to school in a pushchair used for infants and did not have a wheelchair. Thus, the health professionals had advised on transferring Alexander onto a school chair for him to feel at par with his peers. This practice was taken on year after year, despite Alexander getting his own wheelchair. The problem with being transferred onto a school chair is that it obliterates the ability to move around the class, thus, Alexander is stuck at his desk throughout the entire school day. By voicing his wish to be able to stay in his wheelchair, Alexander is also expressing a wish to be more involved in classroom activities. But again, the power of professional's voice silences that of the disabled child. Furthermore, this silencing is not taken into consideration as a possible reason as to why Alexander is at times laid back in class.

# The Manifestation of Voice in Everyday Practice

Reflecting back, it is interesting to note that my first reaction was to question my own and Alexander's voice. Inherently it seemed inconceivable that the education professionals might have a tainted view of who Alexander really is and what he wants to say. And yet perhaps this is a reflection of the power a professional's voice holds within everyday environments, coupled with a perception that views children as incomplete individuals dependent on adult guidance (Clark & Moss, 2011). The notion that is the professionals that know best, not me, let alone a disabled child was the first port of call. And this notion, in turn, is also being manifested in the classroom on a daily basis.

The power of the educational professional's voice in the classroom, I feel, seems to not only silence that of Alexander but also shapes his identity within the school environment. Themes that Alexander never voiced, such as that of the need to normalize the altered body and the ability to walk, take centre stage. Whilst themes Alexander brought up in all of the work we did together, such as accessibility and the importance of play, were not acknowledged as issues affecting his life in school. My initial reflections led me to believe that the probable cause for the difference in my perceptions of Alexander and those presented by the education professionals lay in the possibility of multiple identities. The Alexander working with me individually identified himself differently than the Alexander in class, substantiating the belief that we mould and change our identity depending on the setting we are in. Furthermore, this would confirm the fact that children, including disabled children, do have fluid, multiple and complex identities (Curran & Runswick-Cole, 2014). This is built on the premise that the structural and social forces present influence and negotiate the individual's identity within that social setting (Priestley, 2003). Thus, although individual characteristics influence specific details of identity (Badia, Orgaz, Verdugo, Ullan & Martinez 2011), self-identity is affected and intertwined with the relationships and attitudes of those around, particularly that of parents and professionals (Priestley, 2003). It also highlights the idea that impairment and disability, although they can be identified separately, interact with the many other realities that constitute experience (being) and participation (becoming) within the school environment (Gaffney, 2014).

However, on further reflection and by referring back to my school observation notes, I feel that the main cause for this difference in the way Alexander is seen, is not only caused by multiple identities within Alexander himself. The Alexander I observed in class behaved in the same manner as his classroom peers. He participated during lessons, and chatted away with friends when possible. He seemed identical to the boy I worked with alone in other environments. And yet, the words and tonality used by the teacher and LSA kept resonating in my mind – 'he is laid back', 'he is constantly stressed', 'he is realising he is different'. So is it possible that the difference lies in our perceptions as adults, and our inability to listen?

Using the Mosaic Approach required that I strip myself from my adult and professional mindset, as far as possible, and acknowledge Alexander himself as the expert (Clark & Moss, 2005). Thus, by attempting to start with a blank slate as much as possible, free of preconceived ideas and beliefs, I was open to

receive and hear all that Alexander had to say. Inherently though, as adults and as professionals, we are schooled to assume that we know best, particularly when dealing with children (Priestley, 2003). Being in a position of power puts the voice of the professionals at the forefront, muting that of the disabled child. The disabled child may be voicing his needs and priorities as loudly as possible, but we may be too caught up in our own voice to acknowledge that the disabled child does indeed have a voice of his own. And more importantly, admit and acknowledge that the disabled child knows more about what is important in his life than we do. Our own voice, a voice that is talking in terms of the need of normalization of the impaired body, the need of academic excellence and the infallibility of the practice currently in place not only projects and encourages a disabled identity onto the child himself, but it also projects such a view onto his non-disabled peers.

Non-disabled peers have an important role in determining the quality of school life and inclusion (Gay, 2009) and despite the limited opportunity to socialize with friends during break time, the relationship between Alexander and his friends has been described as very positive by both the teacher and by Alexander himself. My observation sessions at school confirmed this and there seems to be no obvious indication that Alexander identifies himself differently from his peers. The ability to identify as equal to his peers is of even more significance, as disabled children tend to feel different and excluded from their peers given that they have to share their spaces with (De Schauwer, Van Hove, Mortier & Loots, 2008), and are under constant surveillance by adults (De Schauwer, Van Hove, Mortier & Loots, 2008. This feeling of sameness can possibly be attributed to the rich diversity present in the class. In Alexander's class, out of the twenty students, only eight are Maltese. All other students come from a varied array for cultural and ethnic backgrounds from all around the globe, and although he is the only student having a disability in his class, there are other students who have a disability attending the same school, as mentioned earlier. This leads me to question whether this diversity in gender, colour, religious beliefs and cultural backgrounds, allows the children to view the presence of impairment as simply another variant. Thus, Alexander's voice is equal to theirs.

Still, although I saw the interaction at school as extremely positive and reflective of children from diverse backgrounds and abilities getting on well together, the teaching staff interpreted this interaction differently. As can be seen in the following excerpts from the interview with the teacher and LSA, friendship towards Alexander was described in terms of love and caring. It was also implied that some of the children in class should be commended on their effort to include and care for Alexander.

'In reality the girls take more care of him, they think of him, they want to go in the lift with him. But he is more attached to the boys' (Teacher) 'And when we were talking about their special friends, he didn't mention Anne. And Anne was the one that when we were doing the dancing of the concert offered – she told me "I want to stay with Alexander", and I mean at that age, it's remarkable'. (Teacher)

Although it seemed to me that the pupils were voicing a message of sameness, a voice which said that they enjoyed playing together irrespective of gender, race or physical ability, this is not being heard as such by the adults. When peers include Alexander in their games, or offer to accompany him in the lift, or dance during the school concert, this is no longer interpreted as a sign of friendship. Instead, these acts are acknowledged as a sign of care, as noble and quasi heroic acts – acts that require recognition and praise. The presence of the impairment seems to taint every interaction of the disabled child, adding underlying meanings, even if unintentional, to otherwise unremarkable traits of childhood friendships. For the professionals, it seems inconceivable that although a degree of support is always part of friendships between disabled and non-disabled children, friendships that are not dominated by the need of care can still form (De Schauwer, Van Hove, Mortier & Loots 2008. Of concern, is that the adults voice this perception within the class environment, promoting the misconception that disabled children, and consequently disabled adults, are in need of care and charity. This might shift the chant of the children's voices that speaks of sameness to one of difference, pity and inequality.

# Giving Power to the Disabled Child's Voice

So how can the disabled child's voice be given the power and acknowledgment it deserves? The first and perhaps most crucial element, I believe, is the creation of an environment that encourages listening. Clark and Moss (2011) place great emphasis on the importance of listening as a prerequisite in allowing for the generation of new knowledge. Listening must be understood as an active process combining hearing with interpretation and construction of meaning that is a necessity in everyday life (Clark & Moss, 2011). Clark and Moss (2011) suggest a number of conditions that should be present in order to enhance listening. First and foremost, a climate that promotes listening must be created - a climate that values children's opinions. As adults and professionals we must therefore learn to step down from the upper position our age and professions put us in and embrace a position that allows us to learn from our students.

Secondly, listening cannot be a rushed activity and therefore both the child and adult must be allowed to take their time in listening and interpreting (Clark & Moss, 2005). Hence from the start, I ensured that Alexander felt comfortable in sharing his experiences with me and in knowing that he had ownership and control over the project and could decide on what to divulge with me and could refuse to continue sharing at any stage in which he did not feel comfortable. I also did not set any given time frame for the duration of the sessions, and it was Alexander who decided when time was up for our work together. It was this mindset, and the creation of a safe environment, that allowed for Alexander's voice to be heard with the respect it deserves. Applying the exact same principles may not be as straightforward within a classroom environment, where systems currently in place require a rather inflexible time schedule and a vast curriculum to be followed. However it is not impossible. Children should be given the time to express themselves, using media that go beyond the spoken word, such as drawings and role plays (Clark & Moss, 2011). We, as professionals, must be ready to listen and dedicate time to look beyond the work given at face value, as well as respect what is being told and be aware of areas where the child was silent.

Allowing children to make their voice heard is useless unless we the adults learn to listen to what is being voiced and move away from a view that focuses on the impairment rather than disabled children's potential (Salamanca Statement, 1994). It must also be taken into consideration that there is a risk that the authenticity of voice may be interpreted as sentimental or anecdotal by various stakeholders in the child's life (Barnes, 2003 as cited in McColl & Adair, 2013), stemming from the stereotypical portrayals of children, particularly disabled children. Disabled children have often been depicted as courageous, and yet in need of our pity, in a variety of settings (Shaprio, 1993), and this may inadvertently bias the adults interpretation of the child's voice. For listening to actually generate knowledge, thus being given a power equal to that of the voice of the professionals, children (including disabled children) must be recognised and respected as experts in their own lives. Besides acknowledging the children's expertise, and creating environments conducive to listening, we must be open to thinking outside the box.

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# From adversity to success: Four life experiences around resilience

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Abstract: Despite high rates of educational exclusion of adolescents and young adults with disabilities reported by Colombia's Ministry of Health and Social Protection, 3.7 % of disabled people have reached some level of education. The process of adaptation to the school environment led them to the successful completion of this phase of their training. They confronted adverse conditions and registered some important achievements, notwithstanding adversity. This invites us to think of 'resilience' in this population group as a process that 'arises from' adversity and not 'in spite of' it. Resilience is a transactional process between individuals and their context, a process with strong roots in the individual's history. This qualitative study emerged in order to understand what happens with disabled young people in Bogotá, Colombia. It was developed using oral life history as a method. Prominence is given to the subjectivity of the collaborator, the social and cultural context and its vision of process, rather than the result. This study seeks to identify and describe the process of adaptation and resilience in schools, as lived by a group of four people with disabilities during their adolescence and young adulthood. The results are presented as suggestive material to design strategies to support students at secondary level. The participants' own voices, perceptions and expressions were the focus of the study.

# Introduction

The experience of disability and social inclusion is unique to each disabled individual. There is a complex combination of factors that influences this experience, which is why we must address it as a biopsychosocial phenomenon that affects the whole person, going far beyond the concrete manifestation in the body, or behaviour (Zola, 1982). It is important to note that disability can no longer be conceived of as a purely biomedical phenomenon that begins and ends in the body of individuals. Perhaps its most visible aspect is manifested in the biology of people, but the said biological or functional impairment only reaches the 'status' of disability when in contact with the material, social and attitudinal characteristics of the environment which prevents the implementation of daily activities and social participation. For these complex reasons, it is possible to say that disability and social inclusion are multi-determined and multi-determinant phenomena which leave effects at the social, family and individual levels. Educational inclusion as part of social inclusion is also determined by multiple factors involved in the process of adaptation to the school environment and the success of children, adolescents and young people with disabilities.

Most programmes of educational inclusion in the Colombian context are aimed at children with disabilities (MEN, 2014). Even when they grow up, programmes remain the same, ignoring what adolescence and adulthood mean. Because of these shortcomings, it is still very common to hear testimonies of individuals and families who must confront stigma and discrimination, often stemming from the institutions themselves responsible for the social inclusion programmes that do not yet take into account inclusive narratives and practices in their bureaucratic, pedagogical and organizational processes (Correa and Castro, 2016). It is also because of these situations that many teenagers and young people with disabilities still have problems accessing basic education and also why they cannot aspire to job training in line with their interests and abilities, still less can they aspire to enter university.

The Registry for the Location and Characterization of Persons with Disabilities (RLCPD), under the Ministry of Health and Social Protection (2016) has found that in Colombia, up to July 2016, 7.55% of the population of people with disability are between 10 and 18 years old. In the group of 10 to 14 years, i.e., the expected section for admission and attendance at a basic secondary education level, 34% of adolescents do not attend an educational institution, a figure that rises to 37% in the group 15 to 18 years, i.e., the expected age to attend vocational secondary education and enter higher education. Among those not attending educational institutions, 69% admit not studying, or not having studied because of their disability. This evidence suggests that when talking about the attributed absences on account of disability, we are not only talking about the differences in anatomy, physiology, or individual functionality, but also about the result of disabled people's interaction with the characteristics of the educational system in the architectural, educational and attitudinal dimensions (Moreno, 2011).

Despite high rates of educational exclusion of adolescents and youth with disabilities reported by the RLCPD, the same record suggests that of the 1,265,328 persons with disabilities registered in the country, 3.7% have attained a level of technical, technological college, or graduate education. Without taking into consideration those within this small group who would have acquired disability after school age, the evidence invites one to consider what are the factors inherent in individuals, their families, their immediate social environment and in the process of adaptation to the school environment that led them to the successful completion of this phase of their training, especially considering the fact that they faced adverse conditions equivalent to those that did not achieve such success. This invites us to identify the characteristic of resilience in this population group (Cárdenas and Moreno, 2014).

# **Resilience and disability**

The term resilience comes from the Latin *'resilire'*, which can be translated as 'to jump, or bounce back'. This concept was originally used in the field of physics to characterize the resistance of a body to shock and its ability to retain its structure despite the impact (Colmenares, 2002). From the psychosocial point of view, it can be defined as 'the set of social and intrapsychic processes that enable access to the psychosocial wellbeing, despite adversity' (Melillo, Soriano, Mendez, & Pinto, 2004: 23).

Authors like Waller (2001) and Manciaux (2003) have established that resilience is not absence of vulnerability, nor is it a characteristic of personality, but rather an interactive, dynamic and evolving process between individuals and their environment. Resilience is the result of risk factors and protection, but often this distinction is artificial because the same factor may be 'risk' or 'protection', depending on the context, nature and intensity of stress of the person and the stage the life each individual has reached. It should be remembered that resilience does not mean a lack of risk or total protection (Manciaux, 2003). Throughout its history, research into resilience has maintained a strong inclination toward the individual level of analysis which is the predominant trend today.

However, there is growing recognition that resilience is multi-dimensional and multi-determined, and can be best understood as a product of transactions between multiple systemic levels over time (Walsh, 2005). The relationship between humans and adversity, and their source of resilience is neither linear, nor unidirectional. This perspective is relatively new in the study of resilience, and invites the interdisciplinary effort to explore the link between psychological processes and those of a non-psychological environment (Waller, 2001). Understanding resilience requires an analysis of the impact that adversity and protective factors, arising from the different systemic levels, have on people. For this reason, it is necessary to consider the risk and protective factors that may arise from single systems (chronic, biological disease, psychological anxiety, cognitive skills), family (overprotection, flexibility in roles), community (unsafe neighborhoods, community support groups) and social factors (poverty, affirmative action). These risk factors and protection within a given ecosystem are dynamic. They are not fixed attributes and their effect is only evident in the context of the interaction and meaning that each individual gives to a certain factor (Waller, 2001).

The detection of such a wide variety of factors that influence the development of resilience is only possible if it is part of a theoretical model to organize knowledge about the interrelationship and interdependence between individuals and social systems, observe the phenomenon and then use the results both for science and for public policy (Bronfenbrenner, 2002).

From the perspective of the ecology of human development, proposed by Bronfenbrenner (2002), development is conceived as a continuous process of adaptation and mutual accommodation between individuals and their physical, social, class and cultural environment. The environment is defined as something that extends far beyond the immediate situations that affect the developing person to include interconnections between these environments and external influences emanating from the wider environment. Thus, topologically, the environment is conceived of as a serial arrangement of concentric structures, in which are contained the following dimensions: a microsystem, a mesosystem, an exosystem and a macrosystem.

This study seeks to determine identity and describes the process of adaptation and resilience in an educational setting experienced by a group of four persons with disabilities during their adolescence and youth, with special emphasis on factors like self image, perception about disability, social relations with relatives, interactions with other people and school peers. Additionally, personal protection, social and family strategies that facilitated their process, were also observed. These factors come into the analysis as Bronfenbrenner (2002) suggested. We presented this conceptualization in the next section.

Applying to resilience the hypotheses that Bronfenbrenner (2002) poses about development in relation to the mesosystem, we could argue that the potential to promote resilience by the environments is increased if there is a person binding between both environments and if their roles, activities and relationships stimulate the emergence of mutual trust, a positive orientation, a consensus of goals between environments and a growing balance of power. Relational processes can be understood as the activities, roles and relationships that people experience in their immediate environments (Bronfrenbener, 2002), especially the family, which are sustained on the basis of communicative processes and organizational norms influenced by beliefs and cultural practices (Walsh, 2005). The influence of both intra- and extra-family relationships on the development of resilience, is marked by some properties of relations: reciprocity, balance of power, and emotional relationship.

Another determining aspect, which in turn is determined by relational processes, are roles. These are often identified with labels that are used to designate different social positions in a culture, and generally differ according to age, sex, relationship, occupation or status (Brohenbrenner, 2002)

A person's social position, and therefore their role, can be defined in response to the question 'who is that person?', from the perspective of someone who knows her and the social context in which she or he is located.

# About social support

Today, it is recognized that health, both mental and physical, depends to a large extent on the social factors that characterize the living conditions of people. However, exactly how these factors operate remains the question that guides current research on social support (Reblin & Uchino, 2008). In general, it has been shown that when people feel well supported, they also show other favorable characteristics, such as increased self-control, better coping strategies, greater self-efficacy, less depressed mood, better adjustment and well-being in stressful situations (Schmitz, 1998 cited by Schwarzer, Bäßler, Kwiatek, Schröder & Zhang, 2003). Studies have also repeatedly found that those receiving the highest levels of social support enjoy improved health and well-being, increase their satisfaction with life, and show less solitude (Chalise, Saito,Takahashi and Kai, 2007).

After decades of study in the area the need to conceptualize social support has been evidenced, and has been used interchangeably along with other terms such as social networks and social integration. According to Schwarzer et al. (2003), social networks refer to the number of people or possible support givers in an individual's environment. On the other hand, social integration refers to the structure and quantity of social relations, that is, to the size of networks and the frequency of interaction, while social support would refer to the function and quality of social relations, such as the availability of perceived help or support currently received, which occurs within an interactive process and is related to altruism and the perception of reciprocity. Rob (1990, cited by Schwarzer et al., 2003) argues that health and well-being are not only the result of the current support provision but the consequence of participation in a meaningful social context. Receiving support gives meaning to people's lives, because it gives them a reason to give back, to feel committed and attached to their ties.

