

**Reading Stories Of Inclusion:  
Engaging With Different Perspectives Towards An  
Agenda For Inclusion**

*by*

**Andrew Azzopardi**

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# Dedication

---

Dear Claire, Karl and Sue,

I want to dedicate this work to you. You have been too good to me. Can't forget the innumerable times I have travelled without you, the inconceivable amount of financial resources that you have agreed to 'invest' in me, your puzzled faces, Claire and Karl, as I tried to explain to you that even though I will be a Doctor, we still need to call in help when there's influenza in the house! Wholeheartedly I tell you that I have done this for you as well. Whilst risking that this may sound like a cliché, I want to thank you Sue for being there – always, for believing in me, for making me feel so proud of myself, and so proud of you.

Dad

*[Faint, illegible text, possibly bleed-through or a watermark]*

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The twist towards having narrative and story telling methods in social sciences is yielding rich harvest of research conclusions. This method is a way of vitalizing the relationship between policy and practice. It is a technique that provides a more meaningful and creative practitioner-service-user relationship and a better understanding of professional sound practices.

Being an ocular-centred community, we need to analyse what is happening and to read stories that are close to the reality we are succumbed to. These are stories that transcend from the people to the people, rather than from the researchers/academics to researchers/academics. Narratives are often intersected by multiple allegiances ranging from a historical context to political conformity, from grass-root struggles to social constructions and cultural hagemonisation, from researcher consent to economic agendas. Maybe the most complex of all issues is not the presentation of stories but to figure out and recognise what constitutes a story, defining story limits, recognizing the usefulness of narration and finally reflecting whether the morale of narrations is context-bound. This work is based on the power of stories.

This research becomes the process of not only identifying the complex dynamics and snags surrounding the "inclusion" agenda I am engrossed in, but also maps out a way to get back on track and to come up with answers. The core of my research lies in my semi-fictional stories that I have written and relocated back to the varied contexts I am involved in using focus groups as my *modus operandi*. Conversely, this scenario is complemented by autobiographies I assembled from disabled persons, a parent activist and a 'labelled' student. In other words, it is an enmeshment of auto-ethnographic and narrative enquiry.

This work has contributed towards an understanding of the ways the stories of children at the margins can be used to promote critical debates about "inclusion". The different perspectives of parent and disabled activists, university students, labelled students, teachers, and social workers – all contexts I am closely involved with, are drawn upon to inform a transformative agenda and to outline practices that enable "inclusion".

The work is split into three main portions. The first part includes the *Preamble, Introduction and Literature Review* and provides us with the



main ingredients that have fashioned my thinking. The second part of my *Thesis* includes the *Methods* and *Methodological* issues in depth and the *narratives, autobiographies* and *auto-ethnographic* findings that have made up my research base. Finally, part three of this study will take account of the *data analysis* and the mapping out of a transformative agenda, the *conclusions and commitments*.

# Preamble

---

**A Day In 'His' Life...**

.....

...looking back on the days of the committee,  
when everyone felt that a new world  
was opening for disadvantaged children,  
the most strikingly absurd fact is that  
the committee was forbidden to count  
social deprivation as in any way contributing  
to educational needs ....the very idea of such  
a separation now seems preposterous.  
(Warnosck in Clough and Corbett, 2000, p.5).

### **Flash back - Some 20 years or so ago**

'Education needs to be developed side by side with a student's character, temperament, inclinations, interests and potential' – I would say it's a grand statement! When I was still a student it didn't quite work that way for me though!

I was considered a 'drop out' with behaviour inconveniences galore - a teacher's nightmare! Can't forget the stinking smell of coffee served to my mother and father on *Parent's Day* when all or most should be celebrating achievement. Can't forget my mum crying her eyes out every single meeting she had with the teachers. Can't forget the stern, unyielding and uncompromising look on my father's long face! 'Your son is brainy missus, but he just wouldn't sit still!', 'Your son could be doing much, much better Sir!' or even worse, 'His brother is so different, so clever, so obedient, what's wrong with Andrew?!' It always baffled me how I always loved going to school just the same!

### **Present day**

*At home:* I'm having coffee by 05:00, looking over my e-mail after the silly opening tune on my computer, reminding me that morning has broken, trying not to snooze off once again as I sit on my ergonomic swivelling armchair. It's routine, it's dark, very dark, too dark. After e-mail it's a quick browse into my favourite football team's website, hoping day after day that the *News Section* says something about a new player that has joined

the ranks! Then it's the news portals, CNN, BBC, MaltaStar, MaltarRightNow etcetera. As I'm preparing school lesson notes for the morning and university lecture notes for the afternoon, I day dream, early morning day dreams, bringing to mind yesterday's social work visit to the Short-Term Psychiatric Unit!

*You know what, I've been drinking since I was fourteen years. I have this problem mate, big problem. In just six months, I got a stroke some four years ago and I just slipped into drinking even more, trying to forget that I have been sent out of work, forgotten by my brother, loosing two other brothers with heart failures and having unending problems with my left arm and leg.*

*But John you have to react [Thinking that was one of those silly suggestions you come up with, when every idea sounds even more bizarre – couldn't remember anything else I read from the social work manual!] Get on with your life. I know it's pitch dark in your life but you need to move on.*

*[Shirley, another patient, turns to me.] It's not that easy you know. I understand John. I've been on alcohol myself all my life, I just can't do away with it. They call me bipolar, depressed, addicted – I'm just nothing of those, I'm lonely, I miss my kids [Sobs], I had a divorce I just can't handle. I'm lonely [She moves away].*

*Can you believe it Andrew? She's so fuckin' pretty and she's here in this Psychiatric Ward thinking shit about life. [Calls out to another patient]. Pass me a fag mate. [Turns to me again]. What will I do with my life now? I spent three days this week locked up in my room, thinking, thinking, thinking and feeling more miserable and helpless.*



06:00 - it's a rush to the bathroom to get the front seat! By 06:30 I am at the newspaper shop, browsing through all the newspapers but buying just one!

*At the social work office:* I am at the office by 06:40, go through the day's plan, get organised, catch up on some paperwork. It's quiet at that time. Milton, a 'sort of' disabled person, is the first to turn up after me at this old enormous building ironically called *The Saviour*. In earlier times it was a residential home for disturbed and delinquent youngsters run by the Jesuits. Stories of pain and solitude seem to drip out of these three storey roofs, big broad walls and complex un-fashionable *frescos* that load the place. In other words it's a prison turned offices! In a way Milton and his asocial experience comes out of these walls. He's been bullied and treated like the village jester for most of his life. Certain people pity him, some love him, others think he is silly – "act your age", you hear people saying. By half past seven a disabled friend and colleague turns up with his loud, but very vociferous 'hello'! He's in good God damn spirits every single day – wonder of marvels, I keep saying to myself. We speak a lot in that half hour, his life, my curiosities, his pain, my rage. By quarter to eight almost all the social workers are at the office, Laura, Nancy, Rebecca and Sharon. Mark is the last to turn up. Usually it's 08:01. Most of his days start with an angled look from my end and the customary sermon, "but 1 minute or two hours is just as bad Mark, just as bad!" This bloke seems to like my coarse voice in the early morning, 'cause it takes just a day or two to get me saying the same bloody thing again. Then we talk, we laugh, we share, we try to avoid washing the cups we used the day before (there's one or two of us who are crafty in setting home visits at 08:15)! I make sure everyone has their day organised, feeling in good spirits, and then I'm off to my next job, teaching.

*At school:* By 08:15 I'm at school getting myself prepared for lessons. Oh, I love the kids. I'm playing and chatting with them in my free time. It's fun to just chill around with the students – they're great. I teach *Personal and Social Development*, strange subject but a good deal (no exams to prepare, no papers to correct and lot's of talking and arguments to share). I'm also a *Guidance Teacher*. Purportedly it's career guidance, rather strange role considering unemployment rate galore and we are trying to fix them into jobs that don't suit their interests! Feels strange guiding someone down the wrong way – and yet I do it day in day out. 'Dog-fights, cock-fights and boxing', that is all the student speak about. They just hate school, can't handle Shakespeare and Newton nagging about what 'they' think is important in life! Watching these students is strange. Can you remember Mr. Spock in Star Trek...going into that funny machine and getting 'transported' to some planet (into the unknown)? As soon as the students come into school it's the same thing – a completely new reality, made up of unusual characters they're not used to, a different language they cannot understand, an exacting ecology they just cannot cope with – and when it gets too hot for them, than it's trouble!

*At the social work office:* At 14:30 I'm back at the social work office with my *Service Area Leader* hat on - a fancy title for a coordinating role I have. I see to some work there, meet people, meet staff and than it's a rush (yet again!) on one or two days a week to University, zooming into the lecture room – never late, but never early. One or two students always seem to have something to say – it must be my aftershave! Lectures done, it's back to the social work office. By this time I'm knackered, but I still have to go back to the office. Occasionally, I get called in by the *Project Coordinator* on the 'Creating Inclusive Schools Research Project' – a little bit of income does me fine, helps me sort out



my own *Uni* fees. It's an action research project that a group of us are working on with schools all over Malta. At 19:00 I call it a day, that is, when there's no *Parent's Support Group Meeting* happening. This is a group I have known for ages, must have been 14 odd years. We have spoken about every disability issue under the sun. What pains me most is the intolerance of this group towards each other – they hit at each others hearts. I'm an adviser but it feels more like a mediator role that I have! Meetings of this group run till late, really late. I leave the office, rush off home where it's a couple of hours of father's time.

*At home:* When the kids are over and done with, dinner is ended, than, it's into the office at home for a couple of *EdD* hours. Strange thing this office, I'm never there when the sun is shining! Just some time for small talk with my 'significant other' and I'm sleeping like a baby. I'm bushed!

# CHAPTER 1

## **Introduction: Taking The Field**

*This reality is brought to the school by these pupils who are 'camouflaged' in uniforms, time-keeping and school structures (Haralambos & Holborn 1991).*

Independent Living means that we demand the same choices and control in our everyday lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours, work in jobs that are in line with our education and interests, and start families of our own. Since we are the best experts on our needs, we need to show the solutions we want, need to be in charge of our lives, think and speak for ourselves - just as everybody else. To this end we must support and learn from each other, organize ourselves and work for political changes that lead to the legal protection of our human and civil rights. As long as we regard our disabilities as tragedies, we will be pitied. As long as we feel ashamed of who we are, our lives will be regarded as useless. As long as we remain silent, we will be told by others what to do.

(Adolf Ratzka, 2003

<http://www.independentliving.org/>).

Accessed 8/7/2004

## 1.1 INTRODUCTION

We tell stories about our life and our 'self', or rather our 'selves', as a sort of reflective interpretative device, with a view to understanding who and what we are and the things that happen to us. And yet, as Maroula Joannou (1995: 32) points out: 'although the self may only exist as a story that can be told about the self, what is told about the self is not always the same story, and much will depend on how it is told and by whom'. In any case, 'self' is a contested and controversial term. When we talk about our self, are we referring to our public, or private, or personal, or professional, or spiritual possible, or familial, or whatever, self?.... Is it ever to present a comprehensive account? (Goodson and Sikes 2001, p.41).

The title says it all 'Reading stories of inclusion: Engaging with different perspectives towards an agenda for inclusion'. I'm going to use this work to read the stories that I am immersed in day in, day out.

It is a reflective piece of work that applies first and foremost to 'me' and my context. The *EdD University of Sheffield* 'student booklet' refers to the professional doctorate as being designed to contribute in developing professionals that want to research their own field and context. In this study I fluctuate from reading "inclusion" as an isolated notion to speaking about "inclusion" in a focused applied concept in education, a contestable idiom seasoned with a mass of 'currents and beliefs' (Clough and Corbett 2000). There are two important annotations I need to make at this point.

- Firstly, 'inclusive education' is turning out to be a cliché – a politically correct term that is used by politicians in their speeches and for policy-makers to silence all woes. Service providers cover the tracks that often lead to a different direction than that of social "inclusion" (Clough and Corbett 2000). We really need to assess in what way the stories of children can expose issues of "inclusion" and what are the practices that permit "inclusion". I will be exploring whether narratives make a valid contribution towards the understanding of this agenda.
- Secondly, "inclusion" is a more encompassing term within a whole assemblage of events that I am personally and professionally involved in. It will be exciting to surface these debates of the different contexts I am attached to. This term is full to capacity with arguments disputes and contestations (Ballard and McDonald 1999).



## 1.2 LITTLE ISLAND – COMPLEX NATION

Where do I come from? (Sultana and Baldacchino 1994; Camilleri and Callus 2001; Sultana 2001) Malta is an independent republic situated in the heart of the Mediterranean basin with a population counting less than half a million. It consists of a small group of islands with an area of a little over 300 square kilometres. This archipelago lies 90 km south of Sicily and 300 km to the north of Africa. Very recently we have become members of the *European Union*, which I believe will be a cultural and economic experience that will affect us considerably (Sultana 2001).

[The colonised].... are evidently human beings, in some respects not unlike ourselves. Indeed, while the bulk of them... are uneducated and half-civilised, they have some of the marks of superior people. They wish education. They are cleanly, are hospitable and obliging. They have a pleasing family life... The climate allows them to be indolent, yet they possess many fine branches of industry... with their patriarchal system of living, they have not learned the art of forming a state and are commonly supposed to be destitute of the capacity of governing themselves ... (Salter 1899, p. 2).

For centuries, the strategic location of these islands was of crucial importance for the indigenous islanders who had moved from one protectorate to the next. The Maltese people always seem to have an immeasurable ability to adapt to the different cultures, attitudes and ways of living that they sometimes inherited, occasionally forced from their colonising past (Inguanez 1994).

Undoubtedly, the hundreds of years of colonising powers has left a compelling influence on the Maltese culture and economy even forty years down the line, since Malta achieved its independence from the last domineering command. In more ways than one, the social context

affected our language, lifestyle, and how we construct our mindset. Imperialism has been described as a process of 'forcible expansion'. Malta for over 2000 years was uninterruptedly colonised and since 1800 for the next 164 years a function of the *British Empire*. Malta's post-colonial age started in 1964 and this process is still active and vibrant (Montebello 1999) especially within the educational institutions (Sultana and Baldacchino 1994). In reality, imperialism did not end but decolonialisation was set into motion by "a legacy of connections" (Said 1993, p.3) and a number of social structures still fasten our country to Britain. For example, one cannot but mention the influence in the way the administrative structures are organised in our country; Parliament, the Courts, the Civil Service and Educational Institutions, are amongst the main configurations that still embrace a British model (Sultana and Baldacchino 1994). This historic event of colonisation affected not insignificantly the social fabric of this Country, and these influences are evident also in the educational structures (Chircop 2001) that exist to date. 'Reading the stories I am surrounded with' helped me 'pin my ears back' to this reality.

...the Colonial State's post-1870's adoption of a cultural imperialist strategy, which propelled the expansion and modernisation of the public school system, was paying off. The new schooling system pushed the process of colonisation in the domestic terrain to an unprecedented deepness. It came to inculcate in the new generations, the essential imperialist notion that "The interests of Malta and those of the Empire do not clash, they are identical" (Chircop 2001, p. 136).

### **1.3 THE COMPLEX DISCOURSE OF "INCLUSION": POSITIONING THE DEBATE**

As I move from one 'role' to another, from one duty to the next, the whole notion of "inclusion" drags in innovative qualities that are tricky to process especially in seemingly diverse contexts, be it in teaching at school,



working at university, doing social work, advising parents and disabled activists. I wanted to analyse this important political claim of "inclusion" because of its relationship to a wider discourse that encapsulates all society. "Inclusion" is no isolated debate that takes place solely in academic journals and amongst intellectuals. It is an engagement with a very complex social reality that is somehow affecting the way we think about difference. In other words 'it' sees to a wider interest (Barton 2000). I wanted to do this by;

- Looking at literature and examining these many-sided discourses;
- Allure a process of self-reflection that will lead me to a better understanding of my own attitudes and practices (Goodson and Sikes 2001);
- Analyse the stories that people have to say, people who want to present a transformative agenda (Sacks 1985).

To be able to explore this agenda for "inclusion", I will be organising my work around four research questions (*Figure 1.1*) which will be analysed singularly and in more depth in my data analysis chapters (Chapters 4, 5, 6 and 7).

A research question is the engine which drives the train of enquiry. It should be formulated in such a way that it sets the immediate agenda for research, enables data to be collected and permits analysis to get started; it should also establish the boundaries of space and time within which it will operate (Bassegy 1999, p.67).

It took me almost four years of reading, reflection and debate to come up with a cluster of research questions that are representative of what I was interested in analysing. The complexity that this entailed emanated from the same fact that the questions I needed to ask, I attempted to answer in my everyday place of work. Research and this whole project are entwined in my entire life (Barnes and Mercer 1997). The research

questions started as an investigation into the meanings, functions and utility of "inclusion". It was a complex pursuit into the actions that this expression created. I was fascinated by what this word was doing to the whole system in education, the way it was changing the experience of the whole school community. I sought to develop my understanding in a rigorous way, using my experience as part of my personal development.

- The first question I asked was; 'In what way can the stories of children at the margins expose issues of "inclusion" and exclusion?' I sought to look at what people are saying within a participatory, ethnographic and emancipatory framework. This work required the 'voice' of disabled people (Barnes and Mercer 1997). I worked hard not to make this sound like some other cliché, but I wanted this work to be first and foremost a journal for those people at the margins.
- To engage with these complex dilemmas I wanted to listen to the different viewpoints of the persons I spent most of my time with ranging from disabled and parent activists to teachers and social workers, from students in class to those at university. I have a schedule that takes me through twelve to fourteen hours of work every day, six days a week as I move from one task to another, trying to keep abreast with the different 'hats' I keep changing; 'what are the different perspectives of parent and disabled activists, teachers, university students, labelled students and social workers in relation to presenting a transformative agenda for "inclusion"?'
- A crucial element in my research is the work I do at school. Teaching has been my main job. I wanted to become a teacher because I was such a bad pupil (I believe no fault of my own)! I wanted to enquire 'what practices enable "inclusion"?' because I

am more than ever persuaded and committed to the fact that teaching can be a positive and enjoyable experience.

- A fundamental dilemma was that of finding the most appropriate research method and methodology that will compliment the intricate, personal and convoluted issues surrounding this discourse. Narrative was chosen for this aim – I needed people to tell me their stories. This quandary was epitomised in the question; 'To what extent does narrative research provide an adequate exposition of "inclusion"?'

**FIGURE 1.1: THE RESEARCH QUESTIONS**

EMPHASIS IN CHAPTER	ANALYSIS	RESEARCH QUESTION
4	Analysis of six autobiographies.	In what way can the stories of people at the margins expose issues of "inclusion" and exclusion?
5	Analysis of five semi-fictional stories followed by five homogeneous focus groups that represent the various dimensions I am involved in.	What are the different perspectives of parent and disabled activists, teachers, university students, 'labelled' students and social workers in relation to presenting a transformative agenda for "inclusion"?
6	Analysis of my own ethnographic experiences.	What practices enable "inclusion"?
7	Analysis of narrative research as the primary research method employed in this research.	To what extent does narrative research provide an adequate exposition of "inclusion"?

The following are some 'brass tacks' that have governed and prejudiced my work. I need to demarcate them before I go any further:

- This work is situated within a particular context and time (Sultana 2001). The local scene has a specific definition of the disability discourse, activism and interpretation of the social constructions.
- Although my experience in the "inclusion" and exclusion debate brings me in contact with diverse forms of social exclusion, I will still be vigorously drawing from the debate that surrounds disability theory (Barton and Oliver 1997; Corker and French 1999).



- There are a number of elements that are very 'culturally particular', amongst which, the involvement of the Catholic Church in every aspect of the social, educational and economical aspects, the strong, pronounced and overriding parent activism, the negligible involvement of disabled activists (Brown 1999; Camilleri and Callus 2001) and the strong influence of our colonising past, even forty years after gaining independence from the British Empire (Sultana and Baldacchino 1994).

Inclusive education can be analysed within a number of varied frameworks, the cultural, the historical, the political and the social (Armstrong 1999). "Inclusion" is an elaborate interaction that is taking place within the social structure and policy enactment (Fulcher 1999). This *Thesis* will attempt to interpret this combination of issues and decipher emerging problems contained in this complex intermix of "inclusion" discourses.

"Inclusion" even in Malta is a contemporary debate in education that raises a great deal of discussion and argumentation but regrettably remains a dispassionate topic, with shallow exchanges. A sociologist I was speaking to some time back explained how policy-makers/politicians and parents are on two opposite polarities. He insisted in saying that the region where the school I work at is located, still lacks the "cultural infrastructure" to accommodate a broad understanding of "inclusion". On one hand policy-makers and politicians petition for a different type of learning, the removal of 11+ exams and the eradication of streaming. On the other hand, all provisions and structures favour exclusion (Ballard and McDonald 1999; Thomas and Loxely 2001).

The educational experience of the children in the urbanised location I teach at reproduces a social experience, which many a times is "robbed of educational worth" (Chircop 1994, p.407). Members of the school were unanimous that at times struggling to achieve an inclusive school community is no easy task. They held that their school could play an important part in the construction of a broad-minded and liberal society. Nevertheless, lack of resources in this region intermingles with a school community wrapped in low morale. A significant contradiction is that it did turn out that schools had the exclusive endeavour of representing standards and configurations that are there to enthral the bureaucrats and academics (Giroux 1999; Giordmaina 2001).