However, it has become clear that the nature of the perception of social support is more complex than the simple recognition that support is received. Dunkel-Schetter and Bennett (1990, cited by Chalise et al., 2007) argue that this is a multifactorial process. If support is desired, if it is sought or received passively, and if the recipient is satisfied with it, they are critical factors in determining the effects of social support.

# **Coping processes**

Based on the results of the stressors' evaluation process and the resources available to address them, individuals implement a 'series of actions that arise from those constantly changing cognitive and behavioral efforts that are developed to handle the specific internal and/or external ones that are evaluated as surplus or overflowing with the resources of the individual' (Lazarus & Folkman, 1984: 86). These efforts are part of what the authors have called the coping process. From this definition, it is possible to differentiate between coping and dominance, since the former implies implementing strategies such as avoidance or minimization, without them leading subjects to dominate the situation.

Coping with a problem has common characteristics with problem solving. The first one encompasses a set of broader strategies that include those that refer to the interior of the subject, while the resolution of the problem implies an objective, an analytical process directed mainly to the environment.

The second role of coping, that is coping with emotion, can be divided into three main groups: one that seeks to reduce the degree of emotional distress, which includes strategies such as minimization, avoidance, detachment, selective attention, positive comparisons and extraction of positive values from negative situations; A second group that includes self-punishment and self-reproaches, aimed at increasing the degree of emotional upheaval, as some individuals need to first experience an intense emotional disorder before they become better; And third are those who use emotional alterations to rush themselves into action.

The theoretical approaches of Richard Lazarus and his collaborators are largely dominated by a process vision rather than by the assumption of basic stable structures such as personality traits; Which implies that the coping is changing, that is to say that the individual modifies its strategies as it changes its relation with the environment (Knox, 2002).

# Individual processes

Individual processes are defined as the individual-level biopsychosocial characteristics that interact with the characteristics of the environment 'to allow the manifestation of resilience' (Polk, 1997: 8). Given its importance in relation to resilience, we will then address the emotional aspects, especially the positive emotions.

According to Vera (2006), experiencing positive emotions leads to mental states and modes of behavior that indirectly prepare the individual to successfully face difficulties and adversities to come. Multiple studies have shown that positive emotions have a wide range of effects on individuals (Lyubomirsky, King & Diener, 2005; Pressman & Cohen, 2005, cited by Ong, Bergeman, Bisconti & Wallace, 2006). Theoretical and empirical studies indicate that positive emotions promote flexibility in thinking and problem solving, counteract the effects of negative emotions, facilitate coping, build social resources, and improve well-being. Often positive emotions can cooccur along with negative emotions, even in the midst of significant stress events. One of the ways positive emotions can play a central role in adaptation has been proposed by Zautra et al. (2001, cited by Ong et al., 2006) in their dynamic model of affection. This model predicts that under normal conditions, positive and negative emotions are relatively independent, whereas during stressful situations, an inverse correlation can increase markedly, making it more likely that positive emotions will decrease negatives in days of high stress.

# Methodology

# Design

This qualitative study was developed using four life histories (Meihy, 2005). The characteristics of this method, including the prominence that is given to the subjectivity of the collaborator, the social and cultural context and vision of process rather than result is included, made it appropriate for the description of the processes of adaptation and resilience, since as has been discussed above resilience is a *transactional process between individuals and their context, a process with strong roots in the individual history*. Additionally, the method of four phases of Madeleine Leininger was used as a strategy of qualitative data analysis (Meihy, 2005).

# Participants

The participants in this study were four disabled people. One of them with mental health issues, and the other three with sensory impairments (2 blind people and 1 hearing impairment). All of them have access to education, as well as to work activities. All of them belong to the National University of

Colombia, as students, or as alumni. All attended primary, secondary and higher education in the regular classroom. They had a good academic performance and adequate social integration during their adolescence. They were included and shared work, social and emotional processes with people of a similar age group, and did not attend special programmes. The researchers have a social relation with them. They were the only people invited to participate in the study, as volunteers. All of them accepted to participate without reluctance.

In Table 1, the sociodemographic characteristics are presented. Real names are changed for another names.

	Midgard	Alejandro	Andrés	Ana Isabel
Age	27	24	27	40
Disability	Mental health issues	Visual	Visual	Hearing
Profession	Social Sciences	Philosophy	Antropology	Linguistics

# Instruments

The study was based on oral histories. A list of questions was prepared which included: self image, perception about disability, social relations with relatives, interactions with other people and school peers. As shown earlier, this categorial list comes from the theoretical approach of micro, meso, exo and macrosystem.

# Procedure

Eight interviews were conducted. Each of them took between one and two hours and each participant had between one and three sessions. All interviews were recorded, and a consent letter was signed before the interview. The consent letter was read for the participant with visual impairment. The questionnaire for the deaf person was presented in a printed format, which she preferred. The interview was conducted orally, because she felt much better with this medium.

Following the method proposed by Meihy (2005) each interview was transcribed verbatim, that is every word spoken during the interview was written down. On average, every recorded hour resulted in 8 hours of transcriptions. A transcription assistant supported us in this activity. This process was very rigourous and systematic. Based on transcripts, the next phase was the construction of the written documents into a textualized oral history. Textualization consists in reorganizing the chronological sequence, identifying the central themes of the narrative and incorporating both into the story, allowing participants' voices to be heard as a 'first person' history (Meihy, 2005). The final stage in the creation of written oral histories is that of transcreation, which is based on the principles of translation (Meihy, 2005). It is committed to building a totally recreated text. At this stage, circumstances that were not considered during interviews become registered and included in the transcription by participants.

Given the leading role that the participants played throughout the construction process of their own oral histories, they revised the version and approved, or disapproved the end product of the transcreation. Participants removed, added, modified or negotiated phrases during transcreation.

# **Results and discussion**

### About the microsystem

The main themes that emerged from the histories were of the participants' self-image, sense of humour, social interactions with peers and relatives. According to the data analysis, the results showed that the main factors associated with the resilience process were found at the microsystemic level (Bronfenbrenner, 2002). In this sense, the closer the context to the participant, the greater the resilience exhibited. Analysis is presented by any of the categories of our conceptual framework based on Bronfenbrenner (2002).

# Self-image

As for the so-called personal processes, the findings reveal that participants have high self-efficacy, that is, a high level of confidence in the resources available to enable them to achieve the proposed goals (Bandura, 1977; Maddux, 2002). Also collaborators show a heightened sense of hope (Snyder, Rand & Signon, 2002), which throughout their lives helped them to generate future expectations, which, in turn, largely have enabled them to achieve the performance levels that have been achieved in today.

I would like to find answers to all my questions, and don't find them, it is like the problem is still here, I have to find the solutions myself because I am unhappy with what I have now. I must find new ways. I feel like my life is consumed in just searching for new ways towards difficult paths, for me and for other Deaf people. Not only thinking in an individual feeling, but in a collective feeling. There is a force that drives me to continue working, to give more, to go an extra mile, not to conform to what I have for myself, I must be unhappy and by thinking that out there, there is much more to do. (Ana Isabel) Of particular importance has been the privilege that collaborators had assigned to their personal interests and that goes far beyond what is strictly academic or work related. Among them is Alejandro's sport.

Compared to my school days, perhaps in the year1999, I began to play in the football club for visually impaired, which is for blind people. At the time I played representing the Bogota team. I went to play in other cities and that was something that I really enjoyed very much. I felt a fascination for the sport. Before I knew I liked it, but now with all that experience I could say that I became a faithful fan of football. Thanks to this sport, I had the possibility to travel a lot. In 2001, I had a chance to go to Sao Paolo, and in the year 2002, I went to Rio de Janeiro to play representing our team at the World's Visually Impaired Football Championship, and we managed to achieve fourth place. It was well done. Then last year we became champions, at the National Paralympics Game. (Alejandro)

### Social interactions with other people

Social relations and interactions play an important role in the participants' lives. All of these interests have served as protection factors for both of these participants. Additionally these factors have been converted into the means for strengthening their resilience strategies, for example in the consolidation of the social support network. They also constructed a favorable concept of independence, with all the positive consequences in which, each one of these processes have for the integral development of their life's project.

I believe that I have two strategies that have helped me to solve all situations that I had been through: one is music and the other one is to share with other people. Let's say that it has been successful in the sense that today, I have started to live on my own. I am working and I finished my studies with honours. It means that all of these interests really work! (Midgard)

### A sense of humour

Another important factor for strengthening the resilience of the participants is a good sense of humour, that is developing a capacity to laugh at and about their own circumstances. This has allowed them to see their disabilities in perspective, emotionally distancing themselves from their difficulties and helping to generate a strategy to create more effective solutions (Cohen 1990 cited by Dowling, Hockenberry & Gregory, 2003). Even though I have a strong character, the majority of my time I am joyful, with a smile in my face and making someone else smile. (Alejandro).

In Cyrulink's words (2002), a good sense of humour has allowed the collaborators to empower themselves and look beyond their own situation and to stop themselves from being dominated by a sense of their sufferings. At the same time, a good sense of humour and the recounting of narratives of their adversity and their stories in a joyful way has worked in their favour when establishing social harmonious relationships, as suggested by Rodriguez (2001).

#### Independence, autonomy and decision-making

In good measure, the collaborators' resilience is related to their tendency to overthrow norms and social patterns of conduct which society expects of people with disabilities (Cardenas, 2008; Cárdenas and Moreno, 2013). This is shown in Ana Isabel's story, once she left her parental home.

I was the first one to say goodbye, and I left my home to search for a job in another city. It was the moment in which I was making a decision to renounce to my small city and to go aiming to study a higher degree, a master's degree. My family was surprised. "You are you going, yes"? "And how are you going to work?" "How are you going to live?" "How are you going to pay the rent?" "How are you going to pay for your studies? That is very expensive." Then I said to myself: "I don't know, but I am going. I will manage it". Then my parents said to me: "Well. You know, it is your decision, if you think that is the best, it is up to you." For everybody it was a surprise, but I went. Now they don't ask me anything. They only ask me to tell them where I am and ask me to inform them where I am, nothing else. They have learnt that I was taking my own decisions and now they understand that I am able to make my own decisions and for this reason I can count on them. (Ana Isabel)

From Alejandro, after he escaped from his home, in order to go school:

To be honest I got fed up of being housebound, so I ran away. I had a great advantage, which was that the school was located just across the street from my house, I had to go around, but anyway it was very close. The day I ran away from home, I met some friends and then I went to register again, after having been suspended. Fortunately I had all my documents in order, so the next day I began to study. From the start, I did settle my position with my family. The reason for which I ran away, was in order to go back to school, and it was somehow a way of telling them: "I know what are you doing to me. It is being

done with the best of your intentions, but not necessarily in the best way." (Alejandro)

And, from Midgard, at the time she wanted to claim her rights instead of the absolute subjugation that is imposed on a patient in a psychiatric clinic.

The positive side of living in a psychiatric clinic is that you develop a 'thick skin', as some people say. You are forced to become stronger. In some ways my life hadn't led me to the point of saying an overwhelming 'NO!'. But this experience helped me to improve my character and to present a bigger challenge to all situations in which you aren't being taken into account. One learns how to become autonomous after being subordinate. For example, if you don't want to take the drug! Awful!! Don't take it! Why do they have to oblige you? Somehow I have managed to gain recognition of my rights. (Midgard)

Experiences make them stronger and let them to grow up, even against relatives' expectations, as we can see in the next section.

#### *Relations with relatives*

Following with the microsystemic level, it has been found that for the participants, the family was a source of protection and a drawback at the same time. This is clear for both Alejandro's and Ana Isabel's families. Alejandro's extended family did not notice his condition, because they were more concerned about the whole family crisis. Ana Isabel's family was dealing with the diagnosis, and did not accept the condition. They had difficulty dealing with the initial complex approaches to disablement, given that they were faced with a completely unexpected situation. Nevertheless, the uneasiness made an important impact on the perception of both collaborators, since they felt it, from the very beginning.

My parents were upset with the situation that I was going through and they had a tendency to protect me, which sometimes I rejected. I did not like it that they were seeing me as very special, or different, from my brothers, or simply that they would spoil me, just for being a deaf person. My brothers and I were very young and sometimes we ended up having difficult relationships. For example, when watching TV I used to ask what they were saying but their reply was, "Ssh, or shut up. Let us listen to it!" So then I used to leave and go away to a quiet place where I could be on my own. Then I began to be less communicative with everybody. I ended up only answering with a "Yes", or a "No", just because I felt like I was bothering others. Finally I decided to remain silent. (Ana Isabel) The traumatic situations experienced by Midgard about his parents' death in a car accident, were very important in his psychological development and become risk factors for his wellbeing.

However, families have also been vital for adaptation and the creation of resilience in family members with disabilities. This is evident in the story of Andrew, and the ways his family managed the visual impairment both from the emotional and the educational perspectives.

My mum has gathered a collection of stories on cassette tape which was wonderful. I remember for example the tale of a girl named Lili who was lost in the forest of Australia. Then a kangaroo rescued her and helped her find her mum and her dad because the kangaroo herself had lost her little son. So I had to ask my mom issues like "Well, what is a kangaroo?" or "What is a platypus?" because in the story mentioned a platypus too. She thought: "How can I respond to that?" Then she tried to get some animals with different scales and found some miniature animals that helped me to understand them. (Andrés)

One might wonder at what point in the life cycle stage of both disabled individuals and their family are affected by the condition of disability. Each family is affected by this situation in different ways. Some of them perceived disability as a punishment, some others as an opportunity to be more spiritual.

With regard to the school microsystem, it was apparent that the family is here also both a risk factor and a protective unit. In principle, the reluctance of educational institutions to admit students with disabilities was a factor which enhanced the fears and maladaptive management techniques of families, and also impacted on the self-esteem and self-image of disabled students and therefore also on their frame of mind. These factors are explored further in the next section.

#### About the exo and mesosystem

The relations and interaction with context were very important for these four disabled people. They recognize that the context was part of their inclusion or exclusion process.

I attended a big school with 1300 students. I was the first blind student that they accepted, and I experienced a lot of resistance from different people. Some of them even recomended that I would be better looked after in a special education school. There was a lot of ignorance and

opposition to my inclusion. One day a teacher told my mom that she could not explain algebra to me because, to explain something like, for example, what a line was to me, she needed to catch a steel rod or hook, straighten it completely and sanding it to show that it was a line. I found this explanation exaggerated and from that day Mrs. P wasn't nice to me. (Alejandro)

All of them were attending institutions without any previous experiences in inclusion, so they were part of a trial-and-error process. Their teachers had no training and all activities and practices were based on intuition.

My classmates laughed at me. I shouted. My teacher was angry because I did not understand what she was talking about, and I didn't understand school rules, or the exam questions. (Ana Isabel)

However, the institutions took up the challenge and, very importantly, they developed curricular and methodological adaptations for each particular case, following simple adjustments. This process was facilitated, in part, because of the small number of students with disabilities in each school, but also because there was sympathy for the students.

I started off with a very cool (i.e. good) relationship with the teachers, so much so that by time, they even decided to let other kids with visual disability attend the school. And it became a more welcoming school for this disabled population. In my case, they took up the challenge and we advanced smoothly. It was not rushed, or traumatic. Just going step by step to see how things were going to develop. We were looking for tools for each other and I tried to do my best within my possibilities to show them that I could do things. An example of this was algebra classes. The teacher had difficulties at the beginning because mathematics is very graphic, but later on we became very close, and she asked to be my teacher from the 8th to 11th grades, and the whole process was quite interesting. (Alejandro)

As we can see in these quotations, individual and peer interactions determine many outcomes in terms of support, successful and self esteem.

All I have comes from my family. As it comes from the family there were not so many things to demand from school, or even university. My needs were rather few and they were very specific and easy to solve. For example, an agreement with my teachers at the school was to be evaluated through oral presentations and invent a different way of doing different things. If my peers were drawing, I was also drawing with a needle. (Andrés) Families become even stronger and promote empowerment of teachers, who learn about disability issues and become aware of challenges of inclusion, not only at the academic level, but also at the social activities.

During my school life inclusion in the regular classroom was beneficial to me not only because of the possibility of having the same training, but also because I had contact and social ties with nondisabled peers. (Ana Isabel)

Something difficult for me was that I did not practise sports, like my other classmates, or not being part of the football team and all those things that seemed very attractive. But just in my physical activity class I was very active and tried always to do everything the teacher asked of us. Everything was done: such as jumps, or running ten laps to school. (Alejandro)

Inclusion must be understood in a broader sense: not only for learning academic content at school, but also for social participation and community engagement.

About the macrosystem

For all participants social relations are a source of protective factors for them, but structural issues were determinant.

On leaving home I became surrounded by many people; not my family, but my friends. I got closer to them and the social networks I developed were important because they helped me understand that the situation was not unique, but that if people accept one, it's because I really want it to happen and when you want it people make a commitment. I think for that reason the relationship with my lifelong friends did not change much. They supported me pretty well. My college room-mates were also super-supportive. In the College of Human Sciences, it is very rare to have close friends because I was a kind of different person. They had no money but I collaborated with their support. For example, one of them stayed in my house supporting me and so they became very important. (Midgard)

Here is something very important: when I was in the seventh grade I started having contact with the deaf community in the capital city of the department, it was part of the Association of the Deaf. For me, it was very important to see what was happening in that community, in that group. I began to realize I had many things they did not have: my ability to study, to learn, my use of spoken Spanish, to write, to express myself, to communicate with other people. They did not have

that. That also gave me the strength to continue studying, because I had a purpose, I wanted to study to help them. I wanted to give back the good things that I was getting. I thought I could help improve the situation in some way. (Ana Isabel)

#### Conclusion

If resilience is a set of social and physical processes that enable people to achieve wellbeing, even against adversity, so this study identified processes in the micro, meso and macro levels from an ecological and transactional perspective.

Findings suggest that, at the micro-systemic level, the most resilient processes are based on a high level of self-efficacy, promotion of autonomy as well as affective relations with disabled and non-disabled people.

Self-efficacy was recognized for all stories. These four disabled people became self confident and found out that they managed to face more challenges that they had expected or were prepared for. In promotion of their autonomy, the role of the families were determinant. In some ways a kind of negation of disability becomes an impulse to promote their independency.

The relations with non-disabled people were very positive. They came into strong relationships with peers and humour played an important role in the daily interactions.

Findings show us that at the meso level, relations have been established among microsystems: school, family, other organizations. School let them make connections with others' experiences and peers that show them another view of life. Family is a link with others, but can also be the barrier to be part of the daily life, because of overprotection and control. Organizations, such as university, provide the social networks, friends and challenges. They have enabled the implementation of joint coping strategies aimed at achieving successful processes in different environments.

At the exosystem level, the analysis was much more difficult. The structures of the environment, the social representations about differences, the culture of normalcy and stereotypes about being normal affected the whole environment, but was not explicit in the stories of our four participants. It can be considered for further studies focusing on this level.

At the macrosystemic level, regulatory and institutional structures related to disability in the country become simultaneously a protective and risk factor. We found that the existing normative development about inclusive education was positive and influenced the educational culture. Schools recognized that inclusion was mandatory and that students' right to education must be considered.

Following the Salamanca Statement in 1994, Colombia promoted Education for All and eliminated special education at the educational public system. Normative advances in inclusive education in the Colombian context are recognized at the regional level, as one of the most significant advances. So all students with disabilities were attending public schools under the mainstreaming model. However, there are still some attitudes of paternalism within public policies for disabled people.

As a result of transactions between multiple levels of socio-cultural factors, through time the collaborators have achieved their targets for expected development through the different stages of life and in so doing they have overcome the adverse factors associated with disability and sometime even reaching levels higher than those of their non-disabled peers in the academic, professional and social level performance. All these findings were very meaningful in order to understand how resilience can play an important role in disabled people's lives.

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# 'Streamed' Voices – Facebook posts and related thoughts on mainstreaming and inclusion

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Abstract: Several studies conducted in the recent past reveal that a large number of Hungarian mainstream teachers say they are unable and unprepared to deal with disabled students in the classroom. This paper aims to examine what the reasons for the above situation might be. In order to gain deeper insight into teachers' uncertainty, we listen to students' voices. As insider researchers, having visual impairments ourselves, we also take a look into the present outcomes of an ongoing research where we examine visually impaired secondary school and university students' narratives, Facebook posts and interviews, so that we can understand how students experience mainstreaming and inclusion. As opposed to the Facebook group, where students actively discuss their problems, in the research secondary school students were silent. Only university students' voices could be heard. This passive attitude provokes numerous questions: What makes them silent? Is it the loneliness of mainstreaming? Are they too often misunderstood? Are they treated according to stereotypes? Students' voices imply that teacher education needs reconsideration, and that, except for the cultural model of disability, each model fails to paint a holistic picture of disabled people's lives. Listening to students' voices is not only an important part of the cultural context but also a basic need whithout which both mainstream and inclusive education remains pure theory.

We sit in the front row of every classroom. We are extremely alert and attentive. While our peers in the rows behind us slump in their chairs, pass notes to each other, or doze behind their textbooks, we are completely focused on the teacher. We hang on every word, follow every move. We are aware of the connotations of our position at the head of the class, and we live up to it.

(Brenda Jo Brueggemann and Georgina Kleege)

#### Introduction

This paper places mainstream education under a critical lens. There are several reasons for the critical discourse. Firstly, mainstream teachers say they are unprepared to receive disabled students at any level of education (Cassady, 2011; IDDC, 2013). Secondly, in order to improve the current situation, researchers seldom ask the students concerned to talk about how they feel at school. Thirdly, successful disabled persons' ways to success is hardly ever investigated from a pedagogical point of view.

Disabled persons are a diverse community. Consequently, there is not a single way to assist mainstream teachers to be prepared for involving students with disabilities in the mainstream classroom activities. Each disability carries special attributes and each disabled person is different. One way to understand the problems of mainstreaming is to get acquainted with the diverse nature of disability and that of disabled persons. Therefore, we have chosen one segment to listen to Hungarian blind university students and their voices. The reason why we are focusing on this group is to demonstrate the hidden values of blind persons and also to emphasize the significance of trust in persons with disabilities in general, and the importance of disabled students' voices in teacher education in particular.

In this paper, we suggest reconsidering the advantages and disadvantages of mainstream and inclusive education. On the basis of students' voices and our experiences of the recent past, together with the still determinative paradigm of special education, we imply to re-think current paradigms regarding education in the contexts of social, human rights-based, diversity and, first of all, cultural models of disability. Finally, we propose to consider cultural disability studies as an indispensable resource for improving future teacher competencies.

#### Frames and positions

In Hungary, mainstreaming together with inclusive education pays little attention to the significance of disabled communities (Hoffmann & Flamich, 2015). Students with various disabilities are expected to act as independent individuals, though, due to several disability-related factors, independence is much too hard to be acquired on one's own in mainstream circumstances. As a result of this attitude and practice, most of them are isolated in the classroom and even within the family. Consequently, as we insider researchers experience, persons with disabilities wish to find their disabled peers with the help of the social media. The role of social media in disabled students' lives can best be proven by reflecting on their Facebook posts. While listening to their voices, we intend to understand why they feel it is indispensable to create closed groups in order to discuss their disability-

related experiences. Is it a critical message about their mainstreamed lives? Is it a wish to belong somewhere? And what can we learn while listening to them?

#### **Provoking voices**

'Do not think that you can do anything, because you are disabled!' (Hoffmann & Flamich, 2015, p. 93). No one would ever suppose that this sentence was uttered by a professor at a doctoral school at one of Hungary's most prestigious and acknowledged universities. Yes, it was. Indeed. It dates back to 2003.

Those days the idea that disabled persons' lived experience-based knowledge could be added to the world of academia was almost unimaginable and totally unknown in Hungary, although equal opportunities were guaranteed by Act No. 26 of 1998 on assuring equal opportunity for persons with disabilities (ILO, n.d.). Utterances, similar to the one quoted above, however, were usual at mainly secondary and higher education. Students talked about their feelings and what comments their teachers had made to them at various forums:

At one of my exams on law a professor said to me that as long as he was at the university, I wouldn't be a lawyer. And added the blind were not suitable for the job. He just hated the blind. (Bánfalvy, 2014, p. 259)

In the first quarter of the 21st century, when disability awareness is of major importance owing to the concepts put forward through disability models, blind students still complain, and try to find advice and sympathy as members of closed groups on Facebook. At the same time, teachers keep emphasizing that they are unable to manage a blind student in the class, which means that teachers either have unrealistic or no expectations regarding blind students' performance, and, as our blind students and their parents sadly tell us, secondary schools tend to reject blind students' applications. In the meantime, blind students are dreaming of becoming lawyers, interpreters, teachers, psychologists, musicians and work hard to achieve their goals. Our attempt is to find answers by calling attention to two very significant pillars of inclusive education. One is trust, and the other is the knowledge that generations of blind people developed in special schools to make life easier. These two pillars may provide possible alternatives in improving inclusive teachers' competencies. The very first pillar, the concept of trust immediately suggests two significant questions:

- 1. Whose role is it to assist teachers if not that of the disabled community?
- 2. Who trusts the knowledge generated by people with disabilities?

The latter question is hard to answer. In fact, in several cultures it is distrust, rather than trust, in persons with disability that has always been present (Pelka, 2012). It is so in spite of the fact that the concept of disability is relatively young, as it dates back to the 19th century (SEP, 2016). Very intelligent, or highly educated people have always lived among those 'who could not see, walk or hear; who had limited mobility, comprehension, or longevity, or chronic illnesses of various sorts' (SEP, 2016). Therefore, the question of education is not about managing disability or not, but about accepting and respecting persons who do their utmost to live with it.

Acceptance and respect are two components of trust and confidence. Supposedly, in order to gain trust and confidence in persons with disabilities, persons without disabilities need knowledge on disability-related issues that could best be obtained through disabled peoples' voices. In numerous cases these voices talk about lived experiences. However, although disabled persons' lived experiences play a significant role in making awareness and promoting trust, there are mental images deep in our minds that we can hardly eliminate.

There are situations in life when persons without disability accept disabled persons, as the mental image and the situation are in accordance. Owing to the mental image there are traditionally accepted 'roles" for blind people, for example:

When I was growing up in London in the 1930s, I especially enjoyed the visits of Enrico, the piano tuner, who would come every few months to tune our pianos. We had an upright and a grand, and since everyone in the family played, they were always getting out of tune. Once when Enrico was ill, a substitute tuner came – a tuner who, to my amazement, got around without a white stick and could apparently see normally. Up to that point, I had assumed that, like Enrico, all piano tuners were blind (Sacks, 2007, p. 160).

Consequently, disabled persons in non-traditional, unusual roles, such as that of a professor at a university, greatly influence acceptance and raise awareness, as Georgina Klege claims:

Part of what our body teaches in the classroom has to do with role modeling. Both students with disabilities and students without disabilities see a person with a disability in a position of authority and, without having to say anything about it, it's a way of demonstrating that one can have authority and an intellectual life and a career and all these things. Over time the novelty of otherness can disappear. (Brueggeman, Garland-Thomson & Kleege, 2005, p. 5)

These fragments illustrate how trust might develop. It is a general human characteristic that people trust what they know. That is why people trust more disabled persons in traditional roles. The second quotation shows that disabled persons in unusual roles working or performing at the same high level as non-disabled people are at first seen as surprising. It usually takes a certain amount time for trust and confidence to be established and developed.

# Why listen?

When we decided to get involved in disability studies, we had already had at least twenty years of experience in teaching English as a foreign language. We teach all kinds of students, primary school children, young adults, nondisabled and disabled adults, sighted and blind persons. Consequently, when we started teaching, we learned to listen to them. Firstly, because we believe that teaching a foreign language means giving our students keys to various cultures as well as to open up the world and enable them to find their places in it. And secondly, because being visually impaired ourselves, we have always felt it our duty to listen to how our visually impaired students get along in the world we have helped them discover. Needless to say, their stories have inspired us to turn our attention to mainstream education and disability studies. For we know that disabled people are seldom taken seriously, disabled students are hardly ever listened to – even if they have a lot to say.

Actually, students think and talk critically. They talk in classes, at breaks, at parties, on public transport, wherever they are. Being information and communication technology (ICT) fans or even addicts, and moreover, most of them being equipped with some kind of assistive and enabling technology devices, they conquer the worldwide web, they chat on various forums of the social media. Thus, if we teachers really want to know what they think, we can get in touch with them – listen and be ready to assist. In most cases, blind students seem happy to welcome us teachers to their closed Facebook groups. Supposedly, this is how they want to let us know how they feel in the wider world. And if we listen carefully, it turns out that we can understand that the current practice of mainstream education must be changed, at least in Hungary. Consequently, the question is not whether there is a need for a change, but rather what needs to change in mainstream education and how to do that.

Before discussing what and how to change, we need to take a close look into the current situation of mainstream education. And it will turn out that this time the changes should be based after considering the students' aspects, the ones that have often been neglected so far.

# Who to listen to? - The issue of impersonality, invisibility, voicelessness, avoidance

Our immediate answer is that we should listen to everyone who is concerned although it is obviously impossible. Teachers, parents, classmates, and of course, students could talk for hours about what it means to have or to be a disabled student in the classroom. Actually, as far as mainstream education is concerned, in Hungary teachers and parents are relatively frequently asked the first question, whereas classmates and students are almost never asked the second. Moreover, when mainstream education is in focus, disability is mentioned as one big grey umbrella under which the crowd is invisible. Disability and disabled persons are impersonal. This impersonalized view may be very harmful.

Although we are aware that 'disability affects us all, transcending class, nation and wealth' (Goodley, 2011, p. 1), and the largest minority in the world is that of disabled people (Riley, 2005, p. 1), the general attitude of avoidance strongly influences our everyday lives in the streets as well as in the world of academia (Bolt and Penketh, 2016). On the basis of our actual and factual presence, the disabled persons' international community should have a much stronger role in policymaking, including the policy of education. One factor that may weaken our influential role is the words that are used to describe us, or we use to describe ourselves: the question of political correctness.

Being politically correct does not mean that the applied term is inoffensive (Umstead, 2012, p. 8). Let us first take into consideration the most widespread words: disability, disabled. According to Dan Goodley, 'disability' with which that minority group is labeled, 'is an expression of wider socioeconomic, political and cultural formations of a very specific though complex form of exclusion: the exclusion of people with impairments' (Goodley, 2007, p. 5). This statement implies that, those who are excluded' cannot be diverse, therefore they are uniform. Goodley (2007) also suggests that disabled students are not only labeled but also put under the colourless umbrella of disability, and remain invisible and unseen. More importantly, they remain voiceless. This invisibility and voicelessness promotes the lack of knowledge about the diverse nature of human beings resulting in a 'deconstruction of disabiling pedagogies or pedagogies of disablement' (Goodley, 2007, p. 5; see also Oliver, 1990).

We are convinced that doing research on disability in general in the context of mainstream education fails to prove applicable to improve the quality of mainstream education practice, simply because students are considered disabled with uniform attributes. Invisibility and voicelessness are both dangerous – they break lives into pieces. One of the worst ever outcomes of invisibility, lack of knowledge and avoidance is that societies deprive themselves of numerous values of the colourful groups of impaired persons. Needless to say, we regard the large minority of disabled people a diverse community. We believe that focusing on one 'colour' of the thousands will deepen our understanding of disability without which inclusive education remains a utopia. Therefore, in this paper we are highlighting the thoughts of Hungarian blind university students. Before we present the reasons why we have chosen this target group, let us explain what the words disability and people with disability mean in Hungarian, as its connotations may help you getting a picture of the significance of different cultures and their relations to persons with disability.

The Hungarian word for disability (*fogyatékosság*), instead of containing the word 'ability' contains the word 'lacking something'. Consequently, a person with disability means a person who lacks something. Words and language can be as dangerous as invisibility and voicelessness.

It is in the context of a particular culture and language that our created identity is validated by the recognition best owed by others. So any lack of respect for our culture and language in turn devalues our personal self-respect. In recent times, awareness of the centrality of this has increasingly shaped the way people show respect for the dignity of others. (Glover, 2003, p. iii)

All the invisibility, voicelessness, avoidance may well be attributed to the stereotypical images of the past. It is much better to be invisible than evil or any other of the most frequent stereotypes Biklen and Bogdan (1977) identified, though remaining invisible or voiceless never results in either acceptance or respect.

There are several ways of showing and requiring respect for people whose attributes are strongly associated with stereotypes and prejudice. One of them is to ask those who are concerned to tell us their stories and listen to their narratives and learn from them, in our case blind university students' narratives. The reason why we have asked this small community to talk is so that they can be considered successful subjects of mainstream education. They are supposed to be good at ICT competences, and some of them may have experiences in both special and mainstream school education. Consequently, this small group of people are not supposed to face numerous difficulties in the classroom.

But before we unveil what they think, we should explain why we consistently use the expression 'mainstream education' instead of 'inclusion'. This phase of the paper gives us the possibility to introduce the present and the past paradigms and practice of educating blind students in Hungary.

#### **Competing paradigms**

In Hungary, there is a long tradition of special education. 'The unified Special Education College for Primary Teachers was established in Budapest in 1904' (ELTE, Special Education, 2013). Therefore, the presence of the special education-oriented paradigm is extremely significant. It can best be proven by the fact that there is the Faculty of Special Education of Eötvös Loránd University of Science (ELTE Special Education, 2013), one of the most recognized universities in Hungary, where both BA and MA degrees can be earned (Flamich & Hoffmann, 2013).

Hungary has a 'traditionally separated schooling system for mainstream and disabled children' based strongly upon the diagnose-centered model of pedagogy (Tóth Németh, 2014). As Tóth Németh (2014) describes, the current structure of education has not changed significantly since 1989, the year when it is considered that the Iron Curtain was ripped apart. Changes in ways of thinking concerning disability though had somewhat preceded the political changes; the main goals and issues of the notion of empowering disabled people, the social model, the human rights-based model and independent living movement reached (most of all young) Hungarian disabled people and challenged the country several years before the significant year of 1989.

Although these new models and concepts implied new perspectives, the culturally inherited ways of thinking of persons with various disabilities remained strongly influential. Still, there were attempts and initiatives to change disability-related attitudes and beliefs. Let us mention the outstanding fact that it was legislation to react first to the new constructs. As a disability policy-makers introduced a consequence, legislators and revolutionary act, Act LXXIX of 1993 on Public Education, to open up and provide new opportunities for disabled students, their parents and teachers in both mainstream and special education. Since the Act came into effect, these perspectives have constantly meant new challenges for all the parties concerned. Owing to the very fact that the topic of this paper is students' voices, we will leave detailed descriptions of the legal changes out of focus. Efforts and various modifications to the Act have been made to clarify the existing uncertainty regarding what disabled students are able and unable to do in mainstream education. Significantly, listening to the students' voices was hardly ever used as a resource when attempts were made to change.

The long tradition-based, powerful presence of special education implies that special needs teachers and special-needs oriented paradigms still play a crucial role in mainstream education in spite of the fact that disability should no longer be restricted or limited to special education (Flamich & Hoffmann, 2013), since it affects all aspects of life (Bolt, 2015). Representatives of the pedagogical paradigm of mainstreaming, the traditional paradigm of special

education, as well as the medical, social and the human rights-based models compete, while hundreds of teachers say they are unaware of 'how to treat disabled students' (Hoffmann & Flamich, 2015, p. 94). They argue they are simply unprepared. The gap between unprepared teachers and unprepared disabled students seems to slow down the appearance of positive outcomes mainstreaming in primary, secondary and higher education. Despite the confusion and uncertainty, mainstream education of students with various disabilities has been popular with their parents recently regardless of readiness of schools, families, teachers and students (Flamich & Hoffmann, 2013). Numerous people tend to believe that the earlier mainstreaming starts the more effective it is concerning the acceptance of persons with disabilities (Nagy F-né, n.d.; Fischer, 2009). In order to explore this issue, it is mostly the attitudes of teachers, special needs teachers and parents that are surveyed. Fischer's (2009) results reveal that while parents generally show positive attitude towards mainstreaming disabled students, teachers are rather sceptical about it. According to Tóth Németh (2014), however, plenty of surveys show that teachers' attitudes are rather more uncertain than positive.

Owing to the fact that Hungary is a country with a long and prestigious history of special education (Gordosné, 1981), that attitude determines the dispositions of special needs teachers, mainstream teachers, disabled students – all in all, education at any level.

#### **Conceptions and misconceptions**

Similarly to many countries, special schools in Hungary have been considered outdated recently. This attitude can most certainly be explained by the constant change of disability-related paradigms. These changes were rather radical, as in our childhodd special schools were almost sacred places, where skills to establish a dependable, secure future could be learned. When we were primary school students (in the 1970s), we could go to the only special school for the blind in Budapest, Hungary. Our parents could come to see us once or twice a month and we could only go home once a month, for summer, Christmas, and Easter holidays. During the school years, we not only enjoyed but also suffered from the individual differences of our schoolmates, thereby experiencing a degree of diversity (Hoffmann & Flamich, 2016). Doubtlessly, we missed our parents very much, but they told us to learn because knowledge was the only way to equal opportunities – a concept unknown in the early 1970s and 1980s in Hungary (Hoffmann & Flamich, 2016).