Education in Malta in recent history, has attempted to focus on standards (Sultana 1994). This current has seeped through most state, private and independent schools. Fundamentally, "inclusion" addresses a search for inducing equality (Slee 1993) and individualised programs suited to the particular needs of students. Assessment, appraisal and evaluative systems embody this standards-based movement in schools. Such a lobby contributes to this polarisation. Contested practices continue to take place in all schools, and students and their parents continue to be affected, sometimes profoundly by the interpretation of the educational needs of academics and bureaucrats (Chircop 1994).

The discourse of inclusive education has its own particular characteristics and has been hijacked by concerns for quality and 'achievement'. Education reflects the struggle of a community of citizens. "Inclusion" is one vital factor that brings this conflict at the forefront based on the principle of social integrity. The following are my own personal engagements in the varied contexts I am absorbed in;

- I teach in a boys' secondary school and so I can listen to what students have to say (Ainscow 2002; Azzopardi 2003).
- I teach prospective teachers at university and so I can see tomorrow's schools happening (Bartolo *et al* 2002).
- I work in disability social work, so I have a clear understanding of the struggles that families having member/s with a disability have to face. There are two important texts that have informed my writing and thinking in this area; *Social Work – Disabled People And Disabling Environments* edited by Mike Oliver (1991) and *Social Work With Disabled People* co-authored by Michael Oliver and Bop Sapey (1999). These two texts have been crucial in my understanding of disability issues and service delivery in my role as a professional social worker. The analysis of this text is contained within a social model framework debate.
- I provide consultancy to disabled and parent activists in a support and self-advocacy group. I can sense the anxieties they have to face day in day out (Azzopardi 2000; Goodley 2000; Read 2000).

#### 1.4 MAKING SENSE OF THE “INCLUSION” AGENDA

The Cottonera district is caught in a degenerate and viscous circle... Uneducated couples (legally married or otherwise), generally living in sub-standard conditions, bear children with little or no possibility of ever being responsible or productive citizens. In all probability, each new generation is more numerous and culturally worse than its preceding one. Is there a way of breaking this viciousness and degeneration, thus pledging the right of socially disadvantaged children to the future? (Montebello 1999, p.1).

The essence of inclusive education is the ability to respond to diversity. It is a process whereby children are given a voice (Dunn 2001; Moore 2001).

The *National Minimum Curriculum* (Ministry of Education 1999) and other



reforms at State level have been responsible for the restructuring in the education system conditioned by a competitive stance (Armstrong 1999). "inclusion" needs to find its position primarily within this trajectory. Children labelled as having 'special needs' rarely get to know the children in their neighbourhood because the school experience is still not conducive enough to embrace such diversity (Rioux 1999). There is also a big debate on what is considered to be diverse within a locality that feels, or is made to feel different in so many ways, to the rest of the *Island*. Knowing who lives in the neighbourhood makes it possible to develop alliances that extend beyond the classroom experiences. The real cure for educational troubles is the rightful interpretation of community goals (Giordmaina 2001).

Any minority group in a society is distinguished by its values and social experiences (Haralambos and Holborn 1991; Potts 1998). "Values are influenced by contextual factors" (Corbett 1998, p.40).

... this process of "inclusion" and the implementation of policies directed at reducing inequalities arising from students' culture, race, gender, disability or level of attainment (Potts 1998, p. 25).

"Inclusion" cannot remain a neutral and an apolitical discourse. It is an event relating to a social experience (Camilleri 1999). Amongst the various factors that contribute to an inclusive school are the roles that each member in the school community plays. Role distinction is imperative in establishing a considerate and responsive community (Reezigt and Pijl 1998). A vibrant school community is one that is constantly on the move where the deep-seated goal is to reach out to all students equally, empowering them with the necessary skills they will need for their future. Students fundamentally need to be able to work in a diverse community, which is respectful of difference. A real world

experience, which draws from the communal context they come from, is the most natural, effective and long-lasting way for children to learn.

Inclusive education speaks to all those involved. It is not an isolated experience. It is an educational pattern that moves from being disablist to contributing to the development of the individual holistically and comprehensively. These complex educational and social patterns are experienced in schools and their communities (Corbett and Slee 2000, p.143).

It is essential that we are careful not to turn inclusive education into another "bureaucratic discourse" (Corbett and Slee 2000). School in itself can be an exclusionary experience (Clough and Barton 1995; Ainscow, Booth and Dyson 1999). We need to reflect relentlessly to ensure that we acknowledge the fact that school culture is still selective, exclusionary, credential-oriented and standards-based (Ainscow 1999; Slee 2000).

### **1.5 SCHOOLS WITHIN A VISION**

Schools as presented in the new *National Minimum Curriculum* (Ministry of Education 1999) have to struggle to be the decisive players in developing an egalitarian society (Giordmaina 2001). Schools need to be striving towards responsibilities beyond the education and qualifications of their students (Giordmaina 2001). In such regions like Cottonera, educational institutions are beginning to overspill to the broader needs of the community. Educationalists need to address the imbalances within such regions. "Inclusion", teaches us this humanity, the need to make our schools a reality that is applicable to all.

Inclusive education is really a process of people inquiring into their own context to see how it can be developed and it is a process of growth. It is a social process and it engages people in making sense of their experience and helping one another to question their experience and

their context to see how things can be moved forward (Mel Ainscow, interviewed 26 October 1998, cited in Corbett and Slee 2000, p.136).

Inclusive schooling incorporates a political dialogue (Corbett and Slee 1999). This chase for standards cannot be challenged before the principles of emancipation, respect and tolerance are primed.

All compulsory state schooling takes place within a broadly common statutory context... What may be noticeably different are the additional requirements and practices, which must be managed within the schools in, order to meet a wide spectrum of need within a framework of rights. However, there may be differences not so much in structure as in culture of practice, differences which have important implications for managing a truly inclusive system (Clough 1998, p.2).

What is now one of the most socially deprived regions in this *Island*, was a couple of hundred years ago the hub of Maltese economy, culture and leisure (Boswell 1994). *Cottonera*, has the highest criminal records (Sultana and Baldacchino 1994) and daunting social deprivation. Hashweh and Njoum (2001) describe education in *Palestine* (which I will transpose to this region) as being uni-dimensional, top-down and centralised system having unmotivated students, an inappropriate curriculum, managed largely through a teacher-centred pedagogy. To compound all this, there are inadequate physical structures. In other words, this system is at a *status quo*. In these last years, I have been closely drawn in this region through my work as a teacher in an Area Secondary School<sup>1</sup>. Although Malta, compared to most European countries is distinctly minuscule in

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<sup>1</sup> The three primary schools in this region 'feed' the school I work at with students who do not manage to make it to *Junior Lyceums* (grammar oriented schooling). Most of the students are de-motivated, come from working class backgrounds and are more interested in finding a job than in receiving formal education.



population, demography and political influence, internally there still exists a contextual variation between several and diverse interests. I have utilised my professional and personal relationships with disabled and parent activists, teachers, university students, labelled students and social workers to inform my work. This region in the south of Malta which, is the mainstay of my research project is particular in its social, political, economic and inclusive dimensions (Boswell 1994; Riddell, Wilkinson and Baron 1998). I have worked here for these last eight years.

Where the society is highly vulnerable... people with additional needs are having to share limited resources with others who also see themselves in need. The context will determine the response.... simple societies can often respond with more humanity to their most vulnerable members... Perhaps they are composed of more people who can offer time, that most valuable commodity in short supply in advanced cultures (Corbett 1998, p. 3).

There are a number of decisive factors that contributed directly to my choice of topic:

- My personal involvement in what I do. I am 'lucky' enough to be involved directly in all of the contexts I am engaging with in my research.
- I have analysed, documented, reflected and betrothed this topic repeatedly in my professional come personal experiences.
- I have amassed a great deal of ideas and reflections that emanated from my numerous areas of practice.
- In a way, I have followed my premonitions and allowed the research to take its own course.

I have never found it a problem to go back to the 'drawing board' and allow my 'self' to read into what is happening at that specific point in

time. The relation between students and the school institution has always been a curious and at times ambiguous notion. In this *Thesis*, I will be looking at this social veracity in a focused and reflective study.

"Inclusion", a philosophy that brings students, families, educators, and community members together to create schools and other social institutions based on acceptance, belonging, and community (Bloom, Permuter, and Burrell, 1999). "Inclusion" seeks to establish collaborative, supportive, and nurturing communities of learners that are based on giving *all students* the services and accommodations they need to learn, as well as respecting and learning from each other's individual differences (Salend 1990, p. 5).

## 1.6 MAKING COMMUNITY

As a society, we construct countless social structures such as friendships, marriage, cult and ritual to affirm ourselves as unique members of the community. At the same time, groups are recognising each other and search for a collective identity. The value of schooling is in the capacity to prepare students for a life that is gripped by continuous decision-making situations (Ministry of Education 1999). School in principle is also there to help students fabricate strategic models and to cultivate a social commitment.

We live in a society that is producing different interpretations to gestures and words, relational dynamics and social roles marking human behaviour as a subjective reality in form and content (Chircop 1994). We need to read what students are telling us even through the complex symbols that constitute their reality.

The experience of education has in these last years taken a new twist. Education is more than ever market and industry-driven. Our schools are introducing subjects and themes that are more in the interest of industry

and other standards created through globalisation and the minimisation of the 'individual validity'. Unfortunately, this research will show that our students are still finding it problematic to identify themselves with school (Sultana 2001). The stories of the children at the margins expose this terrifying reality within a social constructed debate.

## 1.7 UNDERSTANDING THE CONTEXT

The diversity that prevails in the Mediterranean is also apparent if we had to focus on the education sector... An obvious one [difference] concerns the divergent educational histories of each country, where present structures and practices are a complex reflection of colonial influence, and accommodations that have been made to that in response to political, economic and cultural pressures (Sultana 2001, p.11).

Culture and interpretation is at the foundation of understanding the symbols that the school institution is engrossed in (Ritzer 1996). The educational structures have always been thought of as developing a model of adult behaviour. The centrality of the notion of culture depends on its rapport with understanding meaning, positionality and the relationship that develops between power and ideology (Allies 1999; Goodson and Sikes 2001).

Probably, the most dominant symbol in our schools is that related to the *religious practices* that are imposed on our students. Said (1993) says that the components of a powerful imperial creed are; a sense of mission, historical conditions and evangelical passion. Locally, we exist within a society where Catholicism is a predominant value and a political force (Sultan 2001). The ecclesiastical dominion has considerable power in all educational institutions. For instance, the school I teach at has its own



priest<sup>2</sup>, a role regulated by the structures of the local Church (Niekerk 2000). In an informal discussion, the former Head of School said;

Fr. Lawrence is an important component in our school because students believe in him, he knows the community and can give us useful information on the situation of students outside of school.

The ethos, or rather the range of values and beliefs, which identify the atmosphere in a school, is central to the understanding of school life. The priority for the Church is that education in our school is driven by explicit, articulated and implemented concepts of a specifically Catholic ethos. Religion makes part of this intellectual infrastructure in contemporary educational experiences. It seems that for the institution, God cannot exist away from an organised structure, called religion (Nierkerk 2000).

It is a Catholic ethos, built into the faith of God Our Father and loving others. It is about respecting others and sharing and respecting God's will and all those things... These are not set apart in a Catholic school they are brought into your curriculum areas.... in a Catholic school it is different, it permeates the whole day – in the teaching and the discipline Donnelly 1999, p.5).

Another significant representation in our school is *language* (Haralambos and Holborn 1991). Malta is multilingual and multicultural, a situation which has evolved from our past experiences with an assortment of colonisers. Although we have developed our own language which has a semantic base and Anglo-Saxon and Italian influences we still use English very much (Sciriha 1994). In our constitution, both English and Maltese are our official languages - an inheritance from the British Empire.

English serves as cultural capital (cf. Bourdieu) and is the gateway to economic prosperity...

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<sup>2</sup> There are spiritual directors in all state, church and private schools. A spiritual director can only be a priest from the Catholic Church.

earlier, the idea was that English would be the path to economic and technical success... Language policy and educational policy have been tinkered with constantly... the goal now seems to be to create a cultural elite... (James 1999, p.1).

English as a language still retains an important sociological reality in Malta. The use, lack of use or abuse of English in our school represents privileged meanings. At 'my' school we still get assembly time in English once a week, most texts are in English and more than half of the lessons are done predominantly in English. Important school documentation, official correspondence and memoranda, are all communicated using English which represents excellence, significance and thus, "Symbolic control is related through the education institution that specialises in discursive codes" (James 1999, p. 2).

The Head of School works towards establishing and maintaining a set of beliefs that the staff (have to) share. The onus is not on understanding the reality that these students came from, their culture and experiences, but what the people 'higher up the ranks' think is best for them, the *hierarchy*.

We have no students' council. Well we had it for some months but we didn't have any power. All the decisions were still taken by the Head (*John, Student*)<sup>3</sup>.

The structures, processes and events at school are all organised in a way that demonstrate the differentiation between roles and the importance of recognising one's position within the structure. The signs we are surrounded with in a school, communicate ground rules for an apposite behavioural code (Bernstein 1990). Subsequently, school is a community

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<sup>3</sup> A quote that ends with a name and nomenclature in *italics*, for e.g. (*John, School Student*) would be referring to a participants name in one of my 'focus groups' which in this case would have been 'school students'.

that shares a common identity and notions that are epitomised in symbols (Halsey et al 1997).

## 1.8 THE THESIS EPISODES

This is the way my research will develop critically, politically and methodologically; In Chapter 1, I will analyse my understanding on the whole complex issue of "inclusion" and localise this debate. I will also present the main argumentation that this *Thesis* will be dealing with and bring in and initiate the debate on the complex research questions I have identified. Chapter 2, will reiterate the research questions within the literature review and will convey the social model of disability as being in the foreground of my theoretical set-up (this issue will be dealt with in Chapter 6 as well). Conversely, Chapter 3 will engage with the methodology/method debate. I will examine the importance of having life stories, which is my chosen narrative style (Goodley et al 2004) because it brings different 'voices' into contention. Chapter 4, is one of a series of four chapters on data analysis. I am opting to split the data analysis into four chapters for the following reasons; firstly the four chapters on analysis will be focusing in particular but not exclusively, on responding to a research question. Secondly, the data analysis seeks to define the agenda for "inclusion" so that an improved understanding of various topics and positions relating to the struggle for an inclusive society can be achieved (Barton and Armstrong 1999). Finally, the data collated was so voluminous that I had to find a way of presenting as much of it as possible in the restricted space I had. Chapter 4 will be analysing the six autobiographies within the scenario of the first research question. They are the stories of *Dean, Cynthia, Conrad, Adam, Jane and Sandra*.

Then again, Chapter 5 will analyse the debates that took place within the six focus groups that represent the six areas I am professionally entangled



in. Five semi-fictious stories were used to inform this debate. The focus groups were made up of;

- A group of teachers who work in the same school I teach at;
- Social workers, I work with in my part-time employment;
- Disabled activists, I have come to know from my involvement in the disability field;
- Parent activists, I support through my advisory role in a particular family support group;
- Students with a diversity 'label' I teach;
- A sample of university students that come from the different courses I teach in the area of disability studies and inclusive education.

Chapter 6, is the third chapter on data analysis, which will centre on my own positioning in this research. The third research question that I will be dealing with will be asking, 'what practices enable "inclusion"?' It is a Chapter about my own ethnographic reflections, the thinking that surrounds the social model and how it can be brought into life, the search for 'capacity building' rather than 'dependency thinking' and the move towards interdependence rather than independence or dependence (Goodley 2000). This chapter will include both individual and collective debates. This is basically an ethnography that will take us to the different contexts I am engaged with, be it social work, university, school, attending parents groups and disabled people's meetings.

Chapter 7 will be the fourth and final chapter on data analysis. This is the chapter that will tie the ends together. It is a chapter that will take us back to the literature review and analysis on the narrative style of doing research will ensue. This *Thesis* is also about discussing the research methods employed that may be quite popular in some social science spheres but have still to gain a ground within the local scene. This Chapter will include a great deal of self-reflection and will wrap up the

major contestations were debated. Finally, Chapter 8 will reinstate once again the values that encircle my research, the need to look at this topic in a multitude of dimensions and the thinking and reflections that have presided over this intriguing but knotty piece of work.

## 1.9 CONCLUDING THE INTRODUCTION

It is worth emphasising that it is teachers and trainers who are expected to deliver on educational aspirations. Educational research is a service industry (Desforges 2000, p. 3).

In social sciences, there is an on-going commitment to constantly search for knowledge about some aspect of social reality and the linked behaviours (Robson 1993). The primary purpose of this *Thesis* is to look closely at the complex discourses that make up the agenda of "inclusion" by drawing in the protagonists (who are the people at the margins) to say their own stories. This work is also about 'me' and my own reflections of uncertainties that seem to devour this debate, the practices that enable "inclusion" and the extent that a particular method/ology (Goodley *et al* 2004) affects or not the way "inclusion" is uncovered.

[We] set down the meaning particular social actions have for the actors whose actions they are... stating as explicitly as we can manage, what the knowledge thus attained demonstrates about the society in which it is found... Our double task is to uncover the conceptual structures that inform our subject's acts, the "said" of social discourse, and to construct a system of analysis... [which reveals] what is generic to those structures (Geertz 1973, p. 27).

# CHAPTER 2

## Literature Review And Theoretical Snaps

*And this is where I think I have benefited from, psychology in prison, because I've watched people, because the people are watching me... And you get a much better response from a person if you allow them to be themselves (Jepson and Parker 2002, p. 82).*



*My physical impairment is not something I would choose. I would rather be able to walk than have to use a wheelchair. I would rather the spasm in my legs didn't wake me up at six o'clock in the morning. I would rather I didn't have to worry about incontinence when I share a bed with someone. I would rather I didn't have the burning sensation in my legs which is there every waking moment of my day and night. Yet I love how I am and the life I lead. I like what I see when I look in the mirror. I value so much the contact I have with other disabled people and with non-disabled allies – in our struggle against – prejudice and discrimination. (Jenny Morris The Fall in Keith's 1994 Musnt' Grumble, p.170-1).*

## 2.1 INTRODUCTION

Epistemology is only possible if the protagonists in this social experience are understood and given a rightful interpretation of the social constructions that are created around their dilemmas (Ritzer 1996). The logic used for this work is that of ethnographically endeavouring to provide meaningful prescriptions of what is happening in the social episodes of the informants (Robson 1993; Denzin and Lincoln 1998). I have attempted to explore, find out and understand "meanings-and-symbols" that surround the institutions that I am closely involved with. It is only by deepening my own understanding of the cultural occurrence I am absorbed in that I managed to locate, interpret and understand better the reasons for certain actions (Lawenstein-Damico 1999).

Naturally, it is an accepted fact that research, as in all human behaviour is subjective and the process of interpreting the outcomes is particular to my own interpretation of events (Denzin 1998). Rather than considering the result of any course of events as an encoded result of some set of casual factors operating on it, the outcome is instead an emergent and

contingent product, one which will not follow the same course in other comparable situations (Robson 1993).

Schooling in many ways is engaged in both a visible and an invisible pedagogy. Bernstein (1990) in *The Structuring Of Pedagogical Discourse* makes it abundantly clear that schooling need to engage with adapting their pedagogy to meet the needs of students – in the absence of which, schools and the education system will keep failing.

"I don't like school. I don't need to learn German and Maths. I want to have more time doing crafts at the workshop". The teacher replied, "But you can become a good craftsman if you learn maths as well". The student replied, "My father doesn't know any school and he has a lot of people that ask him for work" (*Peter, Labelled Student*).

It is a language that we professionals cannot comprehend (Ritzer 1996). Students, socialise, gamble and achieve status as adults by their ability to think in terms of exclusion – for us educators this does not surface in our pedagogical delivery, but rather it becomes a point of divergence (Sultana and Baldacchino 1994). The systems of meaning are very important for Geertz (1973), and how all this relates to the culture and to potential changes.

The evidence that disabled people experience severe economic deprivation and social disadvantage is overwhelming and no longer in dispute, whether it be from the Government's own commissioned research, from research institutes, academics or disabled people themselves. For example, after over a century of state-provided education disabled children and young people are still not entitled to the same kind of schooling as their able-bodied peers and nor do they leave with equivalent qualifications (Metzer, Smyth and Robus 1989). The majority of British schools, colleges and universities remain

unprepared to accommodate disabled students within a mainstream setting. Thus, many young disabled people have little choice but to accept a particular form of segregated 'special' education which is both educationally and socially divisive... (Oliver 1996, p.64).

The concept of "inclusion" needs to be viewed as a process located within the cultures, policies and practices of a whole school and community. Hence, the focus that this work has been endowed with on an assortment of contexts; school, family, disabled and parent activists meetings, lectures with university students and the social work service.

The diverse experience of student is a rich resource that can augment the skills that one already has (Salend 2001). No school exists in a cultural vacuum and my own reflections on the various processes I am involved in, contributed in helping me to recover and re-discover some of the complex dynamics that are taking place within the school community (Bartolo *et al* 2002). In this chapter, my major reflections focused on notions of identity and belonging. There was also consideration for the influence of changing local, national and global politics and how the culture collision I was experiencing in the school I work at (positioned in a distinct region of Malta) was creating barriers to "inclusion".

Any complex activity is unintelligible until we understand what lies beneath. The whole issue of identity in this work governs these same principles.

Schools are complex and social places and their cultures are not easily perceived even by those working in them. No culture is static or monolithic, but rather fluid and experienced differently by different people depending on their perspectives and understandings. Schools necessarily exist beyond their playgrounds and



gates. Students and staff do not attend school in a vacuum. They bring with them the rest of their lives: their families and homes, friendships, and previous educational experiences. The local community and local and national politics also help to shape the cultures of a school. How people identify themselves, and how they are identified by others, contributes to the culture and is determined by the culture (Black-Hawkins 1999, p.3).

This literature review will be analysed on two main counts: First of all, I will be presenting the main issues contended with in this *Thesis* and arguing within a perspective of written material by other authors. The main topics in question are varied;

- The stories of children at the margins as being used to promote critical debates about "inclusion".
- My own direct personal and professional experience with teachers, social workers, university students, labelled students, disabled and parent activists.
- Designing a transformative agenda for "inclusion" that will enable positive practices.
- Analysing the use of narrative as a research platform that will expose the "issues".

Secondly, I will be reviewing various key texts that have informed this work directly or implicitly. This research is about listening to the voices rather than muffling the echoes of students. It sounds as if we are creating a picture of what this debate is all about. It is about harmonising and establishing the right environment where students can talk their heart and readily be listened to (Campbell and Oliver 1996; Ainscow 1999; Bartolo et al 2002). We need to find the right manner of listening to people. When engaging to any group whose voice has seldom been heard, there is a need to make certain that the listening approaches used are appropriate

(Goodley and Moore 2002). Students need to have the opportunity to share the aggravation that the system is inflicting on them (Potts 2000). It is a shared perception that what we think is an inclusionary process ends up being an oppressive experience and exercise for the protagonists. An interesting chapter in a book by Clough and Corbett (2000), written by Julie Allan, makes a wisecrack by using "inconclusive education" as opposed to "inclusive education". She interestingly enough makes a debate on the fact that "inclusion" is an on-going, eternal process. This in itself can have its positives, but it is also a situation, which brings to my mind circumstances where "inclusion" has a preface but no end to it. It very often turns out to be a philosophical debate rather than a strategic framework. It is described by Allan as "a state of unsettled uncertainty" (p.42). It is providential to be able to converge in my professional career with a multitude of dimensions that are able to provide me with multifaceted understanding of this debate. The endeavour of this literature review is to analyse selected pieces of work on the varied issues of inclusive education. It is also a collection of material evolving from my own rendezvous with the theme. My idea of engaging with this topic was to scrutinise my ideas against a plethora of personal encounters as an outsider to the field of disability. This includes policy-making, teaching, social work, university-lecturing and consultation. The engagement with literature review has been my own personal journey in search of the research questions. It was a way of funnelling my thinking to focus on what I wanted to explore.

All these experiences compounded with the realms of literature that have dug into the "inclusion" process have given me a widened knowledge.

... the literature is one of the sources of preconception that we bring to the design of the study and to the analysis of the data. Clearly, the literature offers a range of frameworks that

affect the way we see data (Arksey and Knight 1999, p.154).

This literature review will attempt to examine how stories of "inclusion" can be engaged within different perspectives towards this agenda, by examining a selection of the existing data that I have betrothed. The literature is made up of regular almost habitual surfing of the *World Wide Web* and material collated from a variety of texts during these six years of post-graduate study.

## **2.2 UNDERSTANDING THE CONTEXT – MAKING SENSE OF OUR PAST**

Attitudes towards disabled persons<sup>4</sup> are deeply rooted in historical and social contexts. These accounts and attitudes demonstrate the durability of the perception of disabled people as a social threat requiring containment (Davies 1997). Winzer (1997) in her contribution to this anthology says, "The treatment the members of any society extend to the exceptional persons in their midst cannot be known or evaluated within a vacuum" (p.75). A number of writers have contributed to my understanding of the historical context that embodies the inclusive research themes. Sultana (2001) and his edited text, *Yesterday's Schools – Readings In Maltese Educational History* gives an overview of the main contentious issues in educational history. It is a book that outlines the whole experience of education. The chapter by Bartolo in this book traces the development of policy and services for disabled students in the education sector.

Though persons with disability have always been part of humanity, their full participation in the educational system is a recent phenomenon.

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<sup>4</sup> I have opted to use the phrase 'disabled person' rather than 'persons with disability' because the former is in line with the thinking expressed by the *Disability Movement* in the UK whereby the identity of a disabled person lies also within his/her 'disability'. The politicising of this term has meant that the use of this term is in line with the struggle.



The history of educational provisions for children with disability is closely tied to the concept of the right of each child for education and development of his or her potential (p.203).

My own Masters dissertation, *Understanding Disability Politics In Malta: New Directions Explored* (2000), also has a contribution on the development of disability and disability politics, activism and education in Malta;

History can be a learning experience that can be used to supply, provide and equip us with data and to hopefully increase our ability to anticipate possible future outcomes. For centuries disabled people have been a group within society that were continually oppressed and repressed (Oliver 1990a; Barnes 1997; Davis 1997) (p. 36).

Barton (2001) in a contribution in his own edited text, *Disability, Politics And The Struggle For Change* declares that it would be improper not to capture the past, which has the added value of helping us map out the present and future struggles. Camilleri and Callus (2001) in this same anthology position disability within a historical framework and interpret today's reality as a gradual move in the construction of disability debate, policy, services and education but now without the pain and conflicts that will ensue.

## **2.3 "INCLUSION" SOUNDS RIGHT**

### **2.3.1 INTRODUCTION**

I have searched for years and done all the reading I can when it comes to "inclusion". There are two books that have contributed significantly to the development of my theoretical platform; Ballard's edited text *Inclusive Education – International Voices On Disability And Justice* (1999). The authors of this book analyse their debates within an emancipatory standpoint. There are concerns that stem from insider and parent

perspectives. Secondly, *Theories of Inclusive Education-A Student's Guide* by Clough and Corbett (2000) which is an extraordinary forthcoming piece of work. They present their own personal journey. This is a reflexive dimension they give to their work, a key methodological principle that carries through my own work. This text passes on a message that theorising is not an exclusivity shared by just the 'club people' but an opportunity for all to contribute towards augmentation of the core issues.

### **2.3.2 DOING "INCLUSION"**

Texts like *Understanding The Development of Inclusive Schools* by Mel Ainscow (1999), *Making Special Education Inclusive* by Farrell and Ainscow (2002), *Towards Inclusive Schools?* edited by Clark, Dyson and Millward (1995) and *Inclusive Education – Diverse Perspectives* of Nind et al (2003) draw upon the way that we need to do "inclusion". They move from a theoretical debate to a pragmatic and applied dimension of "inclusion". "Inclusion" is no longer a philosophical discourse packed with tensions but an empirical 'hands-on, do-it-yourself' stratagem. It is a skill and proficiency. In more ways than one it is a search for effectiveness in school practices. Other texts like Armstrong, Armstrong and Barton's text, *Inclusive Education – Policy, Contexts And Comparative Perspectives* brings into the scene the philosophical and notional debate that we need to engage with. What is fascinating about this text is the diverse 'inclusionary' notions that converge some very interesting and overlapping ideas even though the contributions come from all over the western hemisphere. This edited text may find its converging point in the last chapter by Corbett and Slee.

Inclusive education speaks to all students and it assumes a different epistemic stance on a range of issues counter to traditional educational responses to what are typically described as 'problems' (p.143).

I also enjoyed and found captivating the edited book by Michelle Moore (2000), *Insider Perspectives On Inclusion – Raising Voices, Raising Issues*.

Apart from assembling an assortment of themes related to the discourse of "inclusion", maybe a very under-estimated but as important theory emerges - that of human rights and the relationship between society and the citizen (Oliver 1996; Ballard and McDonald 1998; Marks 1999).

Citizenship is the basis of what our schools are about and the characterisation of citizen-society relationship is the cornerstone of our educational process.

### **2.3.3 POLICY AND PRACTICE**

I have also trailed a number of texts that have scrutinised policy development, which is seen by many, as the structure that encapsulates the formulation of change in strategy and practices in schools. Texts like *Managing Inclusive Education – From Policy to Practice* (Clough 1998), *Difference And Difficulty – Insights, Issues And Dilemmas* (Barton and Armstrong 1999) and Fulcher's, *Disabling Policies – A Comparative Approach To Education Policy And Disability* all present a very comprehensive debate and dispute a central notion in "the politics of making policy" (p.ix). If I had to look at what is happening in the Maltese scenario, I would say that one of our weaknesses is that we lack open debate, research prospects and as a result policy development. Fulcher accurately reveals that "policy is practice" (Armstrong in Barton and Armstrong 1999, p. 81). Policy is regarded as a strategy of action that is pursued by the individual, the community or the state (Oliver 2000).

Inclusive education has always featured as being in need of a policy function. It's not like policy is a detached part of reality but a notion that is woven in the practice of systems. Mike Oliver (1990) in *The Politics Of Disablement* speaks about the meaning we give to meanings and how disabled people have been struggling against the polarisation that has



developed in the struggle against normality, charitable attitudes and exclusion. This is a text that debates the complex issues of research within the participatory framework argument. I am referring to Clough and Barton's (1995), *Making Difficulties – Research And The Construction of SEN*. The authors ensue with a case that is basing an argument on the active involvement and vigorous responsibility of the researchers. This they do in a piece of research they are conducting.

The biggest lie that a so-called 'methodology' tells is of the distance between us and our work; hence we elaborate the clinical nature, the sterile cleanliness of the instruments we use (p.3, 4).

#### **2.3.4 VALUES AND VOICES**

The debate on inclusive education and the language of research voices is reflected in these two edited texts. These books have contributed significantly to the development of my thinking. The first is *Articulating With Difficulty – Research Voices In Inclusive Education* edited by Peter Clough and Len Baron (1998). In this volume the core issue is the participation and voice of those directly affected by the "inclusion" process and how this 'voice' flags up key issues on emancipation. The second text I am referring to is one with sole authorship, *Special Educational Needs In The Twentieth Century – A Cultural Analysis* by Corbett (1998). Her key thinking point in this work is that societies, that she refers to as being 'simple societies', tend to respond more humanely to the most vulnerable members as compared to the highly technological and sophisticated communities. It all points towards the issue of value systems – a re-current controversy in this work.

#### **2.3.5 DEFINING (OR 'DEFILING') "INCLUSION"**

It is a very convoluted state of affairs to develop a frame of mind that is coherent with a reality that is continually altering seemingly faster than

one's own thinking. There are moments when this concept of "inclusion" has left me with a great deal of hazy thinking, not allowing me to settle down and captivate the succinct notions. Jenny Corbett in the book edited by Armstrong, Armstrong and Barton (2000) defines "inclusion" in the following way;

I like to present it as metaphor. Whilst integration was the square peg struggling to fit the round holes, "inclusion" is a circle containing many different shapes and sizes, all interrelating with the whole, and with a caption reading, 'Come in. We celebrate difference here. You can be yourself and not struggle to fit in.' I've recently taught of a three-tier model of "inclusion". At the first level, there is surface "inclusion", led by policy and notions of school effectiveness. At the second level, there are structural modifications to the school environment and to the curriculum.... the third level...is that of what I call deep culture, the hidden curriculum of fundamental value systems, rituals and routines, initiations and acceptance which forms the fabric of daily life. It is at this degree of "inclusion" that real quality of life issues reside. This can be an intelligible process whereby students are taught to see themselves as either valued or devalued group members. I feel this depth of "inclusion" is very hard to monitor or even to fully define but I do believe that it forms the most satisfying type of educational "inclusion" (Corbett and Slee 2000, p.140-1).

While it might be assumed that many of the views described above are now acceptable, it is worth remembering that 'attitudes die hard'.

In reviewing the literature on 'community integration' one notes three kinds of attitude in society (Moore 2000; Salend 2001);

- A lack of awareness that there are disabled people in the community;
- Trepidation bordering on hostility to the idea;

- Watchfulness and preparedness to engage with disabled people as consumers, neighbours or as possible friends.

The term "inclusion" entails more than the simple integration of disabled people in mainstream schools and society. It is an idea or even better, an ideal that takes into consideration all the children as a whole and focuses on changes in schools and their systems. There is disturbing evidence that I have gathered in my fieldwork about people being victimised and intense opposition being expressed to the prospect of disabled people moving into a neighbourhood (Barnes and Mercer 2003).

Inclusive education has been debated as well against a negative scenario (Thomas and Loxely 2001; Bayliss 2004).

There is a strand in the argument against inclusive education that goes like this: 'Inclusive education is all very well, and it is engendered by the kindest of motives, but there is a central problem: support for it springs from ideology rather than rational inquiry, and it is untested' (Thomas and Glenny 2002, p.345)

This literature review will rope in a number of elusive disputes that I have chased in this *Thesis*. The literature review has contributed immensely to a miscellany of ideas and to the development of a mind-set when it comes to reading stories of "inclusion". It is a recognition that can be read from afar. The "inclusion" debate I have set out to investigate is a notion rather than a static concept.

### **2.3.6 "INCLUSION" WITHIN A WIDER CONTEXT**

"Inclusion" invokes in this *Thesis* a particular veracity. I am debating this research on a number of fronts and looking at "inclusion" against an agenda which positions me in a range of contexts. "Inclusion" needs to be radical (Oliver 2000). Obviously, this debate has a different meaning to



different people and what I want to analyse in this literature review are the different influences that have betrothed this perspective of looking at education and more than that at life (Clough and Barton 1995; Clough and Barton 1998; Thomas and Loxely 2001). For me "inclusion" is more than just rhetoric, an stirring cliché that raises a lot of interesting debates in the national and more focused agenda (Armstrong, Armstrong and Barton 2000). I have been asking what "inclusion" is; is it a socially acceptable stalling technique? Is it a way of justifying the divergence that this discourse brings? My engagement with these different experiences converge to my interest in disability, making sense of the disability agenda and identifying the contentious debates that surround what students are trying to recount. This is what this *Thesis* is not about;

- Making sense of "inclusion" as informed by the 'school community' regardless of the students;
- Identifying solutions and techniques that will make our students achieve more in subjects like maths and science;
- Seeking solutions for illiteracy and numeracy deficiencies.

### **2.3.7 AN INCLUSIVE RESEARCH PARADIGM**

Barnes and Mercer (1997) have traced the growth of the disability research paradigm. After exploring the effects that previous research has left on the individual informants and on the disability community in general, they go on to analyse the principles of emancipatory research, a concept developed at the end of the 80's and beginning of the 90's. Oliver called for a 'political commitment' in the adoption of an emancipatory type of research. He advocated emancipatory research that finds its realisation in the social model of disability. This framework where research rests is a commitment to politicising disability issues, advocating and effecting change, interpreting social relations and connecting "research and policy initiatives" (p.5). Texts like Oliver's

*Understanding Disability - From Theory To Practice* (1990), is a classic in its genre. Oliver brings in three very important components to reckon with; understanding the social model as evolved after UPIAS (1976), bringing the researcher close to what s/he is researching and personalising and localising the research study within the researcher. Oliver, basically engages with the notion of the individual that forms the collective. The *Fundamental Principles Of Disability* (UPIAS 1976) is a key and fundamental text in this discourse.

... Fundamental principles to which we are both in agreement: disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people (p. 3).

I have referred to a number of other texts when it came to designing my principles for research. The series by *The Disability Press* has played a role in this debate. *Doing Disability Research* by Barnes and Mercer (1997) outlines the notion of emancipator research and the link with the social model. This is a continuation of the arguments and tensions raised by Oliver (1996). These texts have brought me in touch with a new way of thinking and doing research. Actually, one of my research questions focuses on the aspect of research engagement, 'to what extent does narrative research provide an adequate exposition of "inclusion"?'

*Disability Studies: Past, Present, Future* by Barton and Oliver (1997) is an anthology that ponders the issue of the independent researcher, liberatory theory of disability and this text returns to the difficult theme of oppression. Coleridge's (1993), *Disability, Liberation And Development*

provokes a debate on the different realities of disability and perspectives that are very different from what we are used to reading. These are case studies of countries that are struggling to make ends meet on a social-economical and political dimension; Zanzibar, Zimbabwe, India, Jordan and Lebanon. However, these countries have an interesting and fresh-looking experience to contribute. In their own count, Emma Stone (1999), *Disability And Development—Learning From Action And Research On Disability In The Majority World*, analysis in depth some issues that had already been regurgitated a number of times but this time she localises them within an international context. This book in itself is a process of defining 'disability'. A chapter I particularly enjoyed was that of Stubbs which roped in some reflections on the direction and definition she gives to methodology. She outlines the key complexities that the two terms, method and methodology bring to this debate. In her piece she wanted to challenge the readers/researchers into finding an appropriate method of engagement. She interprets research as making sense within a discourse where people change and society develops. There are two other books I want to refer to at this point, that illustrate in depth the issues related to disability research. The first is Campbell and Oliver's (1996) *Disability Politics – Understanding Our Past, Changing Our Future*. This book written by two leading activists and academics in the disability scene maps out the future within a framework of what has and is happening. This book brings in a multitude of themes ranging from activism to the often tense relationship created through research, amongst researchers and between researchers and informants. There are contestations about how the social model fits within a pragmatic day-to-day scenario rather than constructing a debate that leaves it all on the academic backburner. Probably, the most pronounced issue in this text is that about the organisations of disabled people and how grouping has created a social movement that is re-directing disability policy. The



interview in the last chapter by Bamber Postance with Oliver and Campbell brings a flavour to the composite tensions that encapsulate disability activism, research and movement. Her questions externalise a debate that centres on the need for the politicisation of disability. Disabled people need to guide their allies and promote this struggle to an agenda that can overthrow a society navigated by repressive, aggressive and suppressive constructions of this minority. *Disability* by Barnes and Mercer (2003) is one more text that brings to light the controversies that this social construction is attached to. The authors use the social model as a theoretical platform to analyse such important themes as definition, impairment, disabling society and the barriers created by politics and politicisation. Corker and French (1999) in their *Disability Discourse*, have also taken up a very interesting piece of work where they have managed to bring together some renowned and active disability academics and activists. The focus lies in social theory and the making of a disability discourse. Somehow these authors converge the traditional modes of collating data and of designing methodology to a disability minority application. The crucial theme as delineated in the series editor's preface is about a social construction, disability that has seen a massive oppressive experience imposed by a society that highlights the impairment as being the cause and be-all of the disability experience. Society tries to keep shunning away responsibility.

### **2.3.8 DEVELOPING DISABILITY THEORY**

In this work I have also formulated my thinking within a disability theory that was informed primarily by three texts; *Disability Studies Today* edited by Barnes, Oliver and Barton (2002), *The Disability Reader* compiled by Lennard J. Davis (1997) and *The Disability Reader – Social Science Perspectives* collated by Tom Shakespeare (1998). Whilst all three texts are very different in the energy they put into certain issues, there are

common themes and debates flowing from one text to another; non-disabled researchers doing research, critique of the social model, the engagement with the discourse on homogeneity, definitions, nomenclature, politics, sexuality, policy and activism. These books together with others have served the purpose of de-fragmenting my thinking and bringing it all together in organised clusters. Riddell and Watson's (2003) *Disability - Culture And Identity*, is another edited text, which is an assortment of different themes related to the disability constructions. A number of social-policy issues are raised ranging from social justice to identity development, theories that make up media and generational issues, the arts movement and media treatment. A sentence in the introductory chapter sums it all up, "...the oppression of disabled people has rested, in large part, on the imposition of negative and stigmatising cultural identities" (p.15).

Although the field is increasingly interdisciplinary in nature, the emphasis is predominantly a sociological one, as it is our contention that sociological theories and insights, whether intentionally or otherwise, have and can continue to play a crucial role in the development of disability studies. Although the focus is primarily on theoretical innovation and advancement, the arguments presented here have important political and policy implications for both disabled and non-disabled people. (Barnes, Oliver and Barton 2002, p.1-2).

## **2.4 MAKING NARRATIVE**

People with impairments whether they are physical, sensory or 'cognitive' have traditionally been oppressed by psychological research. This oppression is rooted in assumptions that view such impairments as violating individuals' very personhoods.... However, recent developments in research thinking have challenged these individualistic assumptions and, in contrast, unearthed the ways in which people with

impairments are disabled by societies that threaten to exclude them from mainstream activities. Two research approaches can be identified – narrative and discursive approaches to research – that promise much in terms of highlighting the social causes of disability (Goodley 2003, p.1).

We need to keep in perspective that as Goodley (2003) says, people's stories expose their innermost cultural and social accounts. People seem to understand better and describe events better when they are assisted by the narrative. We are all encapsulated in stories and this research will aim at injecting some understanding on the many matters correlated to "inclusion". Goodley (2003) goes on to describe this notion of narrative that leads to 'the celebration of the insider';

While narrative researchers draw upon a variety of epistemological and theoretical positions, all proponents share the view that (some) understandings can be gleaned through turning to those who have in some way been labelled. A turn to narrative is a celebration of the insider, specificity, indexicality and of lay-knowledge. The strengths of narrative accounts are tied into the inherent personal and constructive qualities of accounting for oneself alongside and with others (p.3).

On the other hand we have had criticisms being made on the value of biographies. Various people have spoken about the strange and intricate situation where stories are told but the intention is to create hero worship or a dimension of perception on the person involved that is unreal (Goodley 2003). The first taste of qualitative research came about through the notorious *University of Chicago* when a number of benefactors decided to fund a project which was later to become known as *The Polish Peasant In Europe And America – A Classical Work Of Emigration History* co-authored by William I. Thomas and Florian Znaniecki



(1918-1920). This is a classic in the area of sociological outcomes and analysis. The value of such a text lies in the fact that this is probably the first qualitative research text to have an impact on the social sciences. Thomas and Znaniecki were amongst the first to propose this new methodology.