In the school for the blind, the standard of education was at a very high level. Therefore, when most of us went to mainstream schools for our secondary education, there were numerous subjects at which we excelled. Obviously, we were able and eager to help our sighted classmates who needed assistance at a school subject we were good at. That was how we managed to mainstream ourselves. And that was when we experienced the disadvantages of having been segregated earlier (Hoffmann & Flamich, 2016).

Going to special schools has always had a stigmatizing message. Despite the fact that students seem to face more difficulties in an educational utopia called inclusion, the message has had an even more negative overtone these days. It is interesting to note how fast paradigms can change leaving behind practices without considering their advantages in the long run.

#### Blind but lost

Hungarian blind students, even if they talk, are hardly ever listened to in surveys. Though their narratives initiate and provoke several kinds of thoughts to reconsider and discuss.

Although they are separated from each other, blind students seek and find ways to share their ideas and beliefs. 'I think, because we are really separated, we should create a group so that we could give advice to each other on how to live blind!' (Facebook post, January 14th 2017). As most disabled students are now mainstreamed relatively early, that is, in kindergartens and primary schools, Hungarian blind students can meet in person only in special camps once a year, or virtually. The current method and conditions of mainstreaming seemingly prove dissatisfactory to make students prepared for secondary and higher education. As they very rarely meet blind peers, they may be misled concerning blind identity. Blind students in mainstream schools are deprived of the various kinds of knowledge blind people have worked out, accumulated and shared with their peers and younger schoolmates and, last but not least, their teachers learned from them throughout the years to make life relatively liveable and easier.

While the present practices of mainstream education cause uncertainty in teaching blind students, and that uncertainty oftentimes results in students' solitude, a large amount of knowledge that generations of blind people have developed throughout centuries is about to be lost. This is simply because to go to special schools and belong to a blind community is outdated. But how far can blind children get if they meet an itinerant teacher once or twice a month for some hours? ... If they are left behind in foreign language classes? ... If they just get a hint of Braille and have no chance to acquire it? Thousands of similar questions are asked and remain unanswered as of today.

Recently, we interviewed the very first itinerant teacher of one of the two special schools for blind students to paint a holistic picture of blind students in mainstream schools. She told us that mainstream teachers frequently refused to cooperate with her, whereas blind students constantly asked her to forward messages from one blind student to another. Subject-specific topics were hardly ever discussed. As far as learning and teaching foreign languages are concerned, the interview reveals that teachers, parents and even students tend to believe that they are easy to learn, because they are easily accessible everywhere. Moreover, there is a misconception which implies that writing also proves easy, as the Braille writing system can be replaced by computers. Most mainstream teachers feel unable to decide what and how to teach blind students. The recurrent sentence that 'We, mainstream teachers are unable to deal with disabled students in the classroom!' characterises pedagogical discourses.

We always hear vocal groups of professionals saying they possess the 'knowhow'. But blind students are almost never asked or listened to. As if they/we were not protagonists of our lives. The inspiring paradigm of 'Nothing About Us Without Us' (Charlton, 1998) has turned into a formal issue of bureaucracy, strongly related to representatives of various organizations of disabled persons, and of mainstream and special needs teachers. The philosophy of being inclusive is either unknown or misunderstood.

#### **Getting higher – facing the facts**

Obviously, blindness is not a discriminatory factor in the Hungarian higher education system, and for the benefit of blind students' undergraduate and post-graduate studies, the criteria of admission have changed lately. As legally guaranteed positive discrimination supports disadvantaged students' university admission, a constantly increasing number of blind students are admitted at various universities. In the academic year of 2014/2015, 318 disabled students took part in higher education. Eight of them received a Ph.D. level education, as a letter from the Ministry of Human Resources, dated on May 5th, 2015 informs us. The statistics of the Ministry fails to differentiate between blind and partially sighted persons. It is also worth mentioning that in Hungary, there is currently no blind or low vision person with a Ph.D. degree. According to the head of ELTE University Service Disabled Students' Centre there were 33 partially sighted and 25 blind students at Eötvös Loránd University. The Hungarian Association of Blind and Partially Sighted has failed to provide us information on the current status of blind students in higher education.

#### A virtual community

As has already been mentioned, similarly to the diverse group of disabled people, blind students too are oftentimes used to being treated as Pelka (2012, ix) says that '[p]eople with disabilities ... have generally been seen as objects

of scorn, or pity, cases to be cured or 'managed', problems to be confronted, or ignored.

That attitude might well be one of the reasons why blind students wish to share each other's company, and have created a closed group in the inclusive world of Facebook. The closed group's name can best be translated as The Group of Recently and Currently Integrated Visually Impaired Persons ("Jelenlegi és egykori integrált látássérültek közössége"). When we started our insider-research two years ago, there were 218 people in the community, at present, on January 28th, the group consists of 238 members. Although it is a closed group, anyone can join who has got something to do with mainstreaming. Most university students are members, although to be blind or to be a university student is not a requirement. Neither is necessary to have a visual impairment. Therefore, special needs teachers are also welcome to the group.

As members, not only do we observe the topics of communication, but also involve the fellow members in our research of students' experiences in the mainstream classroom. Our ongoing research consists of three parts. In the first part we have asked blind and low vision students to describe the characteristic features of the teacher with whom they would like to learn a foreign language. We have received only three emails, out of the approximately three hundred visually impaired university students. Two of the mails were complaining about the present situation concerning foreign language learning, highlighting that teachers should know what blind students are able to do, and what is out of their competence. The third letter is about positive experiences. It is worth mentioning that the person who wrote the letter noted that she had had a blind teacher of English.

In the second part, we asked blind and low vision students to fill out a questionnaire on their lived experiences concerning learning and studying a foreign language at secondary schools and universities. As for the secondary school students, we failed to receive any responses. University students proved slightly more active than blind and low vision secondary school students. Out of the 25 students at ELTE, and the unknown exact number of students at other universities, 16 students answered the closed and open questions of the questionnaire. The statistical data is now being analyzed. When we took a quick look at the open-ended questions, it turned out that visually impaired students meet serious challenges, face severe difficulties in the classroom. As we asked university professors to fill out a corresponding questionnaire, it will be interesting to compare the outcomes. What is worth mentioning here is that forty-six professors and teachers answered our closed and open-ended questions. Although the data is being analyzed, at the preliminary analysis of the open-ended questions shows that teachers miss courses to prepare them for human diversity.

In the third part, we are making interviews with some of the students and professors. We have made only a few interviews in this phase so far. Our aim is to find out what they think teachers should know when working with blind students, what components they all miss from teacher education. Although we are making topic-oriented, semi-structured interviews, our blind respondents turn to narrative, for they believe that in order to understand their viewpoints, we should know its context. We are still in the middle of the interviewing process, but difficulties and challenges of mainstream education are slowly and clearly shaping.

At the very early phase of our research, our aim was to contextualize mainstream education from primary to higher education. Thus, we made interviews with a few itinerant teachers. One of them actually turned her back to mainstream education. We also interviewed the head of the methodological centre responsible for blind students mainstreaming in primary and secondary education, the director of Disabled Students' Centre at ELTE, and the only one blind person, an ICT expert hired at the Disabled Students' Centre. All of them emphasized not only teachers but also students as being unprepared for mainstream education. This fact implies that a profound change should be made. We are convinced that, however favorable or sceptical teachers' attitudes are, without listening to blind students' and successfully mainstreamed blind people's experiences and clarifying one's own relations to human diversity, the visible gap will be even deeper than it is now between the sighted and the blind.

Facebook posts in the mentioned closed group and several letters on special mailing lists show that blind students create their own world – they need each other's company and support. Currently, mainstreaming blind students means they are separated, and from their posted narratives it turns out, they oftentimes feel lonely. Neither blind students nor mainstream teachers seem to be prepared for working together, i.e. for inclusion. They seem unknown to each other, which means that all kinds of teacher education should be reconsidered according to social and human needs.

#### The cultural model of disability

Our research about blind students' Facebook posts reveals that mainstream educators are often unaware of what kind of abilities or talent their blind students have. But they all think and presuppose something and act according to the picture they have formed in their mind of blind people.

#### Student 1:

In the very first month at the secondary school my chemistry teacher said to me: I don't understand how you got admitted here without anyone consulting me. (Hoffmann, 2017, p. 201)

Student 2:

"Do blind people get any extra time at the final exam? Do we get the material in Braille, electronic format or is there a reader? Please, answer soon, 'cause my literature teacher is a bit lost, and so am I. Thanks." (30. 04. 2017)

Comment 1 (blind student):

"Yes, we get some extra time guaranteed by law. I'll find the link for you."

Comment 2 (blind student):

"I got everything on a thumb drive. I got 33% extra time, I think."

Student 3:

"I want to learn Russian. My teacher told me it might be problematic because of the grammar and the Cyrillic script." (06. 03. 2017) Comment 1 (blind student):

"I learnt Russian for a long time. Don't worry about the grammar!" Comment 2 (blind student):

"There are two great screen readers that read Russian. You can download the Russian keyboard layout from: ..."

Stereotypes have been with us for too long to eliminate them as a result of disability rights movements. As we have already emphasized, disabled persons have always composed a diverse minority. Accepting as well as respecting diversity can and should be taught and learnt in every culture. Cultural understanding of any lived experiences is a basic particle of culture. Literary and music representations of disability may play a significant role to understand the philosophy behind exclusion as well as inclusion. Especially, if we take into consideration Couser's (2009) statement that 'cultural representations mirror daily life' (p. 17), we may find responses to Bolt's questions on whether the study of culture really deepens our understanding of disability, and if studying disability really enriches our understanding of culture (Bolt, 2012; Hoffmann & Flamich, 2015).

A significant number of disabled people seem to believe in the power of cultural awareness. Ferri (2011) describes that disability studies scholars often depend on fiction, films, popular culture as well as disability memoir and first person narratives, when they teach or give an account on their scientific work. Although Ferri says the value of these works are that they help us 'imagine' disability, this approach can be rather misleading. Fiction and disability memoir have different functions from imagining what it is like to be disabled. They provide some kind of knowledge of ourselves and that of disability. That is one of the reasons why they are suitable to teach diversity. Disability memoir and first person narratives perform a cultural mission. "They frame our understanding of raw, unorganized experience, giving it

coherent meaning, and making it accessible to us through story" (Garland-Thomson, 2007, p. 121; see also Ferri, 2011).

Therefore, disability memoir and first person narratives – even if the value is sometimes questioned – are very important voices and may be supportive in teacher education. Not only should primary education but also secondary and higher education be prepared for a diverse world. Students' Facebook posts and any other kind of disability-related first person narratives reflect how diverse human thinking is, consequently, they may prove helpful resources to improve teachers' readiness to receive and educate disabled students regardless of the form of education. Listening to disabled students and reading disability in fiction, as well as disability memoir are indispensable, so that we will understand that "there is more than one way to move through space, to access a text, to process information, to communicate – more than one way to be a human being" (Kleege, 2011).

#### Conclusion

This paper has highlighted the phenomenon that 'mainstream teachers are unable to "treat" us disabled students in the classroom!' through students voices. We also described the present outcomes of an ongoing research where we examine visually impaired secondary school and university students' narratives, Facebook posts, interviews in order to understand how students' experience mainstreaming and inclusion. Interestingly enough, high school students remained silent and only a few university students' voices could be heard. What we have learned from this research is that teacher education definitely needs reconsideration, and, that without the cultural model of disability, other approaches fail to show a holistic picture. Listening to students' voices is part of the cultural context and a basic need without which both mainstream and inclusive education remains pure theory. But education is about a great deal of practice and listening to students' voices, is it not?

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# The outcomes of mainstream post-secondary education for young people with intellectual disability: investing in human capital or whiling away the time?

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Abstract: In Malta, as in other countries, the investment in postsecondary and tertiary education is based on human capital theory, whereby education is seen as important on an individual as well as an economic level. This paper analyses the outcomes of mainstream postsecondary education for people with intellectual disability within the framework of this theory. A qualitative study was carried out with eight former students of the Pathway Programme at MCAST and the Key Skills course at ITS, as well as an MCAST representative. The main findings show that education is viewed by the participants as a necessary step to finding employment. This is very much in line with human capital theory which considers education to be an investment in human capital that has economic returns in terms of increasing students' employability. However, the various issues raised by the research participants regarding difficulties with their current job or their job prospects may make it seem as if the post-secondary courses they attended have led to failure. This paper argues that the continued need for support experienced by people with intellectual disability may be seen as undermining their ability to join the labour market, even if the persons with intellectual disability interviewed do not see any contradiction between the two. For young people with intellectual disability to have equal opportunities in the workplace, it is essential for their voice to be heard, and for their perspectives to be understood. It is also essential for their support needs to be attended to, while appreciating that having support needs is not contradictory to being an employee.

**Key words**: Intellectual disability, mainstream post-secondary education, human capital, employment

#### Introduction

Education is a very important tool both for individual as well as for national development. It contributes to combatting social exclusion since it has a very high impact on personal development and the individual's employability. This contribution can in turn help promote economic development. The link between personal and economic development is the basis of human capital theory which, as Williams & Swail (2005) note, has had an enduring effect on the way we comprehend investment in people since it was first introduced in the eighteenth century. The principal idea underlying this theory is that people are part of the economic investment of their own society. Consequently, society can invest in human capital or resources in the same way as it invests in physical capital and the production of goods. On the other hand, this theory has also been criticised on various accounts. Fitzsimons (1999) states that "[h]uman capital theory, then, is an impoverished notion of capital. It is unable to understand human activity other than as the exchange of commodities and the notion of capital employed is purely a quantitative one." (p.2).

In Malta, as in other countries, the drive to invest in the education of young people through post-secondary and tertiary education takes its cue from human capital theory. Continuing education can have a positive effect on economic development through improving people's, especially young people's, employability skills and ensuring that the skills of current and future workers match the needs of industry and of the country's economy. The importance given to the continuation of education after the end of the compulsory school years is attested by the emphasis placed both by the Maltese government and the European Commission on tackling the issue of early-school leaving in the country (Ministry for Education and Employment, 2014).

The commitment in Malta to investing in the human capital of young people extends to those who have a disability. The introduction of an inclusive education policy in 1994 (KNPD, 1993) in mainstream primary and secondary schools has led to an increase in young people with disabilities furthering their studies after the end of compulsory education (Mangiafico, 2016). However, the trajectory from compulsory education to post-secondary education and eventually to employment is very often fraught with difficulties for many disabled students, and these transitions can be even more challenging for people with intellectual disability. These challenges occur mainly because persons with intellectual disability, generally speaking, have low academic qualifications (Borg, 2005) which hinder them from continuing their education in mainstream post-secondary institutions or from finding employment in the open labour market. Additionally, since they have

difficulties in learning, they often need specialised programmes that enable them to further their education and to enhance their employability skills.

In the light of the link between post-secondary education and future employment prospects, the main research question of the research presented in this paper regards the outcomes of mainstream post-secondary education for people with intellectual disability. This research is based on a study carried out by Pleven (2015). Our paper focuses on three research questions:

1. What are the experiences of students in mainstream postsecondary education?

2. What impact do post-secondary education opportunities have on the future of students with intellectual disability after they leave full time education and especially in relation to employment?

3. What are the factors that impact on the opportunities for employment of students with intellectual disability?

#### Background

Stodden & Whelley (2004) identify three types of post-secondary options for people with intellectual disabilities. The first one is the 'Substantially separate model', which is a programme that is different from the curriculum that other students follow. These programmes are many a times held in a different building since the programme is different from the mainstream courses and is based on acquiring 'life skills', living in the community, vocational placements and so on. The 'Mixed program model' involves a combined approach of having students learning the skills mentioned above, which are in separate programmes, but also following some other courses with other students on campus. Finally, the 'Individualized support model' very often provides individual support to students and assistance that they need to follow college courses that they want.

Zafft, Hart & Zimbrich (2004) contend that "[p]articipation in post-secondary education is a known predictor of a successful employment outcome for youth without disabilities. There is research documenting that this is true for youth with disabilities as well." (p.45). For people with intellectual disability the link between post-secondary education and employment is clear. Most of the research carried out in this area has been conducted in the United States. A study by Grigal, Hart & Migliore (2011) notes that students with intellectual disability have less favorable post-school outcomes when compared to students who have other disabilities. Similarly, in a study carried out in Germany, Gebhardt, Tretter, Schwab & Gasteiger-Klicpera (2011) analysed the current German dual system combining apprenticeships with vocational education, and the efficacy of vocational training schemes in the transition from schools to employment for persons with intellectual disability. Some of the results of this study indicate that there are not enough work placements for persons with intellectual disabilities following segregated vocational programmes funded by the state.

These work placements can be very important. In research about the outcomes for people with mild intellectual disability in the United States, Joshi, Bouck & Maeda (2012) conclude that there is a positive relationship between participating in a work placement and employment following school. On the other hand, a study carried out by Baer, Daviso, Flexer, McMahan & Meindl (2011), with 409 students with intellectual or multiple disabilities in the Great Lakes states found that while "inclusion was a significant predictor of postsecondary education, career and technical education and work study programs did not reach significance as predictors of post-school employment. For these students, gender and minority issues contributed to most of the variance" (p.133). Hence, there are still many challenges faced by students with intellectual disability to find employment following post-secondary education.

Not many studies have been identified which were focused on the experiences and perspectives of people with intellectual disabilities in postsecondary mainstream education. Corby, Cousins & Slevin (2012) conducted a review of the literature about people with intellectual disabilities who are in post-secondary education or higher education. They note that:

While research is available in this area it tends to be limited and focussed (sic) more on policy and institutional practices than the experiences of students, particularly students with intellectual disability. Research is needed to examine additional factors influencing both the availability of education at post-secondary and third levels and the experiences of students who are undertaking education at these levels. (Corby et al., 2012, pp. 82-83)

The research presented in this paper focuses on the experiences and perspectives of students in two mainstream post-secondary programmes for people with intellectual disability that were set up since the introduction of inclusive education in Malta. These are the *Pathway to Independent Living* Programme at the Malta College of Arts, Science and Technology (Malta College of Arts, Science & Technology, 2016), and the *Key Skills for Independent Living* course at the Institute of Tourism Studies (Institute of Tourism Studies, 2014). These two courses provide a sheltered environment to students with an intellectual disability, with a high staff-to-student ratio. The method used for carrying out the research is set out below.