The essence of this method was in getting the immigrants to tell their own life stories, either by hiring them to do so or by finding documents, especially letters, in which they did (Zaretsky 1996, p.x). Another important reader for me was *The Man Who Mistook His Wife For A Hat And Other Clinical Tales* by Oliver Sacks (1985). This author has written several stories that emanated from a professional autobiography. Moreover he managed to bring to the surface a number of interesting debates and personal reflections that said a lot about the professional dimension and how this could be more in line with the 'patients' (for him) or service users we are engaged with. He speaks about the passions and the galvanisation of people under the threat of being categorised, pigeon-holed and having their personality segmented. *Documents Of Life 2 – An Invitation To A Critical Humanism* (Plummer 2001) is another key text in my research. Plummer advocated for more life stories in research. He argues that life stories are of an astonishing richness in research. He speaks of concise but succinct life stories that merge into 'a larger map of social suffering' (p. 25). Plummer goes on to speak about 'short life stories' that give a wide understanding of that which is brewing in society. Short stories are relatively more common than long ones, and are often... more likely to be edited down into the 'researcher's 'story' (p.25). Two other key texts that have managed to verse my research dimension are Clough's (2002), *Narratives And Fictions In Educational Research* and Goodson and Sikes's (2001), *Life History Research In Educational Settings – Learning From Lives*. The former helped me design the format of my *Thesis*. I wanted my writing

to have the same set-up, where the protagonists become the authors even if the stories and the autobiographies may have taken a particular twist to safeguard the people involved. The other text by Goodson and Sikes debates on the validity of learning from other people's stories. And from making the research experience close and a collaborative process with the informants. They are two readers I liked and connected to. I must say that these two texts have helped immensely in my learning to enjoy research methods – an inconceivable taught until then! A text I have referred to earlier on by Corker and French (1999) facilitated a clearer understanding of what is implied in the design of the disability discourse. It is already then that narrative identity contributed towards localising the issues within the person, a fault or meander that the social model did not seem to manage to do. The flinging away of the individualisation of the discourse of disability identity has left little space for the person to feature. Narratology seems to have patched up this *lacuna*. This method or rather methodological stance attempted to expose the micro that moves to the macro perception. Thomas in Corker and French (1999);

Joan's story is one of changing self-identity – first the loss of the self she was before her illness, then the reconstruction of a new 'stronger' self. We can see this being played out through and against the public narratives of 'normality'.... Her difficult struggle to 'come to terms' with the changes in her life and an altered self are clearly bound up with her long-standing acceptance of the implicit messages in these public narratives.... She found a way to re-tell her story to and of herself (Thomas 1999, p.51).

I have engaged with an edited life document in my research, which is made up of two main components, written autobiographies and interviews leading to the writing of short semi-fictional narratives. The informants I worked with engaged with this thinking. From the feedback I

got during the focus group sessions, people wanted to read stories in research. They said that in reality research is a big story said (many a times) in complicated terms. They also spoke about how research can be more beneficial if people who are considered to be informants are also direct contributors in this process.

From the narrative perspective, the primary story took place when a person lived his/her life. The first retelling took place when a teacher told or wrote down his/her life-story. This claim is based on Bruner's (1987, p.13) view that a person constructs his/her life while telling about it. The telling or writing does not repeat the event itself, but is an interpretation of the event, i.e. the primary story. Each time we tell about an event, we re-interpret it on the basis of the previous stories and our new life experiences (Syrjala and Estola 1999, p.4).

The key factor influencing this discourse is 'the approach', which has proved effective in methods and changing mind-set. The whole notion of narrative and story telling has been debated at length in this work. Important journals like *Disability and Society* have contributed towards developing this method of telling research; a paper by Camilleri (1999), "Disability: A Personal Odyssey" provides an autobiographical perception on how this disabled person (author) turned activist and policy-maker and how he perceives his own situation and that of the disabled minority as being evolutionary. "Narratives Of Leisure: Recreating The Self" by Fullagar and Owler (1998) represents instances whereby storytelling becomes a new approach of connecting with people. Story telling becomes not only an 'end' but a 'means'.

I intended in the process of this study to bring together another important and contentious point. It took me very long to decide what type of methodology and methods I was going to use because I wanted a system



of data collection and analysis that is not subservient to the very theme that is being debated. My choice eventually led towards the usage of narrative style of doing research. I will be dealing with the text that has informed my narrative stance, Plummer's (2001), *Documents Of Life 2 – An Invitation To A Critical Humanism*, at a later stage. However, there is a text by Goodley, Lawthom, Clough and Moore (2004), *Researching Life Stories – Method, Theory And Analysis In A Biographical Age* that presents four biographies with a varied theoretical and epistemological platform. The authors choose to use life-stories as their form of narrative research. They argue that the stories in themselves, even though localised in time and context, are still able to inform a wider audience that choose to read broadly the issues that are being debated. It is a somewhat intriguing text, which overlaps, and zigzags from the issue to the methodology and methods. It is not a static piece of work but allows the authors, the informants and the readers to read between the lines without the fear of being told off for analysing it the wrong way;

In the process of unpacking life story research we may end up deconstructing the life stories that we initially present. Never mind, we hope we have done some justice to our narrators/narrative subjects and encouraged others to consider stories as the very stuff of research. (Goodley et al 2004, p.x).

Another text, which even though did not have direct relevance to the work I was undertaking, I still found incredibly interesting is Sikes (1997) in her *Parents Who Teach – Stories From Home And From School*. This book diffuses the intricate methodology of gathering the stories and utilises most of the space in the book to give the informants the opportunity to tell their own. She shifted her plan for the book from one that is based on her annotations and some quotes to a more active engagement of the informants, where their stories were presented and occasional

commentary was inserted. This shift was attributed to avoid warping what the informants had to say. Other valid texts that have brought me closer to understanding what is happening around me and in the context I am absorbed in are Morris's text amongst which *The Human Zoo* (1969) and *The Naked Ape* (1967) rank high. This anthropological stance has over spilled values that were suitable to my research thinking.

...locate the teacher's own life story alongside a broader contextual analysis, to tell in Stenhouse's words 'a story of action, within a theory of context'. The distinction between the life story and the life history is therefore absolutely basic. The life story is the 'story we tell about our life'; the life history is a collaborative venture, reviewing a wider range of evidence. The life story teller and another (or others) collaborate in developing this wider account by interviews and discussions and by scrutiny of texts and contexts. The life history is the life story located within its historical context (Goodson 1992 cited in Sikes 1999, p109).

The narrative research is gaining ground as a major method/ological tool. Being a constantly developing orientation, which combines the interests of the research on teacher thinking and knowledge and the interests of emancipator and participatory research.

Narrative identity can be defined as a constantly evolving story, which compounds the past experience of human life. A person constantly renews his or her narrative by re-creating mental experiences in the form of words and sentences.... Narrative identity is closely related to the view that identity comes through a dialogue between the self and the environment. In order for a narrative to come about, there has to be true dialogue between participants who listen to each other. And even more: people want not only to be listened to, but also to be understood, which enhances the self-knowledge

of both the narrator and the listener/reader  
(Syrjala and Estola 1999, p. 3).

It is asserted that ethnographic fieldwork should involve 'self-awareness', and 'personal exposures'. Indeed, researchers are challenged to put their preconceptions to creative use. Here, ethnography is viewed as a process of two-way exchange... (Davis 1998, p. 331). Another valid text in the aspect of ethnographic research is Norman K. Denzin's, *Interpretive Ethnography – Ethnographic Practices For The 21<sup>st</sup> Century*. This is a text that analyses at close range the myriad debates surrounding the ethnographic post-modernistic debates. He not only debates the techniques in ethnographic research but also discusses methodology as a literary in search of 'new ethnics of enquiry'. There are various other texts that have informed my methods; *Research Methods In Education* of Cohen, Manion and Morrison (2000), Bassey's (1999), *Case Study Research In Educational Settings*, Burton's (2000) edited, *Research Training For Social Sciences*, Rubin and Babbie's (1993), *Research Methods For Social Work* and finally Arksey and Knight's (1999), *Interviewing For Social Sciences* amongst others. Finally, there is a paper by Claire Tregaskis (2000), in *Disability And Society*, "Interviewing Non-Disabled People About Their Disability-Related Attitudes: Seeking Methodologies". She argues about the in/visibility of disabled people within a social context where the same experiences trigger disability studies. This paper sketches "a current study of the formation of such perspectives, and specifically explores the methodological conditioners of such an enquiry" (p.343). All this argumentation takes place against a non-disabled individualistic attitude towards research in disability.

## **2.5 TEACHING: THE CORE BUSINESS**

There seems to be consensus that disabled students have seen a rapid change as a direct outcome of the social transformation that inclusive



education has brought about in these last years (Thomas and Loxely 2001). Furthermore we can now share the experiences of many more disabled students who are either stated or not officially labelled. Disabled students are sharing more in the life experiences of non-disabled students, they are sitting for exams, moving into higher education rather than being locked in institutions away from all and everything. However, undoubtedly, the integration and exclusion of students in every sector and sphere is far from eradicated (Davis and Watson 2001).

..."inclusion" of students with impairments in regular education has indeed made educators think that education is for all students... We should be grateful to the students with impairments and their families for teaching us that every child is worth loving, every child wants to and can learn and grow, every child wants to and should belong fully to the community – home, class, school, town or village – where he or she lives (Bartolo 2003, p.11).

A great deal of material has been written in this regard. Armstrong, Armstrong and Barton (2000) have edited a collection of papers from a number of different countries. Their work centres around the notion of equal opportunities, human rights, and social justice. This text attempts to engage an across-cultural debate where "inclusion" and exclusion are weighed up against the 'value and well-being of all pupils' (p.1).

This debate brings us to the recognized argument that "inclusion" is beyond what happens in a school – it is a community project. Bauman (2001) in his *Community – Seeking Safety In An Insecure World* says;

Words have meanings: some words, however, also have a 'feel'. The word 'community' is one of them. It feels good: whatever the word 'community' may mean, it is good 'to have a community', 'to be in a community'. If someone wandered off the right track, we would often

explain his unwholesome conduct by saying that 'he has fallen into bad company.' If someone is miserable, suffers a lot and is constantly denied a dignified life, we promptly accuse society – the way it is organised, the way it works. Company or society can be bad; but not the *community*. Community, we feel, is always a good thing (p. 1).

A mounting collection of research on inclusive education has provided solid and empirical evidence on what is working and what is failing in our schools. Inclusive education needs to be perceived as an activity that permeates social justice and political action in schools and society. "inclusion" is the vehicle that commends democratic values, equal opportunities and a thorough understanding of social anguish and affliction. The paper by Davis and Watson (2001) also exemplifies a discourse that sees the school community as a whole, engaged in a process of debate. This paper also brings in line the complex argumentation of special and inclusive education. In this work there is frosty dichotomy that perceives special and inclusive education as being an argument on two separate and distinct polarities.

Academic streaming, professional values, issues of safety, fear of litigation, concepts of normality, social class values, and ideas concerning a variety of criteria related to physical and social skills can be employed by professionals to label children. As Armstrong and Galloway (1994) have pointed out, some adults labelled the children to suit their own interests. They allow the requirements of their structural role within the education process to govern their perceptions of the children. This process is combined with and reinforced by the tensions created by the market place educational policy, as outlined by Ridell (1996), Armstrong and Galloway (1994) and Alan *et al.* (1991). One outcome of this is an unreflexive process of diagnosis within special and mainstream schools, which can result in

professionals silencing and excluding disabled children. The children's capacity to make choices is also overlooked (Davis and Watson 2001, p.684).

When inclusive education is approached as a social-political value, it requires that people not only reform educational practice, but they do so with a deep understanding of why these reforms are necessary. This understanding means that attention to school culture is a central issue in implementing inclusive education. Corbett (in Ware 2000, p.46) describes school culture as: "the hidden curriculum of the fundamental value systems, rituals, and routines, initiations and acceptance that forms the fabric of daily life (in schools)". It is at this degree of "inclusion" that real quality of life issues reside. Developing a school culture can be an intangible process whereby students are taught to see themselves as either valued or de-valued group members.

...we are beginning to recognise that, for teachers, what goes on inside the classroom is closely related to what goes on outside it. The quality, range and flexibility of teachers' classroom work are closely tied up with their professional growth – with the way they develop as people and as professionals. Teachers teach in the way they do not just because of the skills they have or have not learned. The ways they teach are also grounded in their backgrounds, their biographies, in the kinds of teachers they become (Hargreaves 1997 cited in Sikes 1999, p.108).

Education has become a cultural determining factor. Things change – and so it seems with education. Even though education is more often than not seen as a very conservative exercise we as teachers end up with a whole potpourri of self-loathing. We end up hating ourselves because we would be unable to re-create the imbalances that exist in schools and that are expected to be resolved by the teaching community. Schooling



is a very complex process even for teachers who are sent to a school whatever background and personal interests they are engaged in. School is not just an institution where students listen to what 'we' are paid to share with them (Avramidis and Norwich 2002). All schools seem to have an agenda to make our students subject to a wide array of rules and restrictions. In relation to students who have a diversity label, these regulations prevent the students from having a voice and everyone starts to assume that the characteristics that distinguishes them prevents their involvement in regular schooling. In relation to disabled children these trivial rules are further compounded by the existing legislation which not only refuses to hear their voice, but assumes that it is the child's behaviour or impairment which is 'the problem' or 'the difficulty' preventing their participation in mainstream education (Kenworthy and Whittaker 2000, p.220).

Unlike the teachers in the chaotic early nineteenth century district schools, modern teachers exercise less personal power and rely more heavily on regulations promulgated by higher authorities. Although frequently prey to arbitrary intervention by parents and other community members, the nineteenth century teacher was the boss of the classroom. The modern teacher is in more ambiguous position. The very rules and regulations which add a patina of social authority to his or her commands at the same time rigidly circumscribe the teacher's freedom of action (Bowles and Gintis, p.39).

Inclusive education is perceived as a human rights debate (Kenworthy and Whittaker 2000). Segregation from special schools has also been analysed within a human rights debate (Armstrong, Armstrong and Barton 2000). It is the right of every person to attend the school of their choice and access the neighbourhood and broader community with the

provision of appropriate support network (Kenworthy and Whittaker 2000; Salend 2001).

Disabled people have increasingly been at the forefront of political struggles for social reform premised not on 'equal opportunities' but on demands for 'human rights' and social justice. They have begun to challenge the representation of disability within an 'opportunities' discourse on the grounds that it discourages a critical stance towards the social conditions underpinning the experience of disabled people (Armstrong, Armstrong and Barton 2000, p. 9).

This whole debate is weaved within a citizenship discourse. The principles of "inclusion" are based on human rights according to Exley (2002);

- Students are entitled to learn together;
- Children should not be discriminated against because of any impairment;
- Society benefits from all children learning together;
- Children taught in the mainstream tend to do better academically and socially (Salend, 2001);
- "Inclusion" enables all of society to develop without prejudice and in tolerance.

Regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system (UNESCO 1994, p.ix, cited in Evans and Lunt 2002, p.3).

At the end of the day, "inclusion" as one could read in the literature is:

- Nothing more than good teaching for all students;

- It is the right environment for students to take on responsibility for their own teaching;
- Families and students are omnipresent in the process;
- Society is able to understand that "inclusion" is a community spirit rather than a school award;
- Teachers have high prospects that will allow the setting of rules and academic challenges;
- Policy-making goes beyond the cost effectiveness of such a project;
- Politician's rhetoric needs to be shelved.

...where calls for 'inclusive' schools and practices are limited by a framework which appeals for 'equal opportunities', or understands the 'rights' of disabled people in universalistic rather than political terms, no serious challenge is made to the conditions under which discriminatory and exclusionary social practices operate (Armstrong, Armstrong and Barton 2000, p.11).

My core thinking has emanated primarily from my work in a secondary school. This reality I am engaged with is at the heart of my reflection processes. There is a world of difference between the experience of school that is prepared for by a childhood spent in a family circle where words define the reality of things, and the experience of unreality given to working-class children I have come across in my teaching experience. The scholastic acquisition of a language tends to make unreal the things it speaks of because it makes up their whole reality: the 'pure', 'corrected language' of the classroom is opposed to the language the teacher's marginal notes stigmatise as 'vulgar' or 'common' (Corbett 1996). Language can be power, supremacy and muscle.

Pupils in schools are being excluded. This is the reality we find in most if not all of our schools. The stories I have presented were used as a basis for



focus group discussion and spoke about this in a coherent and intelligible way. The school I work in expressed repeated concerns about the fact that some or more than some students were uncontrollable. The three options when dealing with the pupils in our school are:

- Try to secure a statement so that a 'disruptive' student can be sent for special provision. This has happened with at least four students this scholastic year in the school I teach at;
- Pupils are excluded from school regularly. This has been authorised through a circular by the same *Minister of Education* in situations that are damaging to other students. I very much doubt if this provision is adequate (Stirling 1992).
- A number of initiatives are taken so that students are discouraged to continue coming to school (Stirling 1992).

Often the processes that lead to some pupils feeling marginalized are subtle ones that occur as part of normal classroom interactions. So, as I watched lessons in one school recently I noted 'throw away' remarks by teachers appeared to suggest that a low level of participation was anticipated was anticipated. For example, a teacher appeared to have targeted one boy as somebody who was unlikely to make such a contribution: Grant, homework, I assume you didn't do it – you never do, despite letters to your mum' (Ainscow 1999, p.61).

## **2.6 TO WHAT EXTENT DOES THE SOCIAL MODEL MOULD MY THINKING?**

Research driven by an adherence to the discursive world promises much for disabled people. The biggest challenge facing the social model of disability comes from those critics who would suggest that disabled people's exclusion cannot be put down purely to societal ills (Barnes and Mercer 2003).

perhaps if we keep trying to understand the social model of disability and the medical model, we will end up with loads of theory and little to gain from it all. In the social model lies a basic principle where the person is no longer at the centre of the tragedy but it is society, the collective, that is implicated in this calamity! It also seems that if we take the social context as being at the centre of it all, we will end up realising that in actual fact there lies the whole community. We need to engage with the social model as a conceptual framework that leads us to understand the dire need of a society that has to take on responsibility for its condescending, demeaning, belittling and patronising position in regards to disabled persons. This debate needs to take us a step further. We need to look at how the oppressive and discriminatory attitude of society is to stop. I believe that the fact that disabled activists are speaking more and more about the social model. This is proving fatal to disabled people who are exposing themselves to the language the professionals, politicians and policy-makers are adopting to be able to make up a strategy that sounds familiar to disabled people but just the same heartens oppression, inequality and discrimination (UPIAS 1976; Oliver 1990a; 1996; Shakespeare 1998; Barnes, Oliver and Barton 2002).

Whilst this study is not intended to give a detailed account of different models of disability, it is important to discuss the sources that have informed me with this model, which has had the greatest impact in current understanding of disability, not least in terms of their commentaries on public attitudes. Needless to say, the *Fundamental Principles of Disability* (UPIAS 1976) is a fundamental text that has influenced greatly my thinking and perception of disability. It is a piece of work with a vision that can still be considered modern and forward-looking twenty-five years after its publication. Way back in the mid-70's the UPIAS was already proposing a social theory of disability (UPIAS 1976; Barnes and Oliver 1995;

Drewett 1999). This document was calling for the methodical analysis of the organisation of society, thus managing to get at the soul of what disability entailed.

... the alternative struggle proposed by the Union is logically developed from a social theory of disability ... We ourselves look for our expertise to the wealth of talent and intellectual imagination of disabled people, which will be freed for expression once we contemplate our own situation from our own collective experience (UPIAS 1976, p.20).

UPIAS (1976) is the launch pad of the social model and the rejection of the individual and charity models that have until then dominated disability issues (Davies, 1994; Mason and Reiser, 1994; Azzopardi, 1999a; Camilleri, 1999). Most of the changes that are being proposed at economic, political and social realms by disabled people today are in fact a regurgitation of *The Fundamental Principles Of Disability* (1976).

The Union therefore seeks to help disabled people to recognise and oppose all approaches, which can only see answers to our problems in terms of different forms of charity (p.20).

This document also engages with the debate of 'voice' (Kenworthy and Whittaker 2000). This work is a symbol of the need to connect with an ongoing debate that ultimately leads disabled people to react against the oppression they are victims of.

We call on physically impaired people and others who want to join the Union and help us build a mass, democratic organisation, with a principled approach to disability that will struggle to win the right to employment in integrated work situations, and to eliminate from our society the disablement of people ... (UPIAS 1976, p. 20).



Oliver (1994) puts forward the concept that in order to comprehend policy issues, it is crucial to realise "discourse". Oliver (1991) quotes Hugman;

Discourse is about the interplay between language and social relationships, in which some groups are able to achieve dominance for their interests in the way in which the world is defined and acted upon. Such groups include not only dominant economic classes, but also men with patriarchy, and white people within the racism of colonial and post-colonial societies, as well as professionals in relation to service users (p.37).

The social model has originally been developed by people with a physical impairment. Its main theory is that disability does not reside in individuals' impairment or 'dysfunction' (as the medical model would contend) but in the material and social barriers, which disabled people (Finkelstein 1991; 2001; Oliver 1990a). During the rise of Western capitalism and industrialisation, disabled people were increasingly seen as financial burdens since they could not undertake heavy physical labour and were therefore condemned to workhouses. According to this formulation, attitudes towards disabled people as dependent and deserving of pity can be traced to this enforced dependency which still exists today, albeit in a more 'humane' welfare framework.