### Method

In order to address the research questions set out above, a qualitative methodology was used, where semi-structured interviews were carried out with eight former students of the *Pathway Programme* at MCAST, and the *Key Skills* course at ITS. Prior to these interviews, a pilot interview was carried out. Some participants also had a family member present for the interview and in some instances, they also provided some additional information. An interview was also held with an MCAST representative. The interview with the representative of the *Key Skills* course at ITS had to be cancelled, since the course was not open that year and, following changes in the management of the Institute, no one was available who was familiar with the course. Some information from the MCAST representative which is relevant to exploring the research questions is included in the findings below.

In line with the principles of emancipatory disability research (Stone and Priestley, 1996, as cited in Barnes, 2001), this study is based on the social model of disability, whereby the difficulties encountered by people with intellectual disability in post-secondary education are seen in terms of the socially-constructed barriers that they encounter. Furthermore, in line with these principles, it is the point of view of the persons with intellectual disability who were interviewed that is given primary importance.

Since the study involved human subjects, there are various ethical considerations that have been given utmost importance throughout the research process. Rubin and Babbie (2005) identify five main ethical considerations, namely: that participation is voluntary and there is informed consent; no harm is done to participants; ensuring anonymous participation and confidentiality; not deceiving participants; and being true in the analysis and reporting of data, also without making the participants easily identifiable. Before actually starting the research, clearance was obtained from the University Research Ethics Committee at the University of Malta and it was ensured that the above ethical issues were addressed during the whole research process.

# The Participants

The table below provides a profile of the participants with intellectual disability who took part in the study, using pseudonyms.

	Ficti- tious Name	Age	Gen der	Primary & Secondary Education	Post-Secondary Education Courses	Previous employment/ work experiences	Occupation/ Status following MCAST/IT S	Other activities
1	Laura	22	F	Special School	ITS Key skills for Independent Living course	Voluntary job experience in a cafeteria	Current: ETC (Job Bridge) –	Special Olympic s,

					Other courses: INSPIRE course MCAST (Pathway to Independent Living)	Work placements (ITS/MCAST)	sheltered employment	travellin g abroad
2	Emma	34	F	Mainstream	ITS Key skills for Independent Living Other courses: • ETC Course - Getting Through (Independe nt Living Skills) • Me2 course • ETC + Inspire - Sheltered employmen t	Work placements (ITS) Sheltered employment Paid employment in a factory (left due to sickness)	Current: Sheltered Employmen t / Job- exposure scheme Voluntary work in a hotel	Compute r courses
3	Peter	26	М	Special School	ITS Key skills for Independent Living	-Work placements (ITS) -Work placements (Special School)	Current: Work exposure at INSPIRE Employed in a hotel (Bridging the gap scheme – ETC)	
4	Keith	23	М	Mainstream	ITS (Key skills for Independent Living) Previous courses: -ETC course -MCAST (other course not completed due to bullying) -MCAST Pathway to Independent Living	-Work placements ( ITS/MCAST) -Work found through MCAST in a factory for 3 years but had to stop due to other commitments	Current: Employed (part-time - contract based)	
5	Tiziana	19	F	Mainstream	MCAST (Pathway to Independent Living) ETC Course	Work placements (MCAST)	Unemploye d (registering for work)	

					(cleaner)			
6	Eman	22	М	Mainstream	MCAST (Pathway to Independent Living)	Work placements (MCAST)	Employed (full time)	
7	Julia	25	F	Mainstream	MCAST ( <i>Pathway</i> <i>to Independent</i> <i>Living</i> ) MCAST Level 1 MCAST Level 2 (not completed) Special School	Work placements (MCAST)	Current: Employed (part time)	
8	Josephi ne	26	F	Special School	MCAST Pathway to Independent Living MCAST Entry Level 1 MCAST Entry Level 2 (not completed)	Work placements (MCAST)	Current: Attends Day Centre/ unemployed	Drama, travel

Table 1: Profile of participants who took part in this study

# Students' employment-related aspirations

The findings presented below show a mixture of positive and negative experiences and outcomes for the eight participants in this study. Needless to say, the responses of these participants cannot be assumed to be representative of other young people with intellectual disability who have attended post-secondary vocational education. However, the insights gained from an analysis of the perspectives of these participants can help us gain a better understanding of the context in which this education is offered. (For a more comprehensive analysis of the findings see Pleven (2015).

Education is viewed by the participants as a necessary step to their finding employment. For instance, Julia noted that she has learnt how to be independent, which is a necessary skill for employment. She explained that her teacher used to encourage her to call herself to make an appointment with the hairdresser: "she told me that when you are employed, you cannot ask others to do things for you, you have to do it yourself".

The research participants showed their awareness of the value of their continuing education, expressing a keen interest in learning more, especially to acquire skills that improve their employability. Two participants reported that they had completed both the MCAST *Pathway Programme* and the ITS *Key Skills* course. Although none of the four participants who completed the latter continued another course at ITS, two out of four participants who completed

the *Pathway Programme* followed other courses at MCAST, namely the ICT Entry Level 1 course and part of the Entry Level 2 course in the same subject. Furthermore, four out of eight participants noted that they have done other courses outside MCAST or ITS, including computer courses such as ECDL, a cleaner course, and a drama course.

With regards to work placements, all participants mentioned that they had had positive experiences with such placements within and outside MCAST and ITS whilst they were following the *Pathway Programme* and the *Key Skills* courses respectively. Seven out of eight participants agreed that both courses prepared them better for employment. In fact, they also directly related the courses they followed with their employment prospects, with Keith for example noting that "[y]ou do not really have many options at ITS, you either go in a kitchen, in a restaurant, things like that. You cannot for example, be a salesman, you know?"

The views expressed by these young people with intellectual disability are very much in line with human capital theory which considers education to be an investment in human capital that has economic returns in terms of increasing students' employability. In the interviews, they presented themselves as able and competent learners and employees or prospective employees, with aspirations that are commensurate with the education they had received and the skills they had acquired. However, the outcome of that preparation was not necessarily in line with their ambitions.

In fact, all participants have the ambition of improving their circumstances vis a vis employment. As can be seen from Table 1, only Eman, Julia and Keith had a job at the time of conducting the research, with Eman being the only one to be employed on a full-time basis. Keith's part-time contract is renewed yearly, while Julia's is indefinite. Laura, Emma and Peter were employed part-time as part of a job-exposure scheme at the time the study took place. Tiziana and Josephine were unemployed and seeking work.

The wishes expressed by the eight research participants during their interviews are a strong indication that the outcomes for them at the time that the research took place were not satisfactory. Even those who are employed are not necessarily happy with their job situation. For example, Keith noted the various problems he was encountering at work:

I do something and it turns out worse. If I wash the floor, he tells me for example, it is not good... you do something well, and it's like they do not appreciate what you do... Even for example, they are always wanting more... or otherwise you try to do your best, and he tells you... 'you are not doing enough.' Furthermore, Eman is the only participant who is in full-time employment but even he would like to do different work because his current job is quite repetitive.

The various points raised by these research participants regarding their current job or their job prospects may make it seem as if the post-secondary courses they attended have led to failure, especially since these are courses which are described as being "particularly designed to help them acquire the skills required to gain and maintain employment" (Malta College of Arts, Science & Technology, 2016). This orientation towards employment is in line with similar post-secondary courses for people with intellectual disability in other countries (Corby, Cousins & Slevin, 2012).

The analysis of the findings presented focuses on those themes that emerged from the participants' perspectives and that throw light on some of the reasons for this situation.

#### Students' need for supportive and protective environments

At the same time as speaking of themselves as being competent learners and as being actively engaged in the labour market, either through being employed or through job seeking, the research participants also spoke about their support needs and even about their need for protection in certain instances. Expressing such needs may seem at odds with presenting oneself as a member (or potential member) of the labour force.

The research participants identified various needs that they experienced at different stages of their post-secondary education, starting from the admission process for the *Pathway* course which entailed taking a written test and sitting for an interview. Most participants needed support with filling in the forms. Tiziana also needed support for the interview: "I was afraid to go inside [the interview room] alone, I wanted my teacher to come with me." In fact, her learning support assistant (LSA) and even her mother were called inside and stayed with her for the duration of the interview. However, like most of the other participants, she then found it easy to start and follow the course.

The lack of difficulty in following the *Pathways* and *Key Skills* courses may be at least partly attributed to the way they are set up. While both courses are located within a mainstream setting, they are provided within a relatively sheltered environment, on the lines of the 'substantially separate model' identified by Stodden & Whelley (2004). In fact, the MCAST representative noted that the Pathway course is tailor-made for the different needs of the

students, with small class sizes, and personal assistants when required and a learning support assistant in each class.

Significantly, difficulties were reported in less sheltered settings. As noted by the MCAST representative, "[t]he support provided is much less as students progress to higher level courses, it automatically drops." Josephine stated that she found it easy to start and follow the Pathway course and Entry Level 1 course at MCAST, but she found it difficult to continue the Level 2 course since the content was very difficult for her.

Josephine's comments about her experience of following the Level 2 course raises a very important issue – that of the relationship between the ex-*Pathway* students and their non-disabled classmates. In her interview, Josephine noted that:

Before, we used to be all together ... then Level 2, they started to not let us stay all together so that we will get used to it, but the normal students used to laugh at us.

Josephine also noted that the teacher used to stop the other students from laughing at her. What the research participants needed to get used to was being in a mainstream education environment learning alongside nondisabled students without one-to-one support from an LSA. This would have been the first time that they were learning in such conditions since, even if they had attended mainstream primary and secondary school, they would have been directly supported by an LSA in the classroom (MCIE 2000).

With reference to their experiences in less supported environments, it is on the relationships with their classmates that the research participants mostly focused. Some of the participants also noted that the course content was more difficult for them to comprehend as they moved to Level 1 and 2 courses.

It is pertinent to note that, on the whole, the participants reported good relationships with their classmates at the *Pathway Programme* and the *Key Skills* courses, with whom they made friends. With reference to students from other courses, five participants referred to friendships they had formed with these students. Julia said that the students from other courses, "were friendly, yes yes, they used to talk to me". On a contrasting note, Keith said that he did not talk to other students:

[w]e did not go next to them and they did not come next to us, we always used to stay on our own and nobody else used to come near us. They did not come with us, they didn't. If we used to mix, it was only with two of them. When it came to these negative encounters with non-disabled students, Keith, who completed both the MCAST *Pathway Programme* and the ITS *Key skills* course, even mentioned how he had to stop following a mainstream course at MCAST due to bullying.

When it came to the research participants' relationship with their teachers and LSAs, only Julia noted that she did not like one of the staff members of the course, since she used to tell her off. Otherwise, the other participants reported positive relationships or did not comment on their relationship with their educators.

The pattern that emerges from what these eight research participants had to say about their relationships with educators and with their peers is that they enjoyed better relationships in the more sheltered environments of the *Pathway* and the *Key Skills* courses. Venturing outside the protection afforded by these environments led to problems, especially for those who referred to being isolated, being laughed at, and even being bullied.

#### Being in non-protective environments

Such negative experiences do not augur well for inclusion in the open labour market. Even if mainstream post-secondary education courses are not sheltered like the *Pathway* and the *Key Skills* courses, they still are comparatively more sheltered than most workplaces. Being able to cope in the less supportive structure of the workplace entails acquiring skills that enhance one's employability but are not necessarily directly related to a specific job.

Among the employability skills identified by Rosenberg, Heimler & Morote (2012), one finds interpersonal skills and within this category one can place the ability to travel to and from work independently. The research participants noted how they were encouraged to travel to and from MCAST and ITS by bus, since acquiring this skill would greatly enhance their ability to take advantage of employment opportunities. Seven out of the eight participants said that they did use the bus to go to their respective colleges, although at times they also used to get a lift from parents or friends. Some participants had support to learn how to use the bus. In the case of Tiziana, her mother explained how she accompanied her daughter for some time because she was afraid that she would be picked up on if she travelled on her own or be run over by a car. It was after the lecturers at Pathways emphasized the importance of fostering Tiziana's independence that the mother stopped accompanying her. Josephine is the only student who kept being accompanied by her parents to attend MCAST. Significantly, in the interview she remarked that one of the problems that she faced in finding employment was "the bus, since I do not know how to catch a bus alone". When asked if she would want someone to teach her how to use the bus, she said that she wanted to since this would enable her to travel to and from work on her own.

As can be seen from the findings presented in these two sections, the eight young people with intellectual disability who participated in this research share the aspirations of most other young people who continue their education after the compulsory schooling age with the aim of improving their employment prospects. At the same time, they also pointed to support needs which indicate that they were quite a long way away from attaining the autonomy and independence that is normally associated with employability and with adulthood in general. This lack of independence can be seen for instance in the way some students needed support with the selection process to start the MCAST course, with travelling independently by public transport, and with facing bullying or other unwanted behavior in unsheltered settings. At face value, the expression of such needs strikes a discordant note with the presentation of oneself as an able worker, especially because they are needs which are more usually associated with childhood and adolescence rather than with adulthood.

## A prolonged adolescence in the world of work

Shepperdson (2000) is among those authors who note that for people with intellectual disability adolescence may be 'a period which is prolonged well into the ages when adult life is usually taken for granted' (p. 55). Given that employment is one of the markers of adulthood, and that the demands of the workplace require adult-like dispositions, having one's adolescence protracted beyond what is considered to be typical can be detrimental to one's employment prospects. Furthermore, as May (2000) states, people with intellectual disability are also denied other experiences which are markers of adulthood, such as intimate relationships, having a family and living independently. The lack of these experiences in turn reinforces the image of people with intellectual disability as eternal children (Gould and Dodd, 2012). By extension, it is a challenge for young people with intellectual disability to be viewed as adults who can make a valid contribution to the labour market through their human capital.

The possibility of people with intellectual disability being seen as inadequately prepared for the workplace, even after completing their postsecondary vocational education courses, is further reinforced by the sense of vulnerability that often surrounds them. Regardless of whether the vulnerability is perceived or actual, and regardless of whether or not it is created by the environment rather than being an innate characteristic of the person (Beckett, 2006), it undermines the effectiveness of presenting oneself as a competent worker. People with intellectual disability following post-secondary vocational education courses can therefore find themselves in a paradoxical situation. While they are provided with the opportunity of continuing to develop their potential, especially in relation to employability skills, they do so in an environment which has a significant degree of support and protection built into it and which thus serves as a bridge to the more demanding mainstream. The responses of the research participants show that they did welcome this support and protection, even while they were preparing themselves to enter the much less supportive world of work. The looser, and therefore less protective, environment of the Level 2 ICT course was found to be challenging by those few students who continued (or tried to continue) their education at that level. This can be seen in the difficulties they reported with having to cope with learning with no direct support from an LSA and with building positive relationships with their new, non-disabled, fellow students.

The students' needs are also highlighted in the support they received to learn to travel independently by public transport, an activity that places them on their own in the mainstream of society. Tiziana and Josephine in particular experienced prolonged dependence on their parents to take them to college. It can be argued that these two students' continued dependence in this area was foisted upon them as a result of perceived rather than real vulnerability. After all, Tiziana did eventually start using the bus on her own. And Josephine identifies her inability to do so as being inimical to her employment opportunities. But there are also instances where the research participants themselves referred to their need for support and even protection in certain situations. It is significant, for instance, that Josephine was grateful for her teacher offering her protection by stopping her Foundation classmates' bullying behaviour, as mentioned above.

The sense of vulnerability and the need for protection and support is therefore perceived not only by educators and parents, but also sometimes by the students themselves. Catering for these needs can undermine the students' ability to become more autonomous and therefore more adult-like, and it certainly undermines their ability to be perceived as adults who are competent enough to enter the workforce. This is because, as May (2000) observes, adulthood requires 'control over one's life which is so often denied people with intellectual disability' (p. 76). This situation can create very significant obstacles on the path to employability and to becoming perceived as autonomous human beings capable of contributing towards the economy, as envisaged by human capital theory. However, the research participants do not necessarily see any contradiction between needing support and becoming an economically productive adult. Employers, on the other hand, may take a different view.

## Dependence on the goodwill of employers

One important aspect that comes out of what the research participants said about their experiences in post-secondary education and beyond is their dependence on other people's goodwill, especially on the goodwill of employers to give them work opportunities. The students' inability to find fulfilling full-time employment has already been noted. For most of them, no paid job materialized from the unpaid work placements. Laura mentioned working in a cafeteria for a number of years, where she was only given pocket money. This suggests that the owner of the cafeteria was only letting her work out of his or her own goodwill, and was treating her like a child in the process by given her only some pocket money.

Similarly, there is evidence in the research literature that the work carried out by people with intellectual disabilities is not always valued or else is perceived as an act of charity by the employer towards the disabled person. For example, many of the people with intellectual disability who participated in the study carried out by Pearson, Wong and Pierini (2002) in their study in Gaungzhou, China, note that they are denied the right to work. 'They could not gain the respect of the community because most of those who had jobs were not carrying out meaningful tasks, but rather their employment was a token of charity or welfare' (Pearson et al., 2002, p. 381). As Camilleri (2015) argues, the continued perception of disabled people as objects of charity means that 'employment is still seen as an act of charity' (pg. 12).

To return then to the question posed in the title of our paper, are postsecondary courses for people with intellectual disability a sound investment in the human capital of these students or do they end up just another way for them to while away the day? It is to a discussion of possible answers to this question that we now turn.

#### The able and support-dependent worker

A pattern emerges from the foregoing discussion of the findings generated from the interviews with the eight participants of their being, on the whole, better understood, supported and have their abilities and potential recognised in contexts created with their needs in mind, than in wider mainstream social contexts. In the latter, their expressions of the need for support may strike a discordant note with their aspirations for finding employment or improving their current employment situation. There can therefore be said to be two discourses in operation here: the discourse of the 'able worker' and that of the 'support-dependent person'. For people with intellectual disability, and for those living or working closely with them, there may not be any contradiction between these two discourses. But the validity of this position is thrown into doubt in a society which places little if any value on the moral worth of people with intellectual disability. Indeed, as Davy (2015) states in her discussion of this subject,

[p]eople with intellectual disability have too rarely been seen in philosophy or in wider society as persons of moral worth in their own right, in part because of the idealized conceptions of reason and autonomy that have informed liberal theory. (p. 135)

These idealized conceptions result in very negative and tangible consequences in various aspects of life for people with intellectual disability, not least the denial of their citizenship rights (Budge and Wels, 2016) and, in the case of foetuses diagnosed with cognitive impairments like Down syndrome, their right to life (Darrin and Dixon, 2008). Within the world of work, one consequence is discounting the validity of people with intellectual disability positioning themselves as both an 'able worker' and a 'support-dependent person', or to combine the two, a 'support-dependent worker'.