However, those who adopted Marxist or materialist position have been challenged for neglecting the role of imagery and the prejudice which is implicit in cultural representations, language and socialisation (Shakespeare 1994). In addition, both Shakespeare and Morris (1991) argue that prejudicial attitudes towards impairment predate western capitalism. Rather, impairment represents the "physicality and animality of human existence, undermining the view that people can overcome the

limits of their nature through the victories of their culture" (Shakespeare 1994, p 298).

I originally conceptualised models of disability as the binary distinction between what is referred to as the individual and the social models of disability (Oliver 1983). This was no amazing new insight on my part dreamed up in some ivory tower, but was really an attempt to enable me to make sense of the world for my social work students and other professionals whom I taught. The idea of the social/individual and medical model was taken explicitly from the distinction originally made between disability and impairment by the UPIAS published way back in the mid-70's (Oliver 1990a). This great piece of work has been acclaimed by academics and activists alike. It is one exemplary classic that has conditioned the thinking and writing of many. This work links to this Thesis because of its profound analysis and the start of what was to become the social and medical model of disability as designed by Mike Oliver.

Language is a key element in culture. The terms used to denote 'disability' have changed regularly over the years. Language is used automatically and unthinkingly in daily conversation so that people become desensitised to the meaning of devaluing words - and their impact on devalued people. Jenny Corbett's (1996), *Bad-Mouthing – The Language Of Special Needs* threats this issue at length. She argues that the power of language is overwhelming, it is used by politicians to create emotions, by professionals to persuade, by activists to engage and by students to justify. Language is a force to be reckoned with. The disabled community has for ever struggled with definitions (UPIAS 1976; Corbett 1996), labels (Barton and Oliver 1997), descriptions and nomenclatures. The question that comes to mind at this point is whether 'political correctness' has in fact become the current that has drifted us away from the real issues to



be contended with. Does political correctness come before or after the themes? Is this a repeat of 'who came first the chicken or the egg?' chronicle where we end up being absorbed with language that defines rather than the definitions that make language? My use of the term 'disabled person' rather than 'persons with a disability' emanates from an argument that is very complex as there is a mishmash of factors involved; meanings, syntax and the use of language within a particular context and culture. The key argument in social model thinking in such a debate is that we need to value the person with whatever characteristics s/he is endowed with. It is necessary to keep in mind that barriers need to be identified not within the person but within a social context that constructs obstacles (UPIAS 1976; Campbell and Oliver 1996; Oliver 1990a; 1996; Corbett in Barton and Oliver 1997). On the one hand we have to be careful not to be wedged with a debate on terminology but language constructs identity and it is as important as the minority chooses it to be (Corbett 1996).

## **2.7 CONCLUSION**

The challenges that we face together in our society could so easily become opportunities if we moved from a culture which seeks to blame and condemn, to one that acknowledges that recent economic and social changes have affected every area of our lives for good and ill. It is not until people see themselves as confident, valued, and empowered citizens of an inclusive society that they can capitalise on the opportunities that may exist. The enquiries that I pose in my research seek to analyse the validity of stories, the different perspectives towards transformation, the practices that allow for "inclusion" and the extent that narrative research exposes "inclusion". Disability can only be understood in relation to a set of cultural norms and values (Riddell and Watson 2003). An issue that has been revealed in this literature review is how particularly



problematical it is to prove "inclusion". To be asked to show that "inclusion" works is like being asked to show that equality works. To promote "inclusion" involves judgements based on values, and there is no reason to be apologetic about this.

Oliver (1990) argues that perceptions of disabled people are varied according to the different ages and places. He cites a number of examples, including *Martha's Vineyard* in the US, where a high incidence of hearing impairment led to the majority of the hearing population becoming fluent in sign language. In this context, having a hearing impairment was seen as 'normal'.

The way we see other people is influenced by a complex interaction of what we know, or think we know, what we have experienced and how we see people portrayed and hear them talked about. This perception depends entirely on our experiences, the contact we've had with the various realities across time. Attitudes to disabled people are a legacy of historical policies and practices as well as a response to current developments. The mind-set of disabled people appears to have been predominantly negative in most cultures and times, maybe an experience I feel as being part of the context I come from. However, such attitudes are often complex and ambivalent.

Inclusive education is understood differently in diverse contexts. However, a common thinking stems from the fieldwork and literature I have engaged with: "inclusion" is 'a concern with minimising barriers to learning and participation in educational settings'. Inclusive education in this sense is concerned both with effectiveness and with issues of equity. This literature review focused on empirical data but also tried to attach with substantial theoretically- and critically-orientated literature in this field.

Inclusive education is an international concern and it was the intention of this literature review, to re-examine pertinent aspects of this international literature. Roger Slee's (1993) *Is There A Desk With My Name On It? – The Politics Of Integration*, sums up the tensions and anxieties that read an agenda of transformation;

The accounts of schools' difficulties in dealing with difference and disability... confirms the resilience of 'old oppressions'. The arenas and agendas for change are chaotic. The challenge becomes that of intervention at a number of levels to support initiatives towards inclusive education (p.4).

# CHAPTER 3

## Methodology And Folly In The Methods

*Revolution is necessary ... the class which overthrows the ruling class can rid itself of the accumulated rubbish of the past and become capable of reconstructing society" (Marx 1845).*



*In a bizarre little experiment conducted in 1969, psychologists measured the performance of cockroaches running away from a light source. They found that the cockroaches ran faster if the runway was lined with an 'audience' of fellow cockroaches, each watching from a perspex box. In other words, the presence of a group had a facilitating effect upon performance. As a researcher who works largely with groups I found this result strangely comforting. It seemed to provide some sort of natural vindication for my methodology. (Anderson 1997, p.1).*

### 3.1 INTRODUCTION

Social science research methods are not neutral but themselves shape the way in which the world is construed. It is therefore important for researchers to be clear about the assumptions underlying their choice of methods (Riddell, Brown and Duffield 1995, p.31).

The "methods section" can be defined as the 'engine room' of every piece of research. It is useless trying to explain how a motor vehicle functions unless one understands how a robust engine compliments speed with its variability. This section of the *Thesis* has the same purpose, that of understanding and being able to read the machine works. The 'beautiful' chassis needs to compliment the engine works of the car - this is methodology. Theoretical debates and analysis of data are important but the capability of method is crucial. If the research strategy is unsound and the methods used are inappropriate, the data, and therefore the arguments in the *Thesis* will be undermined. Nonetheless, we need to keep in mind that a method chosen is another method discarded. The three components that make up my research methods are the following: autobiographies that emanate from the experiences of a number of disabled persons, a parent of an adolescent and another one by an adolescent labelled as having behavioural difficulties. The second part of

my research is a group of five semi-fictional stories that I have written, keeping in mind the contexts I am involved in. These semi-fictional stories were then utilised as a discussion platform for the focus groups I organised. Each represented one of my professional contexts. Finally, all my work is embedded in an auto-ethnographic milieu. The research fluctuates from external observations to personal reflections. As a researcher I interpret the intersection of these two components. Evidently, this approach is connected to a cultural discourse and interpretations that are woven in personal accounts (Denzin 1997).

A number of differences can be identified between these two approaches to participation. The first approach generally starts with policy and the *service system*; the second is rooted in people's *lives* and in their aspirations to improve the nature and conditions of their lives. Both approaches may be concerned with bringing about change and influencing what happens. However, in the consumerist approach, the search is for external input which the initiating agencies (state, service providers, or policy makers) *themselves* decide what to do with. The democratic approach is concerned with ensuring that participants have the direct capacity and opportunity to make change. This latter approach highlights issues of power and the (re)distribution of power. These are not explicit concerns of the consumerist model of involvement (Beresford 2002, p.97).

Research has always been considered a very thorny issue in the field of disability. The disability movement in the UK and in the USA, especially through the study of disability studies, promoted a very intricate debate on how disability research can take a form where control lies within the informant rather than with the researcher.

For Oliver, emancipator research must be located in the social model of disability. It must reject the individual or medical model view that

impairment is the root cause of disabled people's problems. This includes giving proper recognition to disability and disabled people in social research (e.g. in studies of the family, employment, sexuality, education and the like) but more ambitiously, it is suggested that disability research presents a radical alternative to mainstream research theory and methods (Barnes and Mercer 1997, p. 5).

As a researcher I attempted to embrace a thinking process whereby one gives control and jurisdiction to the informants (Beresford 2002). However, the situation still lies in the fact that the issue of time, lack of resources and the need to 'get on with it', creates a scenario whereby commitment to emancipatory objectives is not good enough. The frustrations and tensions that accompanied the writing of this work was centred primarily on the values I believe in. My concern with being a researcher and in such a position of power can be seen in this e-mail I sent to one of my informants after she had sent in her autobiography as part of my data collating.

Wow that was some piece of reading..... in a nut shell I could see the shit (sorry for being rude!) I have put people through with my professionalisation, with using people's stories to write *Thesis's* and articles..... sometime I end up knowing the language of disabled people to such an extreme that I use it, at times playing the vanguard professional that is ready to listen. ... your writing says it clearly..... I keep assuming things, I keep looking into people's lives as if I have the right - 'because I'm a professional, I'm a researcher.....'. .... I'm really sorry (genuinely speaking) that I have to use such intimate, at times I suppose, painful experiences to get myself through this doctorate. I pray that this thing will lead me to a better understanding not of disabled people but of myself... ("In Search Of Answers", June 15, 2003).



On the other hand, maybe the tensions that are created are more serious for some than for others. Disabled people I believe have different standing as how this research would influence their thinking. Most times, and this I experienced through the process of collecting my own data, disabled persons were intricately involved in the work and saw it as a process whereby research can incite change. They also seem to find research as a means of clearing up the sentiment that has been built in them. This is an e-mail I got as a reply to my previously quoted e-mail:

Hello Andrew,  
Thanks for your message.... At least you are aware of some of the problems, but I feel you are working with us, rather than just using us ("In Search Of Answers", July 2, 2003).

Another issue I needed to contend with as I designed my method was the fact that initially I wasn't looking just at the issues of "inclusion" from a disability perspective, and so I was concerned that this type of research will not be able to read well enough for other realities I would come across in my data collection process (Barnes and Mercer 1997). However, this work showed that disability research has elements within it that can be generalised onto other areas of research (Campell and Oliver 1996; Riddell, Wilkinson, Baron 1998; Salend 2001).

The research method and its analysis is based on my own personal experience both on a professional and personal level. I am currently involved in four main activities related to disability. I must also say that all my energy is immersed in this matter incessantly. Disability has encapsulated the way I think and perceive life. This is a reality that I have lived with for these last six years. Studying disability for me is a life style, a channel of self-reflection. The methodology I used is not only a way of accomplishing research but a way of getting my act and me intimately engaged. There are four main facets to my 'professional life'.

1. I am a teacher by profession. I have been teaching for these last eight years in an *Area Secondary School* in one of the most socially disadvantaged regions of the country. During these years I facilitated *Personal and Social Education* sessions for eleven to sixteen year old students. In these last three years I have also been a *Guidance Teacher* in this same school.
2. Following the completion of my *Masters In Education* I was asked to contribute at the *University of Malta*; I teach, supervise students in their research and facilitate seminars. The main participants in the school are students from the *Faculty of Education*. I have also supervised a number of students during their teaching practices.
3. I co-ordinate a social work service. In actual fact I have done so for these last eight years. I have a team of social workers that provide a service within a government-funded agency. The social work service is focused on supporting disabled persons and their families.
4. I am also involved in an action research project with the *Education Division*, which is intended to provide support to a number of schools that are trying to develop and engage with inclusive practices.

What is being encouraged is a form of research in which disabled people are empowered. This is not, as Oliver argues, 'a gift of the few who have it to be delivered to those who do not' (p. 11). It is about people empowering themselves and using the knowledge and the 'expertise' of the researcher towards this end. It will have serious methodological changes if, as he argues, there needs to be the establishment and maintenance of 'trust and respect and participation and reciprocity' (p. 106) between both parties. (Barton in Barton and Clough 1998, p. 32).

Every aspect of these experiences has turned out to be a contributory factor to my research. Having decided on the research paradigm to use,

the next stage was to familiarise myself with the research methodology relevant to this particular approach. In actual fact, the five characteristics that make up interpretative research (often referred to as qualitative research) have been identified by Sherman and Webb (1988), as elements that converge the important events in my life to the research framework I was involved in.

- Events can be understood only if they are collated within a context. Thus, a qualitative researcher needs to be immersed in the setting.
- The contexts of inquiry are not unnatural and manufactured but ordinary. Nothing is pre-defined or taken for granted.
- Qualitative researchers would want the informants to have a voice in their work and to provide their perspectives in words. Research becomes an interactive process in which the persons studied teach the researcher about their lives. Researchers attend to the experience holistically rather than as separate components.
- There is not one general method of enquiry. Methods used in qualitative research are those that are most appropriate to the aims of such a research.

As a researcher-practitioner I hope that this study will in addition help me to start looking at this situation from a different standpoint altogether (Wellington 1996). An essential component in this research, is that of finding a research approach that can ensure problem-solving and a solution to this multifaceted issue. The fundamental objective of this study is to analyse whether these students are achieving to their potential

...where there is an emphasis on 'performativity'.... this is incompatible with more 'emancipatory' ideals. Students who are dominated by concerns over grades and marks; teachers who are preoccupied with measuring up to externally-derived criteria of quality;



institutions whose very existence may depend on the configuration of their performance indicators and systems whose quality is measured by quantifiable results are the educational manifestations of 'The Assessment Society'. They are the visible expression of a culture that celebrates control and conformity and defines education in terms of the inoculation of existing bodies of knowledge (Broadfoot 2000, p.10).

When exploring the available research approaches, I kept looking at a research strategy that can meet this thinking (Burton 2000), maintaining sensitivity to the context being analysed without overlooking my own location in this work. Education requires erudition that can overcome the barriers between research, evaluation and development.

Fundamentally, this project was a dynamic and engaging encounter through an appropriate choice of methods. The achievement of my work depends on attaining the trust of the informants and helping them disclose their experiences (Crow 2000). This research will involve unstructured interviews conducted in an "ethnographic style of fieldwork research" (Bell 1999, p.12-13). This method depends a lot on informant observation and provides me with an opportunity to engage actively in the way students are interpreting their situation. Managing an ethnographic methodology requires a lot of time to make out a realistic and representative picture of what is actually happening (Bell 1999).

The starting point for a research project may be a question or questions that you would like to address (or even answer!). It may be an idea or a hypothesis you wish to test (Wellington 1996, p.9).

Methodology can be defined as the way data is collected (Wellington 1996; Clough 1999). Fundamentally, the purpose of utilising a particular methodology is to engage with the most suitable approach. The methods

employed must pertain to the context of the study (Cohen, Manion and Morrison 2000). This work will do away with mathematical and quantitative approaches and focus more on generating an ethnographic perception of a sub-culture present in the school and the other contexts I am involved in (Cohen *et al* 2000). We need to develop a collective consciousness and develop a stratagem for change. Participatory research is a way to engage people in a process that aims to challenge oppressive structures that manage people's lives.

## **3.2 PRINCIPLES IN RESEARCH**

### **3.2.1 INTRODUCTION**

I would say that the main argumentation around research lies in a fundamental principle - research is about 'me'. It is about understanding the world around 'me' (or rather a part of it) within a particular frame of time and standpoint. I believe being a teacher by profession has an advantage in all of this as Stenhouse in Booth, Swain, Masterson and Potts (1992) says in a very enterprising way;

The basic argument for placing teachers at the heart of the educational research process may be simply stated. Teachers are in charge of classrooms. From the point of view of the experimentalist, classrooms are the ideal laboratories for the testing of educational theory. From the point of view of the researcher whose interest lies in naturalistic observation, the teacher is a potential participant observer in classrooms and schools. From whatever standpoint we view research, we must find it difficult to deny that the teacher is surrounded by rich research opportunities (p.299).

The two most prominent research paradigms are the scientific and interpretative. The scientific paradigm is concerned with objectivity, prediction and the discovery of generalisations unfolding the phenomena

in question (Denzin 1997; Burton 2000). On the other hand, the central concern of the interpretative research paradigm is that of understanding human experiences in a holistic dimension. Researchers of this kind interpret the complexities embedded in these experiences to seek meanings and illuminate their significance.

It is a methodology positioned in the natural settings where human behaviours can be truly reflected upon and the meanings of these behaviours can be well interpreted. It is a method that allows the subject to be in control and present during the whole process. It has often been an important consideration to have a qualitative research that is particularly suitable for school-based research where human activities and relationships are intransigently interlaced.

### **3.2.2 THE SCIENTIFIC RESEARCH PARADIGM**

The scientific research paradigm has a number of characteristics; intensity, accuracy, standardisation and generalisability. One major criticism in such a paradigm is that there isn't an understanding of human nature as individuals in their entirety. Their proper context is neglected, resulting in a partial and distorted picture of social reality.

Ernest (1994) declares that the scientific research paradigm is concerned with objectivity and the discovery of scientific generality describing the event being analysed. Hypothetically speaking, by designing a scientific approach to social science issues, general laws predict future outcomes and people will be in the position of controlling and developing educational goods. This approach is based on a hypothetical approach, which basically takes on the following course of action; the theory proposal is prepared, hypothetical inferences are betrothed and analysis of outcomes by observation on experiment is completed. This approach,



in other words adopts a systematic enquiry into hypotheses for the generation of knowledge. The empirical step-by-step procedures to examine the hypotheses are dealt with in a vigilant and step-by-step manner. The forms of enquiry include methods such as surveys and comparative experiments, which rely heavily on quantitative data.

### **3.2.3 THE INTERPRETIVE RESEARCH PARADIGM**

On the other hand, the central concern with the interpretative research is indulging in the human experience in an encompassing perspective. Researchers of this kind interpret the complexities embedded in these experiences to seek meanings and illuminate their significance. The interpretative research paradigm is primarily concerned with human interaction, interpretation and the engagement of truth as perceived in human terms. Interpretative research is often carried out in natural settings. It is often referred to as naturalistic inquiry. Human experiences are shaped in contexts and best understood as instituted in their natural settings. It is in natural settings where human behaviours can be truly reflected and the meanings of these behaviours can be well interpreted. We need to start from where the person is. The natural location is the context where the researcher is most likely to discover and reveal what is to be known (Booth, Swain, Masterson and Potts 1992). There is no longer a necessity to separate 'my' life and 'my' research. In reality, I saw how they could be structured as one and the same process.

Qualitative research is context specific (Barton 2002), that is, it converges the facts provided by the informants and cannot be understood if isolated from their milieu. Studies concerned with interaction are frequently conducted within this paradigm. Qualitative research is particularly suitable for social construction investigative research where human activities and relationships are intricately interlaced.

There is no general method of enquiry but set guidelines exist.

Researchers approach their research with a fundamental question in mind; 'what is going on here?'. They do not attempt to verify a pre-determined idea. Instead, analysis details in order to achieve a coherent understanding of the complications entrenched in that which is studied, thus interpreting meanings and insights from their discoveries.

Interpretative research paradigms start from a bottom-up position. Power and control is levelled out. Initially as I commenced my research I was still sightless not knowing what I was looking for. I then started to reflect with a broad focus in mind, which originated primarily from the literature and the experiences I came across as a professional. The broad focus is initially open-ended, allowing for important meanings to be revealed.

### **3.3 PILOT STUDY**

The methodology operates entirely on the focus that is being identified from the broad concepts that are being analysed. I started my work by collecting data from a pilot study (Wellington 1996). In the process of the pilot study I attempted to tackle two issues:

1. To share the stories I wrote (that would eventually be used for the focus group discussion). The stories had to be 'checked' for their linguistic soundness and thematic exactness.
2. I also shared the auto/biographies with a disabled activist and critical friend so that they could give me the salient argumentation that was being proposed.

Individual circumstances must be the final arbiter. As far as possible it is better if the teacher can discuss the research with all parties involved. On other occasions it may be better for the teacher to develop a pilot study and uncover some of the problems in advance of the

research proper. (Hitchcock and Huges 1989, cited in Cohen, Manion and Morrison 2001, p.56).

### **3.4 SAMPLE GROUP**

The purposive sample group was selected on the ground I determined represents the range of experience within the phenomenon of interest. Data is analysed as soon as it is collected. Qualitative research does not adopt a linear form of procedure. Instead, collecting data and analysing take place simultaneously in a circular form. When potential topics emerge during or after analysis, the researcher may expand or 'tease out' the variables that emerge to look for new directions. As a researcher I was prepared to change directions as new themes emerged. As the collecting and analysing data procedures are carried out, I compared data and looked at the relationship among the variables from time to time until a core variable emerged. This core variable clarified the 'main theme' and elucidated what was happening in the data. The core variable has three critical features; it recurs frequently, links the data together and explains much of the variation in the data. This variable becomes the basis for the production of theory. The categories and dimensions of the theory are inextricably related to the core variable.

Having identified the core feature for investigation (the transformative qualities of "inclusion"), as a researcher I engaged with a literature that is related to the theme because data could not be collected/analysed in a vacuum. After that, data was collected systematically in accordance with the new direction. I brought data and literature together in order to look for meanings and insights. The insights gained from the investigation were to lead to the implications of the research.