As a consequence, there is little space in mainstream workplaces for arrangements such as providing protection against bullying or other unwanted behaviour, supporting certain workers to travel to and from work, or ensuring that work-related tasks are taught in ways that address the learning needs of workers with intellectual disability. To some extent this lacuna is addressed through the provision of employment support services, such as the ones offered by Jobsplus (2016) through its Inclusive Employment Services. Together with relatively sheltered post-secondary education courses such as *Pathways* and *Key Skills*, such services do enhance the employment prospects of people with intellectual disability and do result in some of the latter finding jobs. These initiatives are a strong indicator of the potential that exists in the labour market, a potential that is not always readily perceived by employers. This may be because the success rate, purely in terms of the amount of jobs secured, is not necessarily proportionate to the amount of effort and resources that are dedicated to supporting people with intellectual disability to further their education and to find and retain employment.

But the limited success of these initiatives can also be attributed to their being equated with 'incentives [that] seem to be a compulsory *quid pro quo* for employing what are seen as basically non-productive, social cases' (Camilleri, 2015, p. 12). This is a far cry from considering the employment of people with intellectual disability as an investment in human capital. As Bouchard (2008) states, human capital belongs to individuals who can foster it and make it grow through education and then put it to profitable use in the economy through their employment. Consequently, whether or not post-secondary education opportunities for people with intellectual disability are seen as an investment depends not so much on the outcomes of their education but on

how they are perceived by employers and, by extension, by society in general. People with intellectual disability thus find themselves in a double bind in which their human capital is not invested in because they are not provided with satisfactory employment opportunities, and they are not provided with such opportunities because they are not perceived as holders of human capital.

This situation is rather ironic given that awareness of the potential of people with intellectual disability and knowledge of how to realize that potential have grown exponentially over the last decades. The direct and simple equation of intellectual disability with cognitive impairment and difficulties in learning adaptive behaviour has long given way to a more nuanced description that also takes into account the positive effect that an enabling environment has on the development of knowledge, skills and competencies of people with intellectual disability (Rapley, 2004; AAIDD 2016). But this more nuanced understanding of the nature of intellectual disability still seems to be mostly restricted to people with intellectual disability, those who live with them and those who work with them as educators or providers of disability-specific support-services.

## **Conclusion and Recommendations**

The theoretical physicist Stephen Hawking (2014) has spoken of the 'attitudinal, physical and financial barriers' that disabled people around the world face, and has called upon '[g]overnments everywhere' to address these barriers so that disabled people can 'unlock their potential' and 'get a chance to shine' (unpaged). However, it can be clearly seen from the research presented in this article that it is not only governments that need to engage in barrier-removal. Employers, and the world of work more generally, also need to appreciate that Hawking's call applies for them as well as for governments. More importantly, they need to realise that his call applies not only for disabled people who possess the type of intelligence that is sought for in employees but also for those disabled people whose abilities and skills can only be realized in support environments that address their difficulties in learning. This realization also entails appreciating the fact that people with intellectual disability who have continued with their education at a postsecondary level have increased further in their human capital and are in a position to invest it fruitfully through employment.

In light of the findings that have emerged from this study, it is recommended that guidance is provided for employers in appreciating the skills and abilities of people with intellectual disability and in finding ways of enabling these skills and abilities to emerge through the necessary support in the workplace. Furthermore, young people with intellectual disability should be provided with more post-secondary education opportunities. The ITS *Key* 

*Skills* course should be offered again. In addition, these young people should be offered individual support to be able to follow mainstream post-secondary courses.

Ultimately, the most significant finding to emerge from this study is the importance of listening to what people with intellectual disability have to say about their experiences in mainstream post-secondary education settings, and about the needs that they identify, and finding ways of addressing those needs to make it possible for them to develop their own human capital to its full potential.

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# Inclusive Education and Disabled Students' Genuine Right to British Higher Education

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Abstract: Access to general education is perceived to be a positional good and the passport to better paid employment opportunities (EHRC, 2010). Yet, more than ten years on from the adoption of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), having an equal opportunity to participate in an inclusive education environment remains an unreachable dream for many disabled people. Mainstream education can therefore prove to be a disabling context as well as being enabling for different groups of learners with certain minority characteristics (Riddell, Tinklin, & Wilson, 2005). Drawing on the voices and experiences of a group of disabled international students within a British-specific context, in this article I assess the inclusiveness of university practices, examining the level to which students feel included in university life. The intersectionality of disabled international students' identities can have a negative impact on their opportunities to access and participate on an equal footing in the university system. The discussion of discriminatory barriers to their involvement in university facilities as a right to full membership to the student body, and its effects on the quality of the education received, will be significant to this article. In conclusion, I will explain that as creative solutions inclusive education practices only require flexible thinking and can transform societal attitudes as well as equalising all students' experiences.

**Keywords:** Inclusive education, disabled/international students, HE experiences, access, participation

#### Introduction

Globally participation in higher education (HE) is coupled with improved life chances; possession of a university qualification can lead to higher paid professions and job satisfaction (Riddell, Tinklin & Wilson, 2005). An unequal

start in life, brought about by lower average levels of education, conversely, forces many disadvantaged young people to a life of poverty, reinforcing their everyday marginalisation. The exclusionary selection procedures underpinning most conventional educational systems, including "innate" ability and class membership, have largely created and reinforced these inequalities (Ball, Davies, David, & Reay, 2002). Traditionally, not all students with specific biological and cultural characteristics have been encouraged to participate in mainstream higher education institutions (HEIs), the assumption being that universities are generally inaccessible to disabled students, but are suitable for a marginal group of financially elite students (Riddell, et al., 2005). The failure to educate disabled individuals often results in many people not attaining the rewards and experiences of an academic life and, more significantly, lacking the personal, social and financial empowerment gained from the relevant qualifications (Fuller, Bradley, & Healey, 2004).

To be able to exercise the same level of choice and control, and feel included in mainstream society, it is therefore fundamental to recognise and respect disabled people's right to access and participation in education. To facilitate this, in 1994 in Salamanca, Spain, the representatives of 92 governments and 25 international organisations met to further the objective of "Education for All" by considering the necessary shift in policy and practice to promote the principle of inclusive education (Kiuppis, 2013), namely enabling schools to accommodate all children, specifically those with special educational needs (Right to Education Project, 2015). The Salamanca framework placed the development of local mainstream schools at the heart of the paradigm shift to support the participation and learning of students with an increasingly diverse range of backgrounds instead of making cursory attempts to integrate "non-traditional" students into the existing arrangements (Ainscow, 2005).

Following the Salamanca statement, in 2006, Article 24 of the UNCRPD was ratified to protect disabled people's right to education. This article not only states that disabled individuals should not be discriminated against but it also proclaims their right to inclusive education as an equal opportunity (de Beco, 2014).

That being said, the impact of this legislation has not yet fulfilled its potential. Over a decade on from the ratification of Article 24, equal access and participation in an inclusive education environment remains an unreachable dream for many disabled learners (Lourens & Swartz, 2016; Babic & Dowling, 2016). While campuses are increasingly becoming diverse (Flanagan, Benson, & Fovet, 2014), a wealth of evidence has shown that disabled domestic students experience disabling barriers in areas such as access, pedagogy and social life in HE (Beauchamp-Pryor, 2013; Collinson, Dunne, & Woolhouse, 2011; Farrar, 2007).

Here I discuss information and physical access barriers experienced by disabled international students in the British HE sector, focusing on the intersectionality of their multiple identities and how sometimes their difficulties are perpetuated, resulting in further marginalisation throughout the university journey. In the absence of genuine inclusive practices, it is this specific area that forms the basis for explaining and justifying the need for inclusive and flexible educational practices. This paper is informed by the questions and findings of a project conducted for my PhD research specifically relevant to the British HE context (Soorenian, 2011).

## **Research Methods**

Based on my first-hand experience of being a "disabled international student", I undertook a qualitative study with thirty fellow students in eleven British universities. Throughout the fieldwork, I recognised participants' experiences resonating with that of my own, allowing me a unique insight into their circumstances. Moreover, employing an exploratory framework and using qualitative methods of semi-structured interviews and a focus group, I explored participants' voiced experiences of university life. As with Messiou (2012), I believe that, through listening to students' accounts, education research can highlight their viewpoints and allow them to be part of the solutions.

Through networking and chain referral techniques in universities and national educational organisations; a snowballing method was adopted to recruit the participants. Thirty "mature" participants with a range of impairments (two with invisible, five with dyslexia, ten with sensory [two with hearing and eight with visual], and thirteen with physical) were hence recruited. In the British HE context, "mature students" are defined as being twenty-one or over (HESA, 2016). Three of these participants were from Africa, four from Asia, six from the Far-East, six from North America, and eleven from Europe.

To stimulate, validate and refine the semi-structured interview topics, a focus group with five participants was initially held. Following this, I conducted three telephone, 12 face-to-face, and 15 email interviews with the participants, depending on their impairments, time and location availability. The barriers participants discussed were grounded in their multiple identities of "disabled", "international" and mostly "mature" and "postgraduate" students in the British HE.

Participants were then invited to read their anonymised interview transcripts through and make any additions, modifications, or exclusions as they saw fit.

Subsequently I used a coding schema based on lists of themes and categories, generated from studying and reflecting on theory and previous literature.

The findings indicated that in most cases students' access needs were exaggerated due to their linguistic, cultural or geographic location-related concerns. In the following sections, I will use participants' voices to highlight the complex interaction of their identities - how being "disabled" and "international", sometimes in isolation and other times simultaneously compounded difficulties experienced, resulting in an unequal university experience to that of their non-disabled international and disabled domestic peers.

## The Social Model and its Impact

Here the term "disability" is interpreted through the social model lens. Accordingly, in the HE context, various educational barriers are identified and recognised as hindering disabled students' progress, and universities are expected to work towards the removal of these obstacles, instead of holding individual disabled students accountable for their inability to access and participate in HE (Riddell et al., 2005). The social definition of disability differentiates between the term "impairment" as a biological experience, and "disability", as societal discrimination and prejudice related to a larger injustice issue (Barnes, 2007). The rhetoric of the social model of disability is gradually beginning to percolate into HE policy in the UK, albeit tentatively. The impact of the social model is perhaps most evident in the implementation of The Special Educational Needs and Disability Act (SENDA) in 2002. The Act not only made it illegal to discriminate against disabled students in the provision of educational services, but it also expected institutions to provide anticipatory adjustments, rather than responding in an ad hoc or reactive way to individual disabled students' needs (SENDA, 2003). In a stark contrast to the medical model rhetoric, perceptions on inclusion that are embedded in the social model retract attention from impairments or limitations, and focus instead on institutional policies and practices that discriminate against and oppress disabled students (Lalvania, 2013).

Despite this marked progress towards officially placing disability alongside other equality and diversity dimensions through SENDA (Riddell et al., 2005), as documented below the medical model continues to exert a predominant influence in university practice. British HEIs generally display characteristics of a more "integrated" education system embedded in the medical and personal tragedy discourses. Conventionally within the integrated model of education, disabled pupils/students were placed in separate units attached to mainstream education settings, which were dominated by "special education" ideology. With minimum support provided disabled students were merely tolerated (Oliver, 2000). Similarly, in a HE setting by offering support, albeit unpredictably and inconsistently, attempts are made to alter students' needs so that the university targets are achieved. The individualised support provided seems to only help students to "overcome" barriers to access an otherwise inaccessible mainstream educational environment, which continues to be largely unchanged. The solutions proposed are therefore often perfunctory and inadequate, focusing on individual deficit and the negative consequences of impairment (Riddell, 1998). Next I will identify some of the university practices, which are based on the integrated model of education and reflect the individualised view of disability, contradicting with the social understanding of this concept leading to inclusive educational practices.

#### Receiving accessible information

To lead an independent life, and feel included in the mainstream community, disabled people should be able to exercise choice and make their own decisions; the 'lack of entitlement to independent living means disabled people are denied their human and civil rights' (Morris, 2004, p. 427). To achieve this, as highlighted in disabled people's "Seven Needs" (Hasler, 2003) in the first instant, disabled people need appropriate information. The relative information provided by the prospective universities to twelve of my research participants, for example, provided opportunities to decide where and what to study.

Disabled students need accessible, accurate and unambiguous detailed information about what university life can offer – how to seek advice, guidance and support for disability-related needs. Without this sort of information, they may experience high levels of anxiety as well as difficulty in preparing themselves for university study (Madriaga, 2007).

Likewise, international students need transparent pre-arrival information to alleviate stress when facing the unknown, helping them with the 'acculturation' process (Ryan, 2000, p. 81). Such communication is prerequisite to a proper understanding of, firstly the British culture, secondly the HE sector generally, and thirdly the expectations of academic facilities and programmes of the specific university at which they will be studying. Whilst all international students are liable to receive poor pre-arrival communication, disabled international students are doubly disadvantaged due to uncertainties regarding crucial disability-related and other support needs. The general prospectus may not necessarily be in disabled students' preferred format (McCarthy & Hurst, 2001), include disability specific information, or indeed be culturally sensitive. Reading the prospectus, Olivia, a research participant knew that there was a support centre for disabled students; however, no information about the specifics of the services on offer was provided. She talked about the significance of receiving information on such details, and how it would have given her a much-needed sense of security prior to starting her university experience.

It was clear that access to robust, timely and reliable information was crucial for all the participants who, like other prospective students, were making decisions about where to apply amid greater choice of universities. However, ten participants, all from different countries, received very little or no information on essential student services. Linda (from North America) had no idea how to access non-academic services. She only found out about such facilities through word of mouth - from talking to classmates. Due to lack of information received, Mlinda and Nicky took the responsibility on themselves of searching for information on their university. As a postgraduate student, Kate complained about the quality and relevance of the limited information received. She criticised the materials for not meeting postgraduate students' needs, primarily being geared for the typical undergraduate students' expectations instead.

Twenty of the thirty interviewees received information, albeit erratic and sometimes inaccessible, offered by various student services. At preadmission, Tina received both written and verbal information from Accommodation Office, Disability Services and her academic department. She found these tailored materials extremely valuable. Whilst twelve were content with the information, the eight participants, who were dissatisfied with the accessibility and appropriateness of various pieces of information received, were with different impairments: hearing impairments (one), dyslexia (two), and visual impairments (five). They pointed to their universities' general assumption that students can read the standard hard copy small print literature readily. In fact, this format was inaccessible for students with dyslexia. Angela needed yellow, blue or pink print background, especially when reading extensively. Her institution failed to provide information in this format, even after her preference was stressed. This was also the case for Nora (also with dyslexia), both before and after the admission stage.

Another participant, Sova (with visual impairments), discussed how, due to the inaccessibility of the small print information received from Disability Services, she was unable to read it independently. She felt disadvantaged, and was restricted to listening to the introductory section only, read and recorded by her course director in her previous place of study. This meant that Sova was ill-informed about the full range of disability services available and was unable to make use of the facilities.

Only six participants were given brief disabled international student specific information on areas such as funding for their disability-support. Lack of information sensitive to this group's additional needs (e.g. particular

disability-related academic support) was disquieting for the participants. They thought receiving the information would have been invaluable, giving them some reassurance beside clarifying their requirements and expectations.

In reference to information on accommodation services, whereas Domenic (a wheelchair-user) was informed that his room could be adapted to meet his specific needs; Ned (also wheelchair-user, from the same university as Domenic) was uninformed about similar adaptations. Ned attributed the breakdown in communication to poor coordination between the Disability Services and the Accommodation Office in meeting students' needs.

Furthermore, a lack of relevant information on social life was affirmed by three participants (one with visual impairments, and two with mobility impairments). Toney (with visual impairments) highlighted the difficulties related to spontaneity when arranging social activities, a privilege that most non-disabled students take for granted, as a major aspect of student life. Toney explained: 'I don't have the same choices. By the time, I get accessible information, it's too late and too sudden. There needs to be sudden plans to organise the transport and support'.

Additionally, participants were frequently invited to visit university websites to obtain crucial information on various student issues. There seemed to be an immediate expectation on students to be able to access the internet. Nonetheless, accessing the internet proved to be problematic for some participants from their non-Western home countries as was the case with meeting staff face-to-face. Some university websites also lacked accessibility features for students with visual impairments and dyslexia. Although 21 participants did not speak English as a first language, none were offered versions of prospectuses in any language other than English. Specifically, at the beginning of their university experience, international students may have difficulty with their English language reading and writing skills; thus, receiving information in their first language may have been particularly valuable. What appears to be the underlying problem here is the universities' unwillingness to provide information in students' preferred formats, be it in audio version, Braille, or large print, and make the provision of information inclusive in general.

Lack of such useful information can add to a feeling of distress for most disabled students (Madriaga, 2007), particularly so for international students who are adjusting to a new culture, an experience, which can reduce students' self-confidence (Soorenian, 2013). Eighteen participants felt that the disability specific information received was inadequate; they wanted to receive more information to help them make the disability-related practical arrangements. It can therefore be argued that participants were disadvantaged on two levels around receiving tailored and accessible format information. Unlike their domestic peers, they were unable to visit or contact their universities by phone/email as conveniently. Angela (with dyslexia), for example, did not receive any accessible information on university services; yet she preferred to keep the number of phone/email contacts with the British HEI from her home country minimal, implying that the process was stressful. It was clear that participants generally had to conduct long and exhausting dialogues with their universities to merely access such entitlements as accessible information, instead of devoting time and energy to prepare for their new adventure.

Despite national recommendations that HEIs should make prospectuses and other information available to students accessible and in different formats prior to the start of the course (ECU, 2010; QAA, 2009), universities' responses appear to be reactive, responding on an ad hoc basis to students' requests, rather than fostering inclusive approaches where information provision was concerned. Receiving inaccessible, or indeed no information, was detrimental to disabled international students, who would have found the literature particularly informative on the grounds of being both "disabled" and "international". Having discussed information accessibility, in the next section access to the university environment and specific student services will be explored.

#### Accessing the built environment

Access to the physical environment, 'to go where everyone else does' has been identified as another of disabled people's "Seven Needs" by the Derbyshire Centre for Integrated Living (Hasler, 2003, unpaged). In addition to accessibility of information, accessing the built environment facilitates disabled students' independence and inclusion in university life. Nonetheless, there remain several serious access obstacles, which compromise disabled students' full participation in academic and social pursuits. These include old listed buildings without lifts or ramps, inaccessible furniture (inappropriate height and layout), inadequate spaces for wheelchair-users, inadequate lighting, and lack of visual signage - not Braille (Causton-Theoharis, Ashby, & DeClouette, 2009; Madriaga, Hanson, Heaton, Kay, Newitt, & Walker, 2010).

Reflecting previous research, the quality of participants' experiences was shaped by the accessibility of physical infrastructure both inside and outside the general facilities as well as specific spaces. Twenty participants highlighted some impairment-specific barriers in entering several buildings. Domenic (a wheelchair-user), Nicky (with a back impairment), and Olivia (with one short arm) criticised the heavy doors to various buildings as, due to their respective impairments, they were unable to pull the doors and keep them held open whilst passing through. Irin and Kate (with physical impairments) and Toney (with visual impairments) felt uncomfortable walking long distances between different buildings. Kate explained: 'When using the accessible route, I often have to walk twice as far to get half the distance. I have to do a lot of planning in advance and do several things together to make the best use of my time and energy'. Participants with physical impairments appeared to expend huge amounts of time and effort in negotiating many seemingly accessible buildings. Elaine talked about the impeding and exhausting effects of finding accessible entrances on her time and energy levels.

This is specifically important because most disabled students experience fatigue as a dimension of their impairments, resulting in limited concentration and energy available for studying and social activities (Viney, 2006). For Linda (with physical impairments), fatigue was a major determining factor in deciding which options/routes were quicker and more accessible; she had to prioritise her limited energy, and use the time available effectively.

The outside environment was also inaccessible to some participants. Tina (a wheelchair-user) complained about the hilly landscape of the city concerned. Because of the severe risk of her three-wheeler scooter getting stuck in the pavement cracks, Elaine decided to use her manual wheelchair instead, which put strain on her hands. Carol, who had sight in one eye only, experienced problems with depth perception. She complained about the uneven pavements: 'I always catch my feet, catch my toes on the cobblestones, almost falling on my face'.

Toney (also with visual impairments) found it challenging to move around the old listed university buildings where the lift services were inadequate, especially one that housed several student support services: 'It is six floors, which is not well labelled. It also has a revolving door, which hasn't made it very accessible'.

Accessibility for people with visual impairments often encompasses use of colour contrast or a range of signs. Universities are expected to provide clear symbols and tactile information so that students can identify the rooms easier (ECU, 2009b). Mary pointed to the overall inaccessibility of the HEI she attended: 'So many stairs, so many signs, not Braille, so many heavy doors. It's just completely inaccessible for a visually impaired student'.

Furthermore, HEIs are expected to adapt the specific learning environments for disabled students to the greatest extent (ECU, 2009b; QAA, 2009). Elaine discussed an important yet often overlooked issue about the way paper notices were placed within glass notice-boards, and not pinned with drawing

pins on the boards in and around her academic department. This meant, helpfully, her wheelchair was not punctured for over a year.

However, seven participants with physical/mobility impairments voiced dissatisfaction with some physical characteristics of their academic departments, including broken lifts and steps. Kate discussed the way many of her lecture/seminar-rooms were inaccessible for students with mobility impairments, and how she was not able to attend occasional departmental workshops. As an ad hoc solution, Kate met her research supervisor weekly in the visitors' centre instead.

It appears that the Quality Assurance Agency's (QAA, 2009) recommendation regarding flexibility where the meetings/seminars were held including moving individual student's activities from inaccessible rooms to more accessible places, addressed how Kate's difficulty was handled. Although this solution may arguably have created an equivalent access opportunity for Kate to that of her course-mates, the resulting social and personal negative implications cannot be overlooked. The advantages of participating in an academic setting together with other students are said to include: 'Intellectual stimulation, emotional growth, academic gains, an expanded social network, increased self-confidence, and independence' (Causton-Theoharis et al., 2009: 90). Considering her university's individualised response, Kate was clearly denied the opportunity to interact with her course-mates, possibly leading to increased levels of confidence amongst other academic and non-academic gains.

Elaine and Ned's (both wheelchair-users) two contrasting views on the size of the lecture-rooms indicate a lack of standardisation in the provision of accessible rooms for disabled students even within the same university setting. Yet, Wald (2012) recommends to ensure adequate teaching spaces for wheelchair-users.

As a student with a back impairment, Nicky was unable to sit down and work for long periods at a time. Despite the QAA's (1999) recommendation expecting the institutions to consider the height and layout of lecture-room tables, Nicky's request for a higher desk to enable her to study whilst standing was not met in her learning environment. As an alternative arrangement, she had to ask every lecturer to allow her to stand during lectures, and to take regular breaks.

Nicky also needed additional time to complete the course assignments, and often had to use the computer lab on the weekends to work on specific projects. Yet, the accessible route to the lab was closed on Saturdays. Once again this was despite Equality Challenge Unit's (ECU, 2009a) recommendation, encouraging institutions to develop an access guide to

suggest ways of entering university properties so that the access is not compromised, if a specific route is closed at a certain day/time. Sova (with visual impairments) criticised the complicated electronic entry device attached to the front door of her academic department. To enter this building during weekends and holidays, Sova could not operate the system independently and always needed to be accompanied by her personal assistant (PA).

Carol dealt with her sensitivity to direct light in the seminar-rooms by improvising - having the lighting more indirect or to open the curtains and not have the overhead lights on. This may indeed have created a new obstacle for other students (particularly students with hearing impairments who need to lip-read), conflicting with their needs. Nonetheless, Carol insisted that other students had no problem with the arrangement. It is thus important to recognise the need for variety and flexibility in pedagogy, affirming that what works for one student may not work for another.

With regards to utilising technology, Harris (2010) suggests that legislation on inclusive design for each product group is a huge undertaking, and must be supported by detailed research into practicalities, and health and safety issues. The QAA (2009) also stipulates that the equipment in laboratories and teaching-rooms should be accessible and user-friendly. However, looking at demonstrations or operating the small size machinery in the physics lab was difficult for Toney.

Participants' access difficulties described above are not exclusive to international students and can be applicable to most disabled students. Yet, Mlinda (with hearing impairments) had a specific disabled international student's concern. She found the size and nature of the university campus daunting and impersonal, reinforced and even exacerbated given her double identity and status as an "international" student, who needed to lip-read daily in English.

Here I identified a range of physical barriers faced by participants with different impairments. Students with mobility difficulties discussed their problems largely with uneven pavements, inaccessible routes and distances between buildings and steps inside the built environment; whereas students with visual impairments complained about incorrect lighting, visual signage and use of inaccessible machinery in the university environment. Apart from Mlinda's experience, regardless of their nationality, access difficulties seemed to be general for all disabled students. That said, to receive the appropriate disability-related support, students like Kate and Nicky had to justify their needs to university staff often in a second or third language to that of their own, which was a challenging process for some students.

Whilst participants appeared to have addressed some physical access difficulties, often through improvising, inaccessible physical locations (be it due to hilly landscape or heavy doors) were unmovable barriers for students, unless they were supported by their institution. These settings remained significant barriers to learning and demonstrated a weakness in the system. However, nationally, policies (ECU, 2009a; QAA, 1999; 2009; Wald, 2012) exist to address similar barriers to the ones experienced by the participants, ranging from Kate's concern with broken lifts and the physical inaccessibility of her learning settings to Nicky and Sova's difficulty with the closing hours of certain buildings, and Toney's problem in using the machinery in the physics lab. Ultimately to address physical barriers, institutions are required to ensure the accessibility of their physical properties under relevant legislation and general building regulations (QAA, 2009). Despite various national recommendations (ECU, 2009b; QAA, 2009) about such inclusive provisions as sliding doors and tactile information, for instance, the HEIs generally did not seem to have taken their legal duties on board, making the required "reasonable adjustments" to the physical environment specifically. In an academic setting, reasonable adjustment covers not merely the 'additional aids and equipment', but it also involves 'changes to working practices' (Felsinger & Byford, 2008: 26), and university culture at large. Participants' experiences indicated that instead of providing anticipatory adjustments, universities mainly acted on an ad hoc basis, responding to students' needs only individually. This was evident when Kate was met in an accessible yet different room to her course-mates, or when Nicky was granted regular breaks rather than being provided with an appropriate height desk and an ergonomic chair.

#### Discussion

The barriers I have examined in this article were in relation to information access and the accessibility of physical environment. Whilst living in their home countries, at pre-admission stage, participants had difficulty receiving accessible and relevant information, through post and phone contacts from their British universities. The provision of inaccessible information as the first barrier to the university experience thus restricted participants' choices of suitable British HEI. This did little to reduce the anxiety related to being a "disabled" and "international" student, acting as the first obstacle to their equal participation in university life.

When settled in their British universities, access barriers prevented disabled international students from having an equal and fulfilling experience like their non-disabled peers. Although most access difficulties were applicable to all disabled students, regardless of their nationality, the justifications that participants needed to conduct to ensure adjustments were in place were emotionally draining and time-consuming. These negotiations meant that they were not able to fully realise their academic potential, often forced to devote time and energy to self-advocacy. It therefore appeared that participants had to often compromise in all the areas discussed in this paper.

More specifically, despite ample national policy and guidelines on inclusive practices, universities' approaches in responding to participants' needs were more indicative of the "integrated" model of education, which is not only inconsistent and unpredictable, but also reactive and based on the individual medical interpretation of disability. Although policy and public view purport to have moved forward, lived experiences of the participants on what is delivered in the name of "inclusion" did not necessarily reflect this shift in perspective. The way HEIs address the agenda for inclusion often represents a superficial interpretation of the social model of disability instead of being a true application of the inclusion ethos (Hydera & Tissota, 2013).

As a transition to a fully inclusive education system that allows "all" students to participate in the university environment, regardless of disability, nationality or any other characteristics, such individualised efforts must be accompanied by wider structural changes. This system will help to break down barriers and traditional distinctions between all groups of people, with far-reaching implications for disabled and non-disabled students, and more generally for society at large. As Fovet (2014) believes creating an inclusive learning and teaching setting does not require expert knowledge, but rather a layperson's practical reflection on methods of curriculum and delivery.

An "inclusive" education environment is where 'the majority of students who have a disability are accommodated most of the time without anything "additional" being done 'for' them' (Fraser & Sanders, 2005, p. 130). Reflexive, flexible and responsive "inclusive" pedagogical and social procedures at pre, during and post university experience will benefit all students, and prevent the need for "retrofitting" adjustments with extra costs for students with "additional" needs. Although the implementation of inclusive practices may initially result in an increase in expenditure, these short-term financial consequences will be outweighed by the long-term benefits that will accrue from targeting compounded forms of social and educational disadvantage. Next I will highlight some examples of inclusive practices related to the topics covered in this article.

Universities need to provide both verbal and written tailored, accessible and culturally sensitive information on their student services in a range of alternative formats, pre-arrival, in a timely manner to all prospective students to allow them choices in selecting universities and to know what to expect on arrival. The specifics of disability-support services on offer must be included in the information with an accurate explanation of the cost involved for international students particularly. Universities must be able and willing to provide the information in different languages so that students' families, who may not be fluent in English, can help them with the university selection process. Furthermore, the language and pictures used in the universities' publicity materials must be carefully selected to reflect the institution's approach to equality and diversity matters.

The HEIs must have extensive guidelines on the physical accessibility of the entire university campus, complying with "universal design" principles. They need to have a firm commitment to review the implementation of these recommendations on a regular basis to promote an environment that can automatically be adaptable to "all" students.

Enactment of the above recommendations would help contribute towards creating an "inclusive" access experience, and removing some of the barriers participants experienced. Ultimately, it is crucial, however to eradicate the source of oppression that creates a non-inclusive education system. A truly inclusive and democratic society should recognise education as a human right and challenge inequalities and segregation whilst promoting creative and responsive approaches to learning and participation for all students.

## Conclusion

In contrast to the "integrated" system currently in operation in most British HE settings, an inclusive educational framework is framed in the context of social justice, where demand is on difference not being rejected or merely tolerated, but publicly understood, identified and celebrated (Ainscow, 2005; Barton, 2003; Norwich, 2010). To achieve this, the 'irrelevance, discriminatory and exclusionary features' (Barton, 2003, p. 14) of present policy and practice based on biological and cultural determinism should be understood and challenged. Universal policy and legislation alone is insufficient to engender significant change; a more complex strategy of reviewing procedures and active consultation of disabled students is paramount to work towards a more equal HE system (Vickerman & Blundell, 2010). Inclusive practices equipped with creative and flexible thinking grounded in general education reform (Ainscow, Booth, & Dyson, 2006) are capable of facilitating and strengthening the mandates of Article 24 of the UNCRPD, which stipulates that states parties shall ensure that: 'Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live' in addition to 'Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion' (UNCRPD, Article 24).

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# The values of inclusive education: A political debate

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Abstract: The ontology of lived experiences of young people with physical and sensorial disabilities was used to understand the experience of inclusive education (IE) within further education (FE) and higher education (HE) institutions in Malta. The inquiry problematised the environmental, social and educational disabling and enabling factors. Underlying values of inclusion and exclusion that promoted social cohesion or social conflict emerged from the discourse. This research paper focuses on the accounts of four disabled young people. Seven semi-structured interviews were carried out per participant over two years while they were attending a course at FE and HE level. Narrative analysis was utilised to understand the underlying themes of the stories. The analysis indicates that successful stories of inclusion are influenced by the extent to which disabled and non-disabled persons practise values that promote social cohesion within a community. Virtues of social cohesion affect the extent to which environmental and educational disabling barriers are challenged and changed. The evidence from this study contributes to the debate that active participation of disabled young people, valuing the voice of others, embracing values of inclusion, and the appreciation of individual's variations inculcate growth in the quality of IE. Social transformation affects the environmental and educational milieu within FE and HE institutions.

**Keywords**: Inclusive education, disability, further and higher education, values of inclusion

#### Introduction

Borg, Cardona and Caruana (2009) endorse "the moral conviction that education is inherently political" (p. 1). The politics of inclusive education (IE) are contentious as according to Corbett (2001), it exposes a structural and an ideological debate and

"it is often the case that these practical and political elements are kept separate in debates on inclusion" (p. 29). This discourse applies to the local scene as although Malta has been implementing an IE policy in state schools since 1995 (Ministry of Education, Culture, Youth and Sport, 2005), these political discourses are relatively new as the number of disabled students at further education (FE) and higher education (HE) levels is still less than 1% of the student population (CRPD, 2010, p. 18).

This paper discusses evidence from research that stemmed from Dewey's theory of experience (1930) who claims that "the very process of living together educates" (1938, p. 7). However, it is argued that the political direction driving the experience of living together is as important since the experience of living together through IE could promote social cohesion or social conflict. In fact, Allan and Slee (2008a, 2008b) argue that IE is considered a troubling field that encloses a series of emotive and highly charged contexts.

Shakespeare (2006) proposes that disability studies should present rich empirical research "of how disabled people experience barriers, and how they experience their impairments" (p. 198). To fill this epistemological gap, the experience of lived experiences of young people with physical and sensorial disabilities was used to problematise the environmental, social and educational disabling and enabling factors within FE and HE institutions. By utilising students' accounts, this paper aims to discuss the extent to which political discourses that are permeated with values that promote democracy, social justice and human rights could influence practices within FE and HE institutions. The analysis indicates that successful stories of inclusion are highly influenced by the application of values that promote social cohesion. Virtues of social cohesion that are implemented by stakeholders affect the extent to which environmental, social and educational disabling barriers are challenged and changed. However, the journey towards IE is multifaceted and intricate and necessitates praxis at all levels of the education system and society (French and Swain, 2004).

The evidence contributes to the debate that active participation of disabled young people is politically important as their participation and advocacy inculcate "growth" in the quality of IE (Dewey, 1930, p. 357). The promotion of an inclusive culture that shares values of social cohesion can transform the structures within the educational milieu whereby the political dualism between the needs of disabled young people and educational institutions is advocated on the basis of human rights, democracy and social justice.

#### **Theoretical Framework**

Jerome and McCallum (2012) maintain that a rights-based approach in education entails that students are voiced and listened to. Thus, it could be argued that the voices of the silenced can contribute to a cultural praxis where our society develops a proactive approach in providing quality learning and assessment measurements that are equitable, respect student diversity and reflect the integrity of educational institutions and examination Boards. Adams and Brown (2006) report that most HE institutions "require a significant cultural shift from seeing disabled students as 'outsiders coming in', to an institution which openly embraces 'all comers'" (p. 4). Similarly, Hurst (2009) argues, that there are various challenges in educational institutions in having inclusive routine policies, procedures and practices where disability services are considered as "valueadded" rather than "an additional institutional expense" (p. 95).

Ballard (1999) argues that the inclusion of voices that were previously excluded and who then present their realities could stimulate "a radical revision of thought and practice" (p. 172). Gramsci (1916) (in Forgacs (1988, p.57)) explains that culture is "the attainment of a higher awareness, with the aid of which one succeeds in understanding one's own historical value, one's own function in life, one's own rights and obligations". By bringing to consciousness concrete and immediate experiences which are parts of the whole of IE, the dialectic political tensions in the implementation of IE on a pragmatic and ideological level could be utilised to inform each other to nurture a culture of inclusion. In other words, by developing spaces of ongoing consultation and dialogue between service users and service providers, stakeholders would be empowered to voice the political and practical standpoints that are enabling or disabling the implementation of IE from a rightsbased perspective.

Lack of consultation could be interpreted as subversion, as a means to promote manipulation and oppression. As Freire (1993) argues, by "attempting to liberate the oppressed without their reflective participation in the act of liberation is to treat them as objects which must be saved from a burning building" (p. 47). To achieve a praxis, "it is necessary to trust in the oppressed and in their ability to reason" (Freire, 1993, p. 48). Unless there is a collective transformation of an inclusive culture rather than cosmetic reviews amongst those who construct structures, decision-makers and policy-makers, there is not much hope for empowerment and emancipation of disabled persons in education. In fact, Gramsci (1929-1935) (in Forgacs (1988), p. 199) sustains that, "ideology is identified as distinct from the structure, and it is asserted that it is not ideology that changes the structure but vice versa". The human impact is crucial because, as Dewey (1930) debates, humanity should realise that "the ultimate value of every institution is its distinctively human effect – its effect upon conscious experience" (p. 8). Therefore, educational institutions need to create systems that promulgate inclusive experiences that support social cohesion.