Once my focus was identified, I started my analysis by identifying the 'sample group' that was going to be involved in my research. The issue of



power is present even at such an early stage. The sample group is selected on the grounds that the researcher considers it represents the range of experiences within the phenomenon of interest. At this stage, data should be analysed as soon as it is collected.

### **3.5 INSTRUMENTS OF ENGAGEMENT**

The data of qualitative inquiry is most often people's words and actions, and thus requires methods that allow the researcher to capture language and behaviour. The most useful ways of gathering these forms of data are participant observation, in-depth interviews, group conferences, and the collection of relevant documents. Observation and interview data were collected by me in the form of field notes and audio-taped interviews, which were later transcribed for use in data analysis.

Given that the nature of qualitative research, investigations related to this methodology are often connected with methods such as in-depth interviewing, participant observation and the collection of relevant documents, which in turn generate qualitative data such as transcripts or text. Qualitative inquiry is often considered to be the citizens words and deeds. It therefore requires methods that allow the researcher to capture language and conduct. The most constructive and functional customs of gathering facts are the following; group interviews, participant observation, in-depth interviews and the compilation of documentation. Interview data is collected by the researcher in the form of research diary notes and taped discussions, which are than transcribed for use in analysis.

Miles and Huberman (1994) point out one major tenet of well-collected qualitative data is that they focus on naturally occurring, ordinary events in natural settings.

### 3.6 DESIGNING THE STUDY: WHY THESE METHODS?

My own interpretation of methodology is: the activity or business of choosing, reflecting upon, evaluating and justifying the methods you use (Wellington 1996, p.16).

In the 1980s, there was a considerable growth in using interviewing as a method for educational research and now it is generally agreed that interviewing is a key method of data collection. There were many kinds of interviews. Hitchcock (1989, p.79) listed nine types: structured, survey, counselling, diary, life history, ethnographic, informal/unstructured and conversational interviews. Cohen and Manion (1994), however, prefer to group interviews into four kinds; the structured, unstructured, the non-directive and focused interview. This all contributed to the bearing that my methods started to take.

The triangulation of methods attained the goal of bringing in the data necessary to answer the research questions I started out with (Wellington 1996). Whilst there are a variety of triangulation interpretations, the aspect I engaged with in my work is what Cohen, Manion and Morrison (2001) refer to as "combined levels of triangulation".

...triangulation is characterised by a multi-method approach to a problem in contrast to a single-method approach. Denzin (1970) has, however, extended this view of triangulation to take in several types as well as the multi-method kind which he terms 'methodological triangulation'... (p. 113).

My use of different methods, at various moments in time, in dissimilar locations, among a diverse population strengthens this account. Information learned at an interview was reinforced, and perhaps modified, by observation, and by study of documents – or by more interviews. Eisner (1991) uses the term "structural corroboration" – "a

means through which multiple types of data are related to each other to support or contradict the interpretation and evaluation of a state of affairs" (p.110).

This eclectic approach to research will entice a variety of methodological styles and techniques into play (Hanrahan 1998). Nevertheless, the study will draw on a participatory research framework as its main methodological tool. Nonetheless, I will be triangulating 'a mixture of methods' to ensure that I will extract the maximum amount of accurate facts. It is what Wellington (1996) calls 'a way to bring together the data in a clearer and affluent way'. Triangulation will most surely converge various methodological perspectives into one path of action.

### **3.7 METHODOLOGICAL ASSORTMENT – LOOKING FOR QUALITY**

The methods revolve around the routine of this minority group in the school community (Burton 2000). Indulging with this cluster of the student population cannot come by implementing statistical assessments as there is a danger that this would miss out on the cultural characteristics students bring with them (Stroh 2000). This research will attempt to engage with a methodology sustained by the needs of the focus group, acknowledging the community features which make up this cluster of students (Boswell 1993).

My assortment of methodology had to ensure that the right type of information is gathered. Many disabled people are suspicious of research (Campbell and Oliver 1996). Consequently, I pursued the principle of participation. Quality was also a priority in my work. This research is based on a number of principles:

1. It positions the complexities and richness of the human informant;



2. It assumes that humans attach meanings to their lives behaviour – we can talk to ourselves about ourselves;
3. It presupposes a problematic relationship between official discourse, rhetoric and practice;
4. It debates a fundamental reliance on the goodwill of people in order for research to be undertaken – we depend on the goodwill of others;
5. It infers the issue of power would need to be engaged within terms of the relationships involved in the research process;
6. It presumes a perennial dilemma between experiencing the process of research and representing that in particular ways to oneself and others.
7. It deduces the possible importance of unintended consequences – we need to be flexible.

We need to be cautious on the fact that research can become a very complex trendsetter as well. However, there are a number of modules in approaching research that can lead to the negative engagement of a study;

- Setting a research agenda as the sole prerogative of the researcher – this creates dependency;
- The social relations are built upon a clear distinction between the researcher and the researched – this attracts arrogance;
- Research is to develop separately from the people involved – this is hazardous and in this field of study treacherous.

### **3.8 ETHICAL CONSIDERATIONS**

Research is an activity that brings together at times two different contrasting realities - the researcher's and the informant's perception of truth. The researcher is more often than not conditioned to research for external reasons; money (it may be his/her job), curiosity, career

motivations, study or promotion. Ethical procedures in every study are there to ensure the protection of informants who more often than not are open to the 'elements'.

More problematic is the situation where the potential good for the many that may ensue from research conflicts with the rights of the individual. One possible reaction is that one knows that the infringement of the rights of individuals is immediate and certain, whereas the potential benefits of the research are less certain and one is less able to judge their merits. I personally believe that it is important to be open and honest in talking about one's research: after all researchers rely on other people being open and honest with them in order to obtain valid data. Perhaps the most fundamental principle involves asking how we would want others to treat us and to treat others as we would wish to be treated. This is not I admit, an answer to all the ethical issues, but I find it a helpful starting point (Crow 2000, p.80).

A number of ethical guidelines governed my work; I made it a point never to involve people in any part of my research without them consenting and having an informed choice. The motive why I was engaging with the study was presented in writing. When I had to work with informants under the age of eighteen years, I asked for parental consent, I was very careful not to expose the informants to any stress. This was all a very delicate situation because the people involved in my research, the people in the focus groups, those interviewed and those that contributed their autobiographies could have easily been recognised due to the close proximity of the places of work I was involved in.

Risk is a crucial factor in this study for the researcher but even more for the informants. The issue was addressed at several levels. Asking permission to record interviews (Arksey and Knight 1999). Another fundamental

principle I hung onto was anonymity. Malta is a very small community and the disability field is even smaller - and everyone knows everyone! Privacy matters, when it came to the autobiographies, was slightly more complex. Then again, to ensure that people felt safe informing me about their stories, prior to the presentation of the final draft of my *Thesis*, I sent in the stories they wrote as amended. Another provision I took was to write the stories I observed around me, especially in the school I worked at, so that the protagonists would not be recognised (Clough and Barton 1995; Wellington 1996; Denzin 1997; Goodson and Sikes 2001).

...we need to be clear about what we mean by ethics and ethical issues and concerns. Thus, in the context of research, ethical issues and concerns are generally understood to be associated with the following:

1. with what constitutes a 'legitimate' focus/topic of research;
2. with the conduct of (all stages and aspects of) the research;
3. with the behaviour of researchers;
4. with standards and/or codes of practice; in short, with 'acceptable' ways of doing things;
5. with broad issues of 'voice', values and validity.

The key ethical consideration is how the research affects the people whose experiences, perceptions, behaviours, attitudes, or whatever, are the focus of the study and who are the designated 'research population' (Goodson and Sikes 2001, p.91).

Disability is about researching oppression. Researchers should not be preaching "mythical independence" to disabled people, but joining with them in their struggles to face up to and overcome this oppressive mind-set (Barnes 1996, p.110). The guidelines that governed my ethical position were the following;



- It is necessary to ascertain that there is a professional judgement that is taking place all the time;
- I wanted to deal in this research with issues of consent, and how this may be obtained;
- Participants in my research will be informed on "the anticipated benefits, risks or costs" (Arksey and Knight 1999, p.129);
- I will be dealing in my work mostly with students under 'consent age' making it more delicate and appropriate to seek approval from the parents;
- I will be involving an institution in my research and the research could highlight both positive and negative dimensions of the respective organisation but keeping in mind that criticism was constructive.

Doing research has become in many ways an event close to the informants. Conversely, there are two issues that we as academics need to contend with. Firstly, there is a guise we are capable of wearing and skilful in operating. This makes us get into people's lives in a very tactful and unobtrusive manner. This in itself can be an oppressive attitude (Goodson and Sikes 2001). Secondly, there is the issue that disabled people seem to be contending with, and that researchers have learnt the politically correct language. 'We' are now able to speak the same language of the activists and there were some or many occasions when it has been used to ill affect (Clough and Barton 1995; Oliver 1996; Barnes and Mercer 1997; Barton and Oliver 1997).

### **3.9 TECHNIQUES IN RESEARCH**

#### **3.9.1 INTRODUCTION**

Occasionally, it may be appropriate for one to select the sample on the basis of one's own knowledge of the population, its elements and the

nature of one's research aims: in short, based on my judgement and the purpose of the study (Rubin and Babbie 1993, p.255).

Rubin and Babbie (1993), value the importance of detail that every little experience brings with it. This is an important principle that has guided my research methodology and choice of methods;

... the social researcher looks for clues, and clues of social behaviour are all around you. In a sense, everything you see represents the answer to some important social scientific question – all you have to do is think of a question (p.406).

I will be basing my research on auto-ethnography or rather personal reflections, on what I come across in my professional life. This work also has a large measure of story component. Semi-fictional stories are open-ended experiences giving an opportunity to the people who are contributing to voice their own particular interpretation of how their issues are being moulded. These stories were used as the core of the focus group discussions I had with an assortment of people that represent the sectors I am involved with.

This *Thesis* is founded on participatory and emancipatory techniques. Disabled people and students have a central role to play in this work.

In emancipatory research, the central purpose of research is seen as supporting the empowerment of service users and the making of broader social change. Mike Oliver, the disability activist and academic, identifies three key priorities of the 'emancipatory' research paradigm which the disabled people's movement has pioneered. These are reciprocity, gain, and empowerment. (Beresford 2002, p.99).



The aim of every methodology is to bring to light the strength and weaknesses of the methods that are being applied. Methodology is a vital part of every piece of research.

### **3.9.2 IN-DEPTH INTERVIEWING**

In-depth interviewing, also known as unstructured interviewing, is a type of interview, which researchers use to elicit information in order to achieve a holistic understanding of the interviewee's point of view or situation; it can also be used to explore interesting areas that require further investigation. This type of interview involves asking informants open-ended questions, and probing wherever necessary to obtain data deemed useful by the researcher. I used interviewing at the very start of my project when I spoke with four 'labelled' students on their experiences at school prior to writing the stories. Unstructured interviewing also came into my work when I was facilitating the focus groups. In-depth interviewing often involves qualitative data, it is also called qualitative interviewing. There seem to be two basic approaches to conducting qualitative interviewing which have proved to be at the centre of my operational framework;

- The informal conversational interview. This type of interview resembles a chat, during which the informants may sometimes forget that they are being interviewed. Most of the questions asked will flow from the immediate context. Informal conversational interviews are useful for exploring interesting topic/s for investigation and are typical of 'ongoing' participant observation fieldwork.
- The standardised open-ended interview. Researchers using this approach prepare a set of open-ended questions which are carefully worded and arranged for the purpose of minimising variation in the questions posed to the interviewees.



Appropriate interviewing skills are all part of a participatory research rationale. In this type of research, a group documents and analyses the collective experience of a social problem, placing it in a wider context of social, economic and political cause and effect, and integrating knowledge from outside the limits of the immediate experience (Bernard 1996). Participatory research is a process of critical and reflective investigation, which holds hope for the marginalized. Participatory research gives voice to those usually silenced and empowers people to scrutinise their experience as a means of effecting change (Bernard 2000).

### **3.9.3 NARRATOLOGY**

It is the strength of narrative that manages to surface these profound, intense and complex stories of people that know exclusion (Slee 2000) as an acceptable part of their existence (Ainscow 1999). The autobiographies I collated from the disabled activists, parent activist and the student with a 'label' of challenging behaviour were asked to tell their stories. I also used semi-fictional stories as a discussion platform for my focus group discussions. It is my belief that reflection on "inclusion" and diversity is a reflection on the culture which makes this whole thinking more interesting, productive and placed where emotions, passions and intuitions become part of a scientific method of understanding that reality. It is a method that allows the subject to be in control and present during the whole process. It has often been an important consideration to have a qualitative research that is particularly suitable where human activities and relationships are intransigently interlaced.

A new discipline, narratology (the term coined by Todorov in 1969) has slowly emerged which takes as its central task the analysis of stories and narratives (Plummer 2001, p.186).

Considering their role and importance within our lives, there is significant potential for using personal narratives for research purposes. A specific, well-established application of narratology in sociological research is life-story. Individuals are invited to tell the story of their lives or careers. The narratives used in this project were written rather than spoken but this is not an important difference. It merely tends to produce a more thought out outcome. Furthermore they were generally requested as stories about incidents in a person's life. The results are personal snapshots of experience. Given the circumstances of the data collection, students and adults selected their stories to satisfy my request by reflecting on the available personal experiences stored in their memories. The selected experience would therefore tend to stand out in their minds as the optimum choice. The process would represent a distillation of experiences (Goodson and Sikes 2001; Plummer 2001).

Two questions can be posed to explore the position of narrator and writer in collaborative narrative inquiry. First, how does the writer construct the life story of the narrator? Second, to what extent do narrators become involved in the writing of their own life story? (Goodley 1998, p.119).

Through life stories (Wellington 1996), the individual and the social dimension of the informant's experience meet in a relatively static environment bringing a reflective scenario.

I believe that the core of narrative lies in the fact that narrative and storytelling remain bound to a partiality of perspective and thus may reject any form of abstract universalism. Narrative can take different forms of narrative; historiography, oral life story, myth, novel or film as their point of departure. Within social action, there are issues of social, cultural and political belonging. I believe that the core of narrative and its social and



political importance lies in the fact that narrative and storytelling remain bound to a particularity of perspective, and thus must reject any form of abstract universalism. At first, this seems to contrast 'theory', 'concept' and 'narrative', but we also insist on exploring the possibilities of narrative theorizing. The argument always seems to bring it all down to a key notion; can we feature storytelling as a weak form of universalism? Can we find commonality in this method to the world of "inclusion", exclusion (Slee 2000; Stirling 1992) and diversity.

### **3.9.4 ETHNOGRAPHY**

Ethnography is often criticised for producing a weak basis for generalisations to be made. Thus, it might be demonstrated, very interestingly, that a pupil indulges in disruptive behaviour or engages in creative activity when subjected to certain treatment; some might ask, however, quite legitimately, 'to how many pupils does this apply?' We find it useful here to distinguish between internal and external validity. Internal validity refers to the accuracy of the account being presented as it finds its relevance to the people and the issues that are researched. External validity refers to generalisation to other scenarios (Denzin 1997; Clough 2001).

Ethnography is concerned with life as it is lived, things as they happen, situations as they are constructed in the day-to-day, moment-to-moment course of events. That is what I tried to engage with in auto-ethnography. I wanted to take the opportunity to reflect on what I am doing and how I am doing it in my varied roles; teacher, university lecturer, social worker, parent group adviser, professional ally to disabled people and policy development. I needed to seek lived experiences in real situations without disturbing the scene. I needed to be unobtrusive and ensure that data and analysis will closely reflect what is happening. This is not easy



because research becomes almost an obsession, of analysing, reflecting and trying to interpret at the same time that I am writing and noting facts and functioning within that same paradigm.

As a researcher I tried to make as few assumptions in advance on what tensions emerged and to make the familiar strange, not taking things for granted, questioning the bases of action and my own interactions. Though, at other times, profound acquaintance with the context and the people that make up the scene aided my insight.

The fact that I have been involved in most of the contexts that I was converging into my research, gave an added flux to a deep involvement in the natural setting. Social research is complex in its range and variability. There has been some dispute as to whether there are such 'real situations', let alone whether they can ever be represented in research accounts. However few qualitative researchers these days would subscribe to the view that there is one objective reality that is totally knowable. This holds to the view of knowledge as a representation of reality, but that can only ever be known partially.

Ethnographers seek to discover the meanings that participants attach to their behaviour, how they interpret situations and what their perspectives are on particular issues. Just as situations can influence perspectives, so people can redefine and construct situations. Research methods have to be sensitive to the perspectives of all participants, and must sample across place and over time as perspectives may vary accordingly. Researchers have to be close to groups, live with them, look out at the world through their eyes, empathize with them, appreciate the inconsistencies, ambiguities and contradictions in their behaviour, explore the nature of their interests, understand their relationships. Researchers try

to appreciate the culture of these groups, to capture the meanings that permeate the culture as understood by the participants, to learn their particular use of language, and to understand their in-group behaviour. The association of these cultures with social structures might then be traced.

I was interested in how understanding is formed, how meanings are negotiated, how roles are developed, how a curriculum works out, how a policy is formulated and implemented, how a pupil becomes deviant. These are procedural matters, not products. Social life is ongoing, developing, fluctuating, becoming. Some forms of behaviour may be fairly stable, others variable, others emergent. Some forms of interaction proceed in stages or phases. This again emphasises the need for long and sustained researcher immersion in the field in order to cover whole processes and produce 'thick description' (Geertz 1973) that will encompass this richness. Processes for example of cultural induction, labelling, identity formation, differentiation and polarisation, curriculum modification, friendship formation - all require lengthy involvement in the research field, otherwise only part of the process will be sampled, leading to ambiguous analyses. This was a most interesting but arduous process.

My pursuit in developing a methodology for this *Thesis*, that observes and participates in the experiences of the subjects is a model shared by Geertz (1973). Geertz would give this work more of an anthropological stance because of its way of reading through the culture, the experiences, the thinking and the symbols that construct the broader episode. It is a technique based on observation (Denzin and Lincoln 1998). The researcher him/herself 'exists' in the events that are being analysed. It is the role of the ethnographer to describe the rules that govern the researched group. The involvement of the researcher with the

group is of paramount importance – 'ethnography is exploratory' (Robson 1993, p.148). It is a *modus operandi* converging on direct observation of subjects within their culture and setting.

Although I have worked for various years in these settings, I have always respected my role as an outsider to this particular and specific cultural dimension. My observation takes place within a setting and an institution that is intertwined with complex dynamics and relationships. The symbolism is present in conversations (language) and behaviour, images and the general perception of the world (Halsey *et al* 1997). This may sound a very inhumane attitude by mainstream standards, it is a culture which needs to be filtered by a researcher, for this reality to emerge (Geertz 1973; Denzin 1998). The symbolism in all of this is multifaceted. There is a complex interweaving between values and tradition, virility and social status, basic instincts and ego.

There is, of course, no single answer to this question, nor can answers be given before the fact.... It is to enlarge the possibility of intelligible discourse between people quite different from one another in interest, outlook, wealth, and power, and yet contained in a world where tumbled as they are into endless connection, it is increasingly difficult to get out of each other's way (Geertz 1988, p.147).

We are moving away from autonomous educational methodology towards one structured around the needs of the school community and the students (Ministry of Education 1999). Unfortunately, the local educational situation does not tolerate enough differentiated teaching



techniques because of the strenuous syllabus that students have to capitulate. The administration of the school and the *Education Division*<sup>5</sup> consider themselves as the 'gate keepers' of the standards, values that need to be preserved, defended or changed as reckoned by them (Donnelly 1999).

The ethos at this school I work at prescribes the social reality that the students are riveted in (Donnelly 1999). When one analyses the situation with an auto-ethnographic perception (Halsey et al 1997), it becomes evident that what is deemed as natural, proper and right is conditioned by the people who control and have power.

### **3.9.5 ANALYSIS**

The validity and meaningfulness of the analysis is open to debate. The key disadvantage of qualitative research is the time involved. This project involved several hundred hours of work. Apart from the transcripts, the work was thoroughly enjoyable! The study has provided me with an extraordinary understanding of contemporary student life and the tensions and complex interactions that are happening between the different people engaged with the numerous facets of "inclusion". Many aspects can be mere glimpses that are too limited to provide basis for generalisation. There are four chapters (4, 5, 6 and 7) that will be analysing and bringing together the four research questions with my method/ological approaches. These four chapters will deal with the 'autobiographies' as a way of exposing the stories of children at the margins, 'semi-fictious stories' and the 'focus groups' will be analysed against the different perspectives in relation to transforming an agenda

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<sup>5</sup> The *Education Division* is the central administration that determines; recruitment in all state schools, classification of teachers, allocation of assistant/heads of school and other administrators, development of policy and also has an inspectorate role. In other words, it is the central nervous system of the national educational structure.

for "inclusion", 'ethnography' is analysed within practices that enable "inclusion" and finally, the 'analysis of narrative' will be seen in perspective of the extent that narrative research provides an adequate exposition of the "inclusion" themes being contested. Chapter 8 will bring in a meta-analysis of all the methodology and data analysis.

An important event that took place in my life, that influenced my analysis was the first module I had for my *Masters* some six years back. It was called *Insiders Perspectives*. This experience was my own 'road to Damascus'. I came in touch with the social constructions of disability and the accompanying debates, with the theory that underlines the social model, with the definition of disability and impairment as proposed by Finkelstein and the UPIAS in 1976. Since then I started meeting people like Mike Higgins, Jenny Corbett, Dan Goodley, Len Barton, Mike Oliver, Colin Barnes, people who have helped me fashion my own identity and ability to analyse the discourses in contention. This whole debate was flooded with argumentation. The combination of sociology with a qualitative research approach seemed to me an influential resource (Rubin and Babbie 1993; Cohen, Manion and Morrison 2001). Indulgence on one's data is the ultimate objective of analysis.

### **3.10 NARROWING DOWN ON THE INVESTIGATIVE FOCUS**

The challenge remains: how might the voices of boys with difficulty be heard? How might the system of their schooling seek to include them? ....Is there a place for them at all? (Clough 2000, p.79).

The main platform of my research lies in the school 'I come from' and where I spend most of my time and energy. This context will be debated in more vigour at a later stage but some characteristics that make the positioning of the school need to be mentioned;

- A densely populated zone.
- Neighbourhoods are more like extended family relationships than passive neighbourliness.
- People share common passions mainly religious feasts and partisan politics.
- Most inhabitants come from manual work background. A large percentage of the men work in either of the two dockyards situated in the hub of town, 'a low socio-economic status built around the dockyard and the port' (Boswell 1994, p.158).
- Children are rarely encouraged to pursue education and schooling (Sikes 1997) and are more interested to identify opportunities of work in manual oriented occupations and in trade (Sultana and Baldacchino 1994).

All these experiences breed the students whom I face everyday and are now participating in my study. Consequently, we need to find methods from available research approaches that can meet the requirements of this study (Bernard 2000; Holdaway 2000). There exists a culture of non-education. Generation after generation they have learned that education is not an option for them. Consequently, change in this aspect has to be a cultural change, if at all possible.

It took quite a while and a great deal of endeavour to concentrate all the ideas, all my curiosities into one investigative focus (Oliver 2000). The brain-stem of my research lies in the ability to engage with the discourse of "inclusion". This project was intended not only to establish one's career but also to reflect on my personal incongruencies in my professional practice, in my overt eagerness to share this reality I don't really make part of, to engage with a discourse about oppression when the disciplines



I have succumbed to in the past and present were entangled within an oppressive discourse.

My work does not engage solely with students and their experience of exclusion and "inclusion". It is also a debate I make from my own viewpoint as a researcher within a profession or rather a multitude of professions. My thinking is influenced by what I read, but it is also influenced by the way I live, the work I do. It is influenced by the social work context I am immersed in, the argumentation I have with university students, the struggles I have to face in a de-motivated, ill-equipped secondary school and the conflicts that emerge in a parents activist group as they plan their struggles against the hostility of professionals. My work is all about analysing, appraising and reflecting on these laborious issues.

As I narrowed my focus, a fundamental principle that guided me on the methods I was to employ (Corbett 1998). As a researcher I had my own biases, which were present at every stage of my work. There is no such thing as an independent researcher (Oliver 1996; Goodson and Sikes 2001). I had the responsibility of connecting with these preconceived notions, prejudices, and foregone conclusions (Oliver 1997; Barnes 1996; Bury 1996). As a researcher I felt compelled to assume a variety of roles; 'an agent of change', 'a critical friend' and 'as learner' (Clough and Barton 1995);

Of course all subjects – whether researchers or researched – act within an indispensably political arena; their acts variously realise policies as much as they are conditioned by them (p.147).

The main objective in my work was to keep "my voice and that of professionals as hushed as possible" (Swain and French 1998). The deep-

seated component of my research was influenced almost entirely in developing the right atmosphere for my research. This entailed that an adequate milieu was developed to enable the "voice" of disabled people. As soon as I started looking into different methods, it was immediately evident that I would have to face what Campbell and Oliver (1996) refer to as an "inherent tension", that such a choice brings with it.

Mark Priestly presents a fascinating position as a non-disabled person researching disability-related issues and continues in this e-mail;

As a non-disabled researcher, I'm certainly aware that it has often been easier for me to mobilise the resources and produce the outputs necessary to establish and maintain a career trajectory in academic research (M. A. Priestly, "In or out of the ivory tower", June 24, 1999).

Recognising my position in the whole process of research was a critical element (Bines 1995). These were the following core motives that contributed to these factors;

- Regular informal discussion with the disabled community in Malta;
- The importance of self-reflection and the need to have what Clough and Barton (1995) refer to as "critical friends" helped me reflect on every stage of my personal and professional rapport with disability studies (Barton and Oliver 1997);
- Respecting a literature review, which in various instances urges disabled and non-disabled researchers to synergise rather than polarise their expertise and experiences (Clough and Barton 1995; Oliver 1996);
- Individual researchers need to be committed to emancipator and participatory research values (Barnes and Mercer 1997) and "where we position ourselves between the social and material relations of

research production" (Oliver cited in Corker and French 1999, p.187).

### 3.11 VALUES AND METHODOLOGY

Researchers should advocate commitment not value freedom (or thoughtlessness), engagement not detachment. Academics coming from a professional milieu or not can either be with the oppressors or with the oppressed – there is a basic choice that needs to be made (Barnes 1996).

We recognise that many disabled people are suspicious of research (Oliver 1992; Morris 1992; Woodwill 1993), and we encountered this reaction when setting the project up. However, in conceptualising research as collective, self-reflective enquiry, we hope that some of these suspicions can be addressed. The following quotation captures our own position: 'The use of self - the influence/impact of self – plays an important part in the unfolding of multiple realities. In this sense, research becomes part of a shared enterprise or a joint search for truth; a co-production of knowledge' (Atkinson and Shakespeare 1993: 6) (Campbell and Oliver 1996, p.26).

My main concern in the research I was going to engage with was to find a theme on which to conduct a piece of educational research whose essential function is to generate knowledge and promote educational practice. It had to be a study that would lead to the amelioration of professional practice. Yet, with all the books that exist on our shelves, all the material that can be found in the *World Wide Web*, what could I come up with that presents to be original? The value of any research is adjudicated by its contributions to the improvement of professional practice. This reflection is in line with my commitment towards being in a



professional Doctorate. I wanted a methodology that would help me locate answers.

There are a number of decisive factors that contributed directly to my choice of topic (Clough and Barton 1995; Barton 1998; Goodson and Sikes 2001):

- There is a personal involvement in what I do. I am 'lucky' enough to be involved directly in most if not all of the contexts I engaging with in my research;
- I have analysed, documented, reflected and betrothed this topic repeatedly in my professional experiences;
- I have developed a great deal of ideas and reflections that emanated from my area of practice;
- I have followed my premonitions and allowed the research to take its course;
- I have never found it a problem to go back to the drawing board and allow myself to read into what is happening at that specific point in time.

Fundamentally, I will demarcate how a research dilemma was identified from my own personal experience and how this issue was transformed into an educational concept (Barton and Clough in Clough and Barton 1995). When engaging so closely to a research debate, my main concern was that of trying to get away from the hegemony of inclusivity and of listening to the social constructions as narrated by the people who live the argument of "inclusion". I wanted to find a way of trying to understand the social constructions, not as I wanted them to read but as the prime actors intended the message. This *Thesis* aims to identify the connection between the ideal world where "inclusion" is not an issue and the complexities and the consequences that such a notion brings with it. My

thinking is rooted in the social model of disability, which also influenced my choice of methodology (Campbell and Oliver 1996; Barnes and Mercer 1997).

### **3.12 MY RESEARCH**

#### **3.12.1 INTRODUCTION**

My work is based on a number of principles and concepts that underline my thinking. The methods and methodology that I wanted to engage with, had to be a process of emancipation (Campbell and Oliver 1996). I needed to apply a system that would help me design my thinking process. The research questions I engaged with were about the way stories of children at the margins can be used to promote critical debates about "inclusion". I wanted to look at the different perspectives of parents, policy-makers, disabled persons, teachers, students and social workers that I work closely with and explore how this relationship can be a transformative schedule for inclusive thinking. A crucial debate in this study is the analysis whether students in our schools fit within the social structures that contain them (Barton 1997) and whether schools tend to reproduce paradigms that are oppressive and exclusionary. To come to terms with the research questions I had to find methods that can help me read through this debate (Wellington 1996; Cohen, Manion and Morrison 2001).

#### **3.12.2 PILOT STUDY**

I carried out a pilot study. Prior to meeting the focus groups I sent out the fictional-narratives to two mainstream teachers, a disabled activist, a comprehensive teacher and a facilitator (teaching assistant). This pilot study helped me identify a number of grammatical and thematic issues relevant to my eventual sessions with the focus groups. Following the pilot study I listed out ten questions that were to be discussed during the focus

group sessions, eight based on the "inclusion" theme and another two focus on methodological issues (Wellington 1996).

### **3.12.3 FICTIONAL NARRATIVES**

From these stories I wrote five semi-fictional narratives to reflect those experiences. These narratives are an assortment of facts, fiction and issues drawn from other stories/experiences I have come across in my interviews with the students. These narratives were to serve as a basis for my focus group debates. I turned these interviews into narratives for two main reasons, firstly, I wanted to safeguard anonymity in a very exposed research context and secondly, from the literature review it emanated that it is easier that people discuss stories even if they are so closely attached to reality (Plummer 2001).

### **3.12.4 LIFE-STORIES TURNED TALES**

I have collected four stories of students that can be identified as having exacting educational experiences with particular 'labels' attached to them. They all attend at the school I teach at. One of them had a physical disability, another two had behavioural difficulties and one more came from a different ethnic background. All four students are boys, this being an all boys' school. The interviews I had with these students led to the design of the fictional narratives that were later presented for focus group discussion.

### **3.12.5 FOCUS GROUPS**

A focus group is a small group made up of perhaps six to ten individuals with certain common features or characteristics, with whom a discussion can be focused onto a given issue or topic.... It is often a homogeneous group of people.... The focus group sets up a situation where the synergy of the group, the interaction



of its members, can add depth or insight... My own view is that focus groups can be a valuable tool, efficient for collecting data and sometimes gives insights in addition to one-to-one interviews. (Wellington 1996, p.59, 63).

I organised six focus groups representing various interests and professional responsibilities; teachers, social workers, disabled activists, parent activists, secondary school students (with various 'labels') and university students. Each focus group had circa six people present and a critical friend with whom I had a discussion with on the outcomes of the focus group right after each session. I met each focus group once and every session took about one and a half hours. The sessions were recorded and then transcribed. Focus groups in my research have provided me with a wealth of insights and interesting debates. What was intriguing was the cross debate that in a way left the core theme to delve into the complex discussions as understood and perceived by the members in the focus groups (Wellington 1996).

This method is growing in the educational research field and in social sciences in general (Watterson 2000; Cohen, Manion and Morrison 2001). This system works equally effective amongst strangers and people who know each other. The theme that is being debated seems to bring the people into a coherent framework that governs the dynamics of the group. The people who engage with these focus groups spoke highly about the process. They enjoyed the experience of being and talking together. One participant in a focus group said:

When you read stories, you start understanding more coherently the issues that are being passed on. Because in reading a story you're going to engage with it, you're going to feel the spirit there is. Questionnaires are artificial. Just a question and an answer. In a story you will get it, read, think about it. What I found interesting was the discussion we had in

the focus group. Certain stories I read them 'differently' than other people. This helped because I could reflect and come up with my own conclusions (*Anthony, Social Worker*).

All the findings I will endeavour to list in this work suggest multifaceted and contradictory dynamics (Anderson 1997; Cohen, Manion and Morrison 2000). In the field of disability studies, whatever issue is being debated is composite and immersed in tensions. The stories I write about, the reflections I make, the interpretations I give are a clean sheet on which thoughts about disability, citizenship, and social constructions can be written. This research was also about the processes involved when interacting with others who are in some way different to them and how they manage these encounters. The debate that will take place in this chapter will also focus on identity formation - stories tell about us (Booth and Ainscow 1998; Clough and Barton 1998).

The concept of 'identity' has become both a contested and a prolific field of research and theory in recent years. Identity is also, as Shakespeare (1996) has argued, a major area of conflict between disability studies and mainstream social science. Hall (1996) has suggested that within the social sciences there are two historical and strategic approaches to the production of identities. The first model is based on the assumption that there is an essential, natural or intrinsic meaning to any identity.....The second model denies the existence of any identity based on a shared origin or experience. Identities exist only as opposites, they are multiple and temporal, and to propagate the concept of, for example, a male and female identity, or a disabled and non-disabled identity serves only to strengthen essentialist arguments (Watson 2002, p.509-510).

There were six homogeneous focus groups I assembled. Every member was purposively invited (Rubin and Babbie 1993; Cohen, Manion and Morrison 2000). Each of these focus groups represents a portion of my professional life commitments. Some of these fragments are not directly involved with "inclusion", in the narrow understanding of the word, where "inclusion" comes to be defined as the placement of all school children in mainstream schools (Clark, Dyson and Millward 1995). Each of these clusters contributed to my own understanding of "inclusion".

It is essential to regard the struggle for equity in the disability area as part of the struggle for a just society on a broader front (Wills cited in Ballard 1995, p.8).

However, I would say that my main source of data collection featured around five semi-fictional stories that were given to all those who participated in my focus group discussion. I gave out the stories beforehand (two weeks) and asked the informants to reflect on these stories, which were to be the cornerstone of our debate.

Focus group interviews can provide the researcher with detailed and carefully considered qualitative data from the people most knowledgeable about research issues (Anderson 1997, p.1).

The debate in the focus group centred around the following extremely interesting issues and debates that came around from the second research question where the different perspectives of parent and disabled activists, teachers, university students, 'labelled' students and social workers expound an agenda for "inclusion".

This intricate research question amalgamates the core debate that informed my outlook about "inclusion" during the discussion that took place during the focus group sessions. The primary outcomes from those



debates are centred on the notion that the stories say something to all of us. Somehow, practically every member of the focus group managed to identify with every question that was taking place. The stories tell us a lot about how differences are being accommodated or not and the main policy and strategic issues that trickle from the stories.

The essential concerns in the inclusive agenda were debated. The experiences that are taking place in school are effecting in one-way or another the future of these children (Bassegy 1999). A discussion took place on the composite notion of conformity and how schools tend to be laden with compromises with the added concern that schools are not organised enough to respond to narrow-mindedness when it comes to diversity. The collective experience appears to vanish (Thomas and Loxely 2001). The following is an account of the six focus groups;

- Teachers. They were purposively selected for their interest in my work and for the fact that we have talked about these issues in the past. The teachers that were selected came from an assortment of specialisations; maths, languages, sciences and student support services. This group also included two of the three facilitators who's responsibility lies in supporting students that have been statemented. This was maybe one of the most complex of the focus group sessions I had. The main reason is that they could see through the fictitious stories and read right through the narratives, because most of the stories used the characters and the events that were taking place in the school they work at.
- Social workers. I am the *Service Area Leader* in this social work team. I consider these people as colleagues and critical friends. We discuss the various issues surrounding disability construction in our daily work routine. We have also worked a great deal with a number of schools in helping them design *Individualised Education Programmes*, supported schools in general, teachers, facilitators

and administrators in all circumstances that required trouble shooting. We work closely with parents, siblings and the disabled and labelled students as well so that their school experience can be as effective as possible. All the social workers in the team were involved, due to the fact that they are only a group of five social workers.

- University students. This focus group was made up of a range of university students I worked with this year. They came from the following courses; student teachers, psychology students, social work students and student facilitators. I also had a student that is working on her undergraduate dissertation with me.
- Labelled students. This focus group was based on a number of students who have been labelled as being difficult to cope within school. They were selected on the criteria that these five students are completely excluded from every activity that is happening in school, they achieve low marks in examinations and have been unofficially branded as having educational deficiencies. I told them the stories rather than giving them the stories to read because of their low literary skills.
- Disabled activists. This was a focus group that was made up of a number of key disabled activists in Malta. At some point or other I have collaborated with these people in the field of disability.
- Parent activists. These are also a group of parents that have disabled children but are very much involved in the disability field. They all come from different (mostly) impaired based groups. Due to the fact that their children had different disability (sensorial, physical, intellectual and multiple impairments). They brought in different contrasts and emphasis.

It was incredible for me to see how they were the same stories but given a particular interpretation and characteristic on different levels; personal,



societal, social justice, tolerance etcetera, etcetera. University students emphasised the need for training and policy and to do research at an academic level. Teachers stressed the importance of...the experience in the classroom. Interesting really interesting (Andrew, Researcher).

Before featuring the debate, I gave a clear position of the 'what's and why's' for the use of these methods.

One of the things that I will be doing in my research... I have a problem in this research, which is that I cannot say 'look my target is that ...' generally when you do a dissertation you almost start with the conclusion. I cannot. I am depending a lot on you people, on what disabled people have to say. ... But the reason is that what I'm looking for is how are these stories affecting 'me'? How is this reality affecting 'me', and the other is: the participative and emancipatory aspect. The focus group that I'm doing is with the areas I'm involved with in my life, you, social workers, university students, etcetera. I'm also doing it so that I can help you think. ...the process in itself is not only for me but to give the opportunity for people to think and not necessarily agree,... but to think (Andrew, Researcher).

The members of the focus groups accepted that these narratives are a reality, a veracity that is difficult to come to terms with.

This obviously came out in the pilot study. What you said exactly, that ... I was exaggerating and that it cannot be that teachers are depicted in such a negative way ... it's not fair that we do this.... And for you, is it good like this? Do you have a bias? The issue of bias always emerges, you understand? (Andrew, Researcher to Teachers).

There were methodological issues involved:



Apart from this, when I read them I realised how much I became immune to the things that go on here.... I've let them go by. And then I was faced with these events on a paper where I could reflect on them (*Lorna, Teacher*).

Teachers have raised an important question here about whether they have become immune to all the stories that are happening around them. I speak also about the risks I have to take in my work, especially methodological risks that could leave me without a traditional conclusion or outcome. They continue to speak about "inclusion" as a process whereby the changes have to come from the school and from the individual teacher.

They also say that the policy (such as the *National Minimum Curriculum*) does not have the answers and will not resolve the issues that need to be addressed as they are told at University. They mention that inclusive education opens up their understanding and vision and that disability is much wider than just having a disabled person in a school.

Another thing that I think came out of this is that inclusive education opens up a lot our perspective. Many people think that it's inclusive because you have a disabled person... no but the people's perspective is not mine that when they find a disabled person they say 'so let's help him'. In our case we have problems that are 'disability' but are not visible, and to pin point them it's much more difficult than... (*Lorna, Teacher*).

### **3.12.6 CRITICAL FRIENDS**

For each focus group I had a different critical friend who observed the session, took notes and then together we discussed the outcomes of the focus group after each session. The points that emerged were put in writing. The people who acted as critical friends did not involve themselves in the debate during the focus group *per se*, they were silent

observers. The value of having critical friends in every piece of research is indispensable. This whole concept of auditing and self-analysis is given different interpretations by different writers. However, my argument stands ground on the need to find ways how our work does not become a way of making the researcher feel 'great' but a way of providing a revamp to our thinking processes (Clough and Barton 1995; Bassegy 1999). My critical friends were attached to the focus groups because of the intensive debates that I predicted would take place. Their role was to follow up the argument treads that were taking place.

### **3.12.7 AUTO/BIOGRAPHIES**

Auto/biographical research frequently raises unanswered questions, as well as identifying the paths and journeys that have been left behind because of painful memories and experiences (West 1996) ...Auto/biography also implicates the researcher in her own personally reflective truth-seeking and experiential reconstruction. This search takes her to places where multiple regimes of truth reveal themselves and may be highly contested, where the self and the 'subject' of the research are challenged, particularly since auto/biographical research challenges the conventional distinctions between self and other. (Chan 2001, p.1).

I have collated six stories of people I know from the 'field'. Most of these people have become friends. These auto/biographies will be focusing on the notion of "inclusion" and how this concept of "inclusion" is read from the different perspectives they emanate from. In five of the six pieces I collated, I used e-mail as the technical means of getting the data. On the other hand, I interviewed the sixth person because he didn't have access to e-mail. The whole process of my research as having components of auto/biographies lies in the notion of giving voice, of letting the protagonists have their say, of offering an opportunity for the



informants to speak their heart and soul (Campbell and Oliver 1996; Oliver 1996; Clough and Nutbrown 2002; Goodley et al 2004).

Taking an auto/biographical approach to making sense of social experience involves the interpretation, not only of the perspectives of those about whose lives questions are asked but also of the perspectives of those who ask the questions. Dorothy Atkinson writes about her research in the first person: 'there is my voice too, for in working with people, transcribing their words and assembling a collective account, this is also my story' (Atkinson 1997, p.22). The recognition of the inevitably autobiographical character of my own writing both simplifies and complicates: it is a release to value my own perspectives but their explicit "inclusion" adds layers to the already intricate work of analysis. (Potts 1998, p.22).

**FIGURE 3.1 FIELDWORK SUMMARY**

METHOD	INFORMANTS
<i>Pilot study</i>	I engaged with a pilot study that included the analysis of the first part of my work. The following were involved in this process; two mainstream teachers, a facilitator, a disabled activist and a comprehensive teacher.
<i>Student stories</i>	The student stories which I collected through interviews were part of the initial process as part of the writing of my fictional narratives. These students were labelled as being; emotionally disabled (two students), physically disabled and another student came from a diverse ethnic background.
<i>Phase 1: 6 auto/ biographies</i>	<i>Dean, Cynthia, Sandra, Conrad, Jane, and Adam</i> all wrote their own stories.  <i>Research question:</i> In what ways can the stories of children at the margins expose issues of "inclusion" and exclusion?
<i>Phase 2: 6 focus groups</i>	The use of the student stories was utilised to design fictional narratives that were used for the focus groups. There were six focus groups that represented my principle areas of professional involvement; social work, teaching, teaching at university, work with students with emotional and behavioural labels, contact with disabled and parent activists. A meeting with a critical friend took place right after each focus group session.  <i>Research question:</i> What are the different perspectives of parent and disabled activists, teachers, university students, labelled students and social workers in relation to presenting a transformative agenda for "inclusion"?
<i>Phase 3: Auto- Ethnography</i>	Ongoing personal reflections as I moved from one area of practice to another.  <i>Research question:</i> To what extent does narrative research provide an adequate exposition of "inclusion"?



### 3.13 METHODOLOGICAL VALUES

...vary in their general ability to promote the positive development of their students, whether this is in academic progress, attendance, behaviour, or attitude formation. The consistency of school effectiveness in promoting different student outcomes, however, is an area of considerable complexity (Mortimore 1997a, p.79).

The following are the methodological values that will guide this work. First and foremost, I need to bring about change from a grass-roots perspective. This can only be achieved by focusing on the actual situation in which a need for change has been identified. It is necessary that the area in which transformation is required is specified. The 'action' which is decided upon to anticipate changes is then projected and alterations are monitored, weighed up and evaluated. Finally the "...the intervention strategy... is reassessed..." continually to ensure coherence, consistency and lucidity (Armstrong 1994, p. 2).

My work will be guided by values, which I have developed for myself during these years that I was engaged with the field of social sciences and disability (Clough and Barton 1998). The varied experience I had helped me to start thinking seriously about disability and the values that I can extrapolate from the contact I was making with the people involved in the scene. I did voluntary work in all the residential homes that exist on the Island, both the small community homes and the larger institutions. I also did some work at the mental health hospital. For four years I worked in a respite agency as a community worker, driver, support worker, care manager and social worker. I was involved in the different tasks that had to be done. I work with university students, in policy development and in service provision and development. I was involved in self-advocacy and activism. I touched upon most of the issues. All this association and

interaction contributed to my value base. Coming from a Catholic background also influenced (maybe prejudiced) the formation of my values. These different experiences taught me five important factors; firstly, there is the issue of the disabled people's voice, which tends to be muffled. Secondly, there was the worth of emancipation (Barton and Armstrong 1999; Corker and French 1999). Thirdly, part of the disability community always considered me as being an outsider. It was only a small portion of this community that considered me as a professional ally. Fourthly, there is often a collision between the personal and professional. Policy makers and activist seem to find it difficult to cope with the varied personalities that exist. Finally, I engaged with the principles of the social model of disability (UPIAS 1976; Oliver 1996).

Naturally, the most complex process that follows in my research was to find the relevant type of methodology that will suit my attitude and way of thinking, my personality, interests and my research questions. My preliminary criteria was that of trying to get away from the hegemony of inclusivity, of listening to the social constructions as narrated by the people who live the argument of "inclusion" rather than listen to the distorted commentary of people from 'watch towers'; analysts, researchers and self-made experts. I wanted to find a way to try and understand the social constructions, not as I wanted them to read but as the prime actors wanted them to be heard. This *Thesis* aims to identify the connection between the ideal world where "inclusion" is not an issue and the complexities and the consequences that such a notion brings with it. My thinking is rooted in the social model of disability (UPIAS 1976; Oliver 1990a; Finkelstein 1999).

Potential topics emerge during analysis. The researcher may expand or 'tease out' the variables that surface. The researcher should be prepared



to change direction as new themes ascend rather than hanging on groundlessly to some embedded principle. As the collecting and analysing procedures are carried out, the researchers compare data and look at the relationship among the variables from time to time until the spot starts focusing on a core concept. This is not an easy process. The more you read about the theme, the more issues you want to engage with, question and debate. The core variable should illuminate the 'main theme' of the participants' behaviour and explicate 'what is going on in the data' (Glaser 1978). Hutchinson (1988) suggests a way to identify the core variable;

The core variable has three essential characteristics: it recurs frequently in the data; it links the data together; and it explains much of the variation in the data. This variable becomes the basis for the generation of the theory. The categories, properties, phases, and dimensions of the theory are inextricably related to the core variable (p.133).

Having identified the core feature to be analysed I engaged with a broad collection of literature because even though this was a localised piece of work and contextualised in my profession, I still needed to examine the issues against the literature related to the theme, because data should not be collected and scrutinised in a vacuum. The data that I collated had to be systematically entrenched in accordance with the direction taken in the study. I attempted to pull data and literature together in order to look for meanings and insights. The insights gained from the investigation had to lead to the implications of the research. The only dilemma I had was, how to propose a thinking process that is not entangled with clichés on how I'm going to change the world.

Due to the nature of qualitative research, investigations related to this methodology are often connected with methods such as in-depth



interviewing, participant observation and the collection of relevant documents, which in turn generate qualitative data such as transcripts or text.

A major constituent of well-collected data is when the focus lies on naturally occurring, commonplace events in ordinary settings, that we may have a strong clasp on what 'real life' is like.

### **3.14 METHOD AND METHODOLOGY**

Methodology is the science of finding out, of discovering and revealing. It is a sub-field of epistemology, which in many ways is the 'curiosity' that is generated through the process of finding out (Rubin and Babbie 1993). The method is the tool or tools that are going to be applied for this task.

My focus is research methodology. By this I do not mean "methods" of data collection. There is too frequently confusion between these two terms (methodology and methods) which, to me, are wholly different concepts. If I compare the research experience to an archaeological expedition, then the methods will only be the spades and technical tools used to dig up the treasures. The methodology, however, includes all the planning, the values and reasons behind the journey, the choice of companions, the choice of transport to get there, the decisions on which way to get there, the etiquette and behaviours agreed between colleagues during the dig. It includes the responses to objects uncovered, the decisions on what to do with them, who owns them, who should keep them, how they should be kept, and where and when; and the analysis of the importance and value of the objects at the end of the expedition (Stubbs 1999, p. 259).

Oliver (1997) has engaged with a very complex debate on the issues that are generated through research and the methodology applied for 'their'

studies. He speaks about the political role of research and the involvement in this project in understanding and debating the nature of disability studies. The methodology and methods applied seem to take centre stage in research. It is a decisive move towards emancipatory and participatory discourse (Barnes and Mercer 1997; Swain and French 1998). They draw to an especially interesting dilemma, where the progress of methodology are commensurate with the participatory research framework (Barnes and Mercer 1997).

I will not be applying a style of educational research that is historical. Historical research is mostly associated with evaluating and analysing objective factual evidence of a previous epoch, phase or episode (Cohen *et al* 2000). This research will also do away with quantitative surveys that are longitudinal or cross-sectional. Choosing not to engage with such methods is derived from the fact that this type of methodology will focus on describing and interpreting social conditions against comparable evidence. Apart from that, this type of data collection is too structured for the purposes of my study. My intention is to grapple with limited factors observed in depth. This work depends to a large extent on the interpersonal and intra-personal dynamics that would most certainly be wasted in statistical surveys. This study is also exclusive of experimentation and testing out of facts. This method of research surfaces several ethical dilemmas when we treat evidence emanating from social situations in an inanimate and detached way. It is a methodology, which imposes a lot of control and restraint (Cohen *et al* 2000). Consequently, the strategies for the compilation of information will not include structured questionnaires, different forms of tests, statistical measurement and role-play methods.



This eclectic approach to research will entice a variety of methodological styles and techniques into play. Nevertheless, the research will draw on the action research framework as its main methodological tool.

Nonetheless, I will be triangulating 'a mixture of methods' to ensure that I will extract the maximum amount of accurate facts. It is what Wellington (1996) calls 'a way to bring together the data in a clearer and affluent way'. Triangulation will most surely converge various methodological perspectives into one path of action.

Action research [is] a subset of educational case study research: enquiry carried out in order to understand, evaluate and change... action research could always be recorded as a 'story telling' case study and often might be written up as either a theory-seeking study or a theory-testing study (Basseby 1999, p.41).

### **3.15 FOCUSING MY RESEARCH**

If emancipatory research emphasises the equalisation of research relationships, changed social relations of research production, empowerment, and social change, the focus of user-controlled research lies with whoever originates and makes decisions about research and evaluation. The general contention is that such control is rarely positioned with the (disadvantage and oppressed) groups which are most liable to become research subjects (Beresford 2002).

If the culture of the teacher  
is to become part of the consciousness of  
the child, then the culture of the child  
must first be in the consciousness of the teacher  
(Bernstein cited in Brooker 2000, p.2).

I would hope that my work would contribute to a better grasp of my own experience in the contexts I am involved in that enables me to reflect on my own work practices (Condliffe Lagemann 1997). It would elucidate what I bring as a person and as a professional to the experience of the



people I work with that come from a culture and milieu which was alien to me until some time ago (Mortimore 1997a).

This community of students puts to the cord my value scales and ethical principles. So do all the other professional experiences I have to face and struggle with and for. The research approaches I engage with have the responsibility to represent all these intricate dynamics (Bassegy 1999). The objective of this project is that of bringing students and survivors together to discuss, analyse and to react collectively (Arksey and Knight 1999; Armstrong 1999; Bassegy 1999) and individually. It is an opportunity for all to be transformed in this aspect of their life even if the institutions are very strong and rigid. This *Thesis* has the crucial role of bringing in the voices of the people that are involved and engaged with different perspectives towards an agenda for "inclusion".

Students need reassurance that they can generate valid knowledge through careful research of their own....

Increased awareness of the students about their world can lead them to useful solutions of the problems affecting their lives....

Students can be trusted to be creative in finding solutions to their problems and in reflecting upon these solutions....

In order to benefit from enquiry projects, disadvantaged students need an increased understanding of their social conditions and this increase in understanding would allow them to act to change these conditions (Atweh, Christensen and Dornan 1998, p.120, 121).

### **3.16 CONVERGING RESEARCH AND METHODOLOGY**

The research questions derive from a theoretical understanding incorporating in it; the context and the focus that the research will engage with are contained in a method that responds to this inquiry (Robson 1993). As Robson (1993) explains, the research questions develop

following the identification of the topic under investigation, in this case, whether the stories of children the margins expose "inclusion" issues, whether the perspectives of different people I am engaged with present a transformative agenda, what practices enable "inclusion" and finally whether narrative research represents "inclusion" adequately.

The school offers an opportunity for the individual to develop whatever talent he or she possesses. In doing so the individual is aided or hindered by a range of other personal variables to do with their temperament, their motivation and their attitudes' (Mortimore 1997b, p.483).

This work is about the events that take place in schools. Encouraging students to share this part of their life story (Sikes 1997) will reflect these experiences. The research in itself will provide the platform for these children to tell their story.

Methodology is ....the activity or business of choosing, reflecting upon, evaluating and justifying the methods you use. Indeed, the latter is an essential feature of any written report or research *Thesis* i.e. justifying the decisions we have made on methods (Wellington 1996, p.16).

The research methods include three crucial notions;

- The development of research in a way that allows space for the informants to express themselves (Robson 1993);
- The development of a research approach that influences the actions to meet these targets (Robson 1993) and to engage with this research discourse (Wellington 1996);
- Allowing space for the reader to make out of this work the conclusion and recommendations s/he wishes.



### 3.17 TOUCHING UPON MY METHODOLOGY

Why choose this methodology? I need a methodology that is emancipatory in its thinking and style (Cohen *et al* 2000). An ethnographic approach will help feature the cultural diversity of this group of students (Bonai and Rambla 1999). This methodology, because of its emancipatory thinking and ethnographic style will bring the cultural diversity of this group of students to light. What is labelled by the teaching community as street language and fastidious behavioural patterns, will for this occasion have the opportunity to surface, listened to respectfully and analysed by the informants themselves (Freire 1970). Most professionals are looked on by their service-users as 'strangers'. It is here that I take on a 'practical positionality' and align myself with the people that are sharing their story (Allies 1999; Stroh 2000).

As already debated, this study will opt for the use of structured observation methods, ordered interviews and a lot of informal discussion with my respondents. These strategies will be shaped within a participatory research methodology, which can guarantee emancipation. It is a strategy that gives an opportunity for all participants to have an active say in what is written and whatever action is decided upon (Armstrong 1994). The potential efficacy of a school will be investigated through the data I will be gathering with my informants. What will govern the research is the students' and the other protagonists own understanding of how they perceive achievement and fulfilment (in life). However, this work is a strong presence of where I stand, what I think and how I am effected by all these discourses.

Lawrence Stenhouse would have been profoundly against the malign influence of 'performativity' which is such a pervasive feature of the day (Broadfoot 1999, p.3).



The manner the research is structured will provide the platform for the informants to tell their story, in particular their experiences with school. It is vital that research is supported by the right methodological concerns (Arksey and Knight 1999). Ethnography is highly dependent on the observation of a community or any feature within society (Armstrong 1995). This is the reason why such a style is of value and importance, because of what it brings to the researcher in the variety of experiences (Bell 1999). My role as a researcher is immersed in 'this form of observation' with a participatory element. Ethnography within this study will focus predominantly on how experiences can be transformative for students and others involved in this research.

Research in reality is never a neutral process (Clough and Barton 1995). It is always aligned to one or another point on the continuum. My language, the development of my idioms and narrative will make certain that I serve primarily as the author and narrator of what informants want to convey. Using this methodology of narrative life story within the participatory research framework will encourage the informants to reflect on their experiences, past and present (Robson 1993). This work will allow space for students to put forward their recommendations, expectations and vision for better schooling. Naturally, the use of narrative will obviously shift us towards an interpretivism, with a central, subjective and possible static account. In this process, we will be developing a liberating methodology (Cohen *et al* 2000; Freire 1970).

Valuable research will condition me to develop on this program of enquiry.

At this point, you may realise that it will be necessary to refine some of the questions. Ask yourself precisely what you mean by each one.... Each stage is a process of refining and clarifying

so that you end up with a list of questions, tasks or objectives which you can ask, perform or examine (Bell 1999, p.24).

Working in a natural setting will support appropriate and "real world research" (Robson 1993, p.60). This study will connect participatory, ethnographic and emancipatory methods (Marshall, Cobb and Ling 1998). In itself, the study will have to be inherently consented to by the informants (Robson 1993). Any research project requires that such a study will guarantee discretion and anonymity when it comes to the informants (Bell 1999, p.38). The type of study I developed necessitates that the informants are protected because they will still make part of the institution that is being analysed (Cohen *et al* 2001). The research ethics that will be applied will safeguard the nature of this agreement (Robson 1993) as argued earlier on.

### **3.18 METHODOLOGICAL SHORTCOMINGS**

A number of events are linked to the effectiveness of this research. What follows are a few concerns that accompany these events;

- There may have been insufficient time to work on this research. Rushing this program may bring about shortcomings when it comes to interpreting, reflecting and acting on the recommendations made by informants (Cohen *et al* 2000).
- There is also the threat of having a limited context focused understanding of this work. This study may find it difficult to represent also the situation of other similar settings (Atweh *et al* 1998). This overly narrow notion of research is bound amongst others by the environment, social-class and ecological factors (Chircop 1994; Jackson 2000).



- This study may even loose out on the crucial dynamics that are taking place 'after hours', when as a researcher I would not be physically present.
- The outcomes of the research may not be taken into serious consideration because the educational structures are controlled by a strong Central Administration. The structures, to date, do not allow the autonomous development of the curriculum and pedagogy particularly if they are different from the norm (Atweh *et al* 1998; Giordmaina 2000).
- Another possible shortcoming is the language I will be using in the presentation of my work. Will my work be linguistically legible to children? How will my style of writing reflect what the students have to say? Will my work in effect be accessible to the students and still maintain a scholarly level (Arksey and Knight 1999; Jackson 2000)?
- People are after straight forward, quick-fix solutions. I don't present any of these because I strongly believe that "inclusion" is a whole school/community effort (Bartolo *et al.* 2003).

Presenting my final product will raise a number of complicated and intricate matters that include ethical considerations and suitable methods. Methodological questions can only be resolved once the research problem has been adequately specified' (Jackson 2000, p.252). Therefore, from the initial sporadic ideas followed by a few research questions, I was able to build in a methodology that gives space to all possible results (Jackson 2000).

Developing a case for using particular methods necessitates that as researchers we are sensitised to the context. Rather than attempt to change the thinking of my informants, as a social scientist I will intervene



minimally into the lives of my students but actively participate in the whole event (Holdaway 2000).

Thus, on a theoretical echelon, it is possible to have predictable outcomes and all those engaged can potentially predict the effects of the process that they engaging with in the present context. This will obviously entail that people who are in control of educational and service products are able to position themselves better and produce materials and pedagogies that fit with those emerging and projected needs. The forms of enquiry include methods such as survey, questionnaires and comparative experiments. The scientific research paradigm has the strength of precision and accuracy. However, this concept is not without its criticisms. A major characteristic that has taken me away from this method is the lack of understanding there is of human beings as individuals in their entirety and their proper context is neglected, resulting in a partial, distorted picture of social reality.

On the other hand, the central concern of the interpretative research paradigm is that of understanding human experiences in a holistic dimension. Researchers of this kind interpret the complexities embedded in these experiences to seek meanings and illuminate their significance. The value which I extrapolated from interpretative research is because it is a system that is often conducted in natural events (Lincoln and Guba 1985). Human experiences are shaped in contexts and best understood as they are found, in other words in their natural surroundings. Maxwell (1992) argues with Guba and Lincoln (1989) for the need to replace positivist notions of validity in qualitative research with the notion of authenticity.

'Understanding' is a more suitable term than 'validity' in qualitative research. As researchers, we are part of the world that we are

researching, and we cannot be objective about that, hence other people's perspectives are equally as valid as our own, and the task of research is to uncover these. Validity, then, attaches to accounts, not to data or methods; it is the meaning that subjects give to data and inferences drawn from the data that are important. 'Fidelity' requires the researcher to be as honest as possible to the self-reporting of the researched (Cohen, Manion and Morrison 2000).

The exciting value of interpretative research lies in the fact that the exploration that surrounds circumstances and events is facilitated by beginning the inquiry from the roots, those that are effected by the issue in contention. My experience as a researcher, at the beginning of the enquiry, and at times even during the same process that was involved do not know directly what they are looking for. As a researcher I started the research with a broad focus in mind, which was derived primarily from literature, previous research I was involved in and personal experience. The broad focus is initially open-ended, allowing for important meanings to be revealed with time and through actively engaging with those same processes. This method led me to an emancipator approach.

If emancipator research emphasises the equalisation of research relationships, changed social relations of research production, empowerment, and social change, the focus of user-controlled research is with who originates and makes decisions about research and evaluation. Its general contention is that such control rarely lies with the (disadvantaged and oppressed) groups which are most liable to become research subjects. While as yet there are not any agreed definitions of user-controlled research, as the term makes clear, it is committed to service users being in control. Discussion of user-controlled research has developed in parallel with that of emancipator research. So far, there has been little attempt to



connect the two discussions (Beresford 2002, p.100).

In emancipator research, the central purpose of research is seen as supporting the empowerment of service users, and the making of broader social change.

Mainstream discussion about user involvement in research and evaluation. There is now a growing interest in more participatory approaches to research and evaluation, particularly in public and social policy and specifically in health and social care (Kemshall and Littlechild, 2000). So far, what discussion there has been has tended to be uncritical. 'User involvement' in research has generally been presented as a 'good thing' and counter views have so far tended either to be focused on perceived deficiencies in the methods and methodologies employed or not have been clearly or publicly articulated. (Beresford, 2002, p.25).

Mike Oliver, the disabled activist and academic, identifies the key priorities for the 'emancipatory' research paradigm, which the disabled people's movement has pioneered (Oliver 1992, p.111).

This disillusion with existing research paradigms has raised the issue of developing an alternative emancipatory, emancipatory approach in order to make disability research both more relevant to the lives of disabled people and more influential in improving their material circumstances (Oliver 1996, p.141).

### **3.19 CONCLUSION**

Choosing the appropriate methodology helped mount a project within the social reality I am engaging with because specific research gives a particular interpretation of that significant reality (Holdaway 2000). My methodology will attempt to captivate the intuitions of the students and the instinctive reactions, which I hope to provoke. This methodology has



unquestionably created the right conditions for a dialogue that allow one to reflect on the various educational processes. Richard Shaull in Freire's (1970) introduction to his book wrote;

Freire is able to do this because he operates on one basic assumption: that man's ontological vocation (as he calls it) is to be a Subject who acts upon and transforms his world, and in so doing moves toward ever new possibilities of fuller and richer life individually and collectively (p.14).

The objective is that this project is not only emancipatory (Bernard 2000) also serves as a process of self-reflection. At the centre of this achievement has been our ability to turn 'vulnerability' into strength. Put simply, our 'natural' frailty has served as an incentive to cultivate extreme flexibility in interpreting ourselves and the world in which we live. Building on the application of interpretations that have been passed on from generation to generation we have acquired an accumulated body of knowledge which has enabled us to transform the 'natural' environment into a 'social' world for our own making.

The more we refine our methods, the more rigorously we apply them, and the more skilled we become in the art of writing, the closer we approximate to the reality that we are scrutinising. Knowledge is never total or certain and it can be provisional, and subject to alteration or refinement. There is no fixed, immutable truth in social science, no design by which things all fit together once and for all.

.... improve the efficiency and effectiveness of educational experiences. In my view, what earns research the adjective 'educational' is this moral commitment to putting learners in the way of a better lot in life through making some contribution to the effectiveness of educational processes. From this point of view, the