Joseph (2003) sustains that cohesion means "the way in which a group, bloc, order or system is able to maintain itself" (p. 3). Thus, cohesion promotes sustainability as each member would be responsible to maintain the whole educational system on a structural and political level. Conversely, conflict is viewed "as a failing of the system that needs correcting in order to return to equilibrium" (Joseph, 2003, p. 4). Dialogue, collaboration and the inculcation of values of inclusion could shift conflicts to be regarded as opportunities for social transformation to foster democracy and social justice. Dewey (1930) argues that "society not only continues to exist by transmission, by communication, but it may fairly be said to exist in transmission, in communication" (p. 5).

Shuayb (2012a, 2012b) argues that education for social cohesion embraces equity, equality, inclusion, a democratic school environment, participation and empowerment of all individuals to address and promote social cohesion. To prevent oppression and discrimination, the value of equity needs to be enforced as it is through equity that social justice in education can be achieved. Slee (1993) sustains that equity in schools requires "a multi-level approach" that addresses "organisation, governance and administration, curriculum and the construction of worthwhile knowledge, and pedagogy" (p. 3).

Riddell and Weedon (2009) maintain that "changes in institutions tend to take place as a result of bottom-up, as well as top-down pressures" (p. 27). Thus, it could be argued that each education sector is in a continuum and as such, each educational entity needs to work in synergy with another to provide quality IE that implements the right of education and safeguards the principles of democracy and social justice for all students. An attitude that cherishes values of inclusion and a disposition towards collaboration amongst all stakeholders, both as service providers and users, are essential attributes so that disabling factors are reduced while enabling factors are promulgated and celebrated.

#### Methodology

This paper focuses on data generated by a narrative inquiry carried out as part of a research project that used a mixed-methods approach. The aim was to listen, gather information and understand how service users feel or think about their experiences of the phenomenon under study (Cousin, 2009). In line with the 'social model' of disability (UPIAS, 1976), my standpoint as the researcher was partisan to disabled persons. Plummer (2001) explains that narratology is a field "which takes as its central task the analysis of stories and narratives" (p. 186) while 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). Data collection occurred between 2011 and 2014. Over two years, seven semi-structured interviews were conducted with four disabled women. Plummer's (2001) method of analysis was adopted to extract and understand the underlying themes of the stories. The transcripts as 'field texts' were used to identify the "moments" of environmental, educational and social disabling and enabling experiences, and to understand the context, space and time of the whole story (Clandinin, 2013, p. 173. See also Van Manen (2014) and Jeong-Hee (2016)).

## **Profile of sample**

The choice of young persons with physical and sensorial disabilities was based on the premise that the selective examination system in Malta limits the opportunities for persons with intellectual disability to be enrolled in academic FE and HE institutions and "physical and sensory impairments are in many senses the easiest to accommodate" (Shakespeare, 2006, p. 201). A 'criterion scheme' which entailed "choosing settings, groups, and/or individuals because they represent one or more criteria" was used to select the participants of the narratives (Collins, 2010, p. 359). For ethical purposes, administrators of FE institutions forwarded my invitation letter to potential participants. Two participants had a physical disability while the other two had a sensory disability. Three participants shared their experiences while attending a two-year course at FE level. The other participant narrated her experiences during the second year at FE level and first year at HE level. For ethical purposes, the participants were given a pseudonym.

## Findings

The findings shed light on how inclusive values affect the wellbeing and the quality of experiences disabled students have and the type of culture being nurtured in the school community. Conversely, values of exclusion create social conflict and limit the extent to which disabled people can have access to FE and HE at par to any other student. Although the stories shared common themes, in this text the narratives which were originally told in Maltese and English are used to support specific themes.

**Equality and equity.** The participants recognised that the principles of equality and equity are being recognised at the respective FE and HE institution, but there is still more work to be done. They felt disabled from being given the chance to do mundane activities independently as their peers due to lack of environmental access either because of individuals who do not prioritise this issue in the agenda, lack of funds or incorrect budgeting. The participants valued the importance of being given an equal opportunity to learn that brings them at par with their non-disabled peers. The way others treated them also had to reflect equity as they wanted to conform with their peers. The participants claimed that during adolescence, matters are even more complex as the person would become more self-conscious and society expects individuals to portray the image of an able and independent person. Disabling barriers can therefore affect the social and psychological development of an adolescent. Socially, conformity facilitated the propensity that participants were accepted by their peers and felt equal to others.

On an educational level, the participants indicated that equitable opportunities to learning such as distance learning and access arrangements in examinations enabled them to receive what is theirs by right and demonstrate their abilities in the mode that is accessible to them. Attitudes that reflect flexibility and creativity in addressing problems motivated participants to persevere to reach their full learning potential and develop self-efficacy to improve the quality of their life and society.

On the other hand, experiencing a struggle due to lack of standardised procedures at FE and HE institutions made the participants feel disempowered and oppressed. Participants acknowledged that to avoid embarrassment in being dependent on their friends, for instance to provide them with notes, they pretended that they were coping. This approach had negative academic consequences. The experience of a struggle reflects the fact that disabled persons are being suppressed by those who are in authority or institutional directives which were created by individuals. Standardisation and conformity in the quality of educational services are essential so that students would receive what they are entitled to and the integrity of the institution would be strengthened. Equity affects the extent to which disabled students would feel that they belong to the respective institution and can exercise their independence, freedom and privacy. Equity empowered participants to participate in activities without feeling that they were privileged. The participants argued:

If you have something different, it doesn't mean that you have something bad. Society makes you disabled as it won't see you in the same way as someone else. ... You are equal to other students. ... 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. ... For a lecturer to ask and try to help you, well and good, but not making preferences because you have different needs. (Melanie)

Inclusive education, is that every person would receive the same education as another person. I am a person who doesn't want someone to treat me at a lower value because I am normal like others. ... Most of the outings I won't be able to go as they are not accessible for me. Outings are not recorded, let alone a lecture. Sometimes it is lack of thought as when you are a normal person in inverted commas, certain thoughts won't cross your mind. (Alessia)

By inclusive education, everyone has the right to learn equally. If you have a problem, you won't go through hell to get what you need. ... There should be collaboration in everything. If a school doesn't give you the opportunity to enter the normal class, you're already not included. To segregate them, and when they'll grow up, they'll come here, it won't be normal for them. They would not have habituated. (Elena)

The word disability doesn't have to be a negative. People make it a negative. The person becomes defined by society. Basically, your status is according to how society decides it, not according to how you are as a person. A lot of progress is going on, but we still have a lot to achieve. We are different, but our differences should not result into discrimination. (Marie)

**Sensitivity towards oneself and others.** Being realistic about one's limitations and strengths and the possibilities and restrictions within the educational system are essential to balance the politics between the self and the structures within the educational system. The accounts showed that finding practical solutions that lead to positive consequences are attributed to personal commitment, nurturing positive thinking, and being courageous, persuasive and self-determined to accomplish goals. Good interpersonal skills, the drive to take initiatives and being creative to establish a role within a team facilitate social acceptance and cohesion. A social network consisting of people of good will is essential to support disabled people to overcome the limitations caused by an impairment and to act as a pressure group on people who are in authority to remove disabling barriers. Attitudes of individuals who assume that disabled persons are sick or second-class citizens instil frustration, antagonism, anger and helplessness among disabled people that could develop social conflict.

During adolescence, there is the need for an acute sensitivity towards the personal and psychological needs of disabled persons from a trans-disciplinary team consisting of both professional and non-professional individuals. Through collaboration that reflects inclusive values, these individuals could empower disabled young people to gain confidence to explore how they could be catalysts within the school community and develop an identity of activists. Only individuals who believe in the benefits of IE work for disabled people to be given a chance to exploit their unique potential. They also strive for the emancipation and independence of disabled persons from a rights-based principle. The provision of access from a charitable standpoint is oppressive as it undresses a person from one's dignity. Disability activism on a personal, social and institutional level in promoting IE, challenges the structures and politics of the status quo.

The accounts indicated that when lecturers, administrators and examination boards consult students to seek possible alternatives about how the environment and educational activities could be accessed, disabled students would be empowered to develop agency. On the other hand, when people in authority make assumptions about what is best for disabled persons without direct consultation, paternalism and presumptuousness ensue, which force disabled people to be submissive. The more disabling factors are removed by means of communication and action that spring from inclusive values, the more disabled persons are nurtured to a culture of independence and achieve an independent identity. Developing positive relationships between lecturers, administrators and students facilitates the transmission of constructive feedback with openmindedness free from hierarchical political pressures. The experience of being considerate of others instils stakeholders to listen, think and value each other's position, limitations and abilities. Being considerate of others inspires stakeholders to communicate, collaborate, show courtesy, appreciate and reciprocate support. It also instils courage to overcome taken for granted everyday challenges and develop positive relationships. This approach is socially and educationally beneficial in community building. The participants maintained:

My friends give me advice and help me to be positive towards life. ... Friends give you the notes. ... They have to come with me as I can't go to the stationer's on my own. By force you have to depend on others. ... There are youths who speak with arrogance and although you try not to pay attention, it's not easy. Now either you're going to let it break you or you're going to adopt a positive approach towards others. (Melanie)

My disability, even if I don't pay much attention to it, it creates limitations for me. ... The students amongst themselves, it's one thing seeing a person and seeing the wheelchair only and another seeing the abilities of the person. (Alessia)

I don't talk a lot about the disability with people. You'll be afraid that maybe they'll treat you differently. ... You have to put effort too. You need to start thinking positively. You need to fend for yourself. (Elena)

You could have a student who can cope alone, but if he doesn't have accessibility, you've stopped everything. I am not expecting that the school should adapt for everything I need. But I am not saying that nothing should be done. ...Your presence within the school is creating awareness by itself. (Marie)

Living together is educational. Living in a community that is a microcosm of society is educational as it enables different others to interpret difference with inclusive values of acceptance, altruism, generosity, solidarity, tolerance and respect to one's dignity. Participants claimed that sharing experiences enables community members to see beyond the physical body. Unless interdependence is valued, the experience of living together would remain at a plateau level where people exist together. Conflicts could arise due to unwillingness and lack of understanding of how others see and live their world. Sharing experiences is educationally and socially enabling as disabled persons, who are suppressed by overprotection for instance from parents, would have the opportunity to get out of their cocoon. Members who belong to a group tend to support each other to break barriers and overcome limitations. When lecturers cherish inclusive values and organise inclusive learning environments, the chance for inclusive group dynamics to be developed is increased as students learn through observation and role modelling.

Both disabled and non-disabled persons require inner strength to face challenges and demonstrate a welcoming approach towards others. However, unless there are opportunities for social inclusion and social cohesion to develop, disabled students would be systematically put at a disadvantage and could experience loneliness, rejection and social conflict. For example, in Malta, due to the small cohort of students, Deaf people can experience loneliness. The number of sign language interpreters is small and Deaf persons experience difficulties to keep the momentum in class. Respect for the Deaf culture needs to be instilled so that the way communication is conveyed would be accessible to Deaf persons and persons with hearing impairment. Habituation and adaptability to student diversity contributes to the development of personal and group resilience and by being receptive to difference, one's notion of what is normal could be extended. Thus living in a community with inclusive values makes a difference in being nurtured to internalise habits of good citizenship. The participants argued:

Inclusive education is beneficial as you won't feel different. I experience the culture of inclusivity. ... When I told them, and they made accommodations for me, I felt included. ... The fact that you'll be in society, you'll be living with them, that makes the difference. The mentality is a bit backward, we are still something different. (Melanie)

They are accepting me, but it is step by step. It is dependent upon the disabled person's approach towards others. (Alessia)

They [friends] help you in everything. You'll appreciate those things as otherwise you'll need to ask the teacher, and you'll get annoyed in front of others. ... People who know me, they start thinking a bit before they speak. ... Previous students with disability sort of pave the way for someone else. Inclusivity is a culture, sort of the habits of people. (Elena)

As benefits of inclusive education, they are socialising amongst each other, persons with disability are getting to know the real world. Many of them would be sheltered by parents. ... There are going to be alterations, but those alterations could be for the benefit of the school and the students. ... Many teachers told me, "I've never had a special student in my class," "Listen what do I need to do?" They are learning different ways of teaching to accommodate different students. (Marie)

**Mutual understanding and effective communication**. IE requires flexibility and creativity to accommodate the diverse needs of all stakeholders. Mutual understanding of the pressures that each stakeholder is experiencing is a prerequisite to create an equilibrium between what is available at present and what is possible. By understanding the position of disabled persons through direct consultation and evaluation of the services and facilities, disabled persons would

be in a position to access learning and assessment without additional stress than their peers. Investment in having accountable and qualified persons to assist disabled persons would contribute to strengthening the integrity of an entity.

In experiencing understanding, parties are encouraged to dialogue and listen to each other's challenges and possibilities and, in a collaborative way, put effort to make the implementation of IE on a structural and political level a reality. The creation of a positive, ethical climate about the benefits of disclosing and dissemination of information could encourage stakeholders to be prepared for change, and celebrate diversity and difference as an opportunity for growth. A negative culture about disclosure could permeate a deficit mentality and discrimination as difference and disability would have a negative connotation and define a person's identity.

Mutual understanding and effective communication entail stakeholders to value the need for becoming adaptable and pliable to get used to new systems and practices that are more universally accessible that can benefit all students. The power of social capital can be utilised to ease transition periods and to plan inclusive paths between educational sectors. Intermediaries would be in a position to empower disabled persons to voice themselves and enforce anti-discrimination legislation in entities that limit access. These factors position individuals working within FE and HE institutions and other related entities in a state of becoming as they are continously deconstructing their ideologies and practices to reconstruct a culture that exhibits inclusive principles. The participants maintained:

Someone who hasn't ever spoken to a wheelchair user, won't know, won't even realise the difficulties that you'll find in everyday life. My friends that's what they tell me, "Before we didn't see life like this, now we are more conscious." ... If you 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. To make my voice heard, apart from being a right, I think that it's my duty. (Melanie)

It is team work because if you won't have a good relationship with the teacher, you'll have a hard time. ... The major challenge was communication. (Alessia)

I think you always need to tell as if you'll need something at the middle of the year, maybe it will be more difficult. But then it shouldn't define you. ... If there are steps only, I'll have to ask for the help of others. You'll be creating more disability as you are forcing someone to beg for help. ... No one knew that I had to stay at the front. There wasn't much communication. If there are two or three students who have additional needs, the teachers need to know about them. (Elena)

I should tell them that I am visually impaired. They'll be alerted so that they'll be able to prepare from beforehand, and it's nothing to be ashamed of. ... Communication amongst the students and the lecturer is very important. ... You should understand to be understood. There would be students who are afraid of talking to me, of saying something wrong and I'll be offended. I'll turn and smile to them, then they'll come and talk to me. (Marie)

#### Discussion

The significance of these findings is to contribute to the growing body of research exploring the daily lives and experiences of non-traditional students within FE and HE institutions that could be the contexts that reproduce or reduce existing social disparities (Riddell, Tinklin & Wilson, 2009). The results show that there are multilayer social, educational and environmental relationships between disabled students and diverse stakeholders within FE and HE institutions in the provision of IE. The present culture is that disabled people form part of a minority group with a disability identity. This reflects that disability is a social construct and, as such, it could be challenged and changed (Siebers, 2011). The evidence supports the argument put forward by Shakespeare (2006) where the quality of experience is dependent upon intrinsic factors to the self, such as effects of the impairment, personal attitudes, personality and abilities. Experiences are also affected by extrinsic factors present in the context the individual finds him/herself such as disabling barriers in the built environment and negative attitudinal barriers from others. Generally, the participants had positive experiences of IE, but they lived a continuous struggle to overcome environmental, social and educational disabling barriers which are created by a majority consisting of non-disabled persons. This strengthens the "context of identity politics" for which the social model was developed (Shakespeare, 2006, p. 33).

Evidence shows that the experience of living with different others makes others recognise that difference does not have to signify a negative. Living in an inclusive context nurtures values such as collaboration, interdependence, solidarity and moral responsibility towards others that promote social cohesion and community development. Shevlin (2010) argues that consultation embeds democratic practices within the nuclei of classrooms and institutions that are basic in an inclusive agenda while Kadlec (2007) concludes that to reduce unnecessary competition and antagonism, our education system needs to stem from values that reflect an inclusive culture. Moreover, Ainscow et al. (2006) remark that values of an inclusive culture are "concerned with equity, participation, community, compassion, respect for diversity, sustainability and entitlement" (p. 23).

The participants agreed that the participation of disabled persons at FE and HE levels is beneficial for the school community and society. FE and HE institutions need to strive for community building and social cohesion where every person is empowered and valued to have a meaningful function for the school community to

become a whole (Shuayb, 2012b). Ngwana (2009) argues that, "creating and supporting sustainable development requires individual and collection positive action" (p. 43). However, the creation of sustainable inclusive contexts calls for a political debate on how to transmit policy into practice.

#### **Implications of study**

The participants' voices on experiences did not remain a mere summary of the participants' life, but were embodied with reflection in transforming meanings of IE as a fertile terrain for possible suggestions (Dewey in Boydston, 2008). Regarding policy-making, the accounts put pressure on having an updated FE and HE Act that regularises the philosophical and pragmatic ideology of IE in the local milieu. Fuller, Riddell and Wilson (2009) claim that changes in the legislation transformed institutional practices as it requires universities to make "'reasonable anticipatory adjustments' to their provision rather than making reactive accommodation which require students to declare an impairment before adjustments are made to teaching and assessment practices, as was formerly the case" (p. 8). Healey, Bradley, Fuller and Hall (2006) claim that in the long-term, "the main beneficiaries of disability legislation and the need to make suitable adjustments in advance are the non-disabled students" as good teaching and learning practices benefit all students (p. 41).

Sharing and understanding experiences of inclusion/exclusion are essential from a class-based context to policy-making for the benefit of all (Beauchamp-Pryor, 2014; Rose, 2010). Thus, direct consultation with individuals at grassroots level needs to be an integral part during the training of diverse stakeholders, development and implementation of policies and during research about any minority group. Armstrong, Armstrong and Spandagou (2010) sustain that for inclusive practices to progress there should be "leadership that values and supports inclusion" (p. 110). Fernie and Henning (2006) purport that strong leadership and collaboration among the teaching staff are contributory factors to optimal inclusion. Howeover, the implementation of inclusive teaching and learning does not have "clear-cut solutions that 'work' for all school or class situations" as the school culture or shared value systems and the educational policies or infrastructure need to be considered (Watkins and Meijer, 2010, p. 241). These reflections imply that social transformations embedded with inclusive values affect the quality of IE that propagates social justice, democracy and human rights.

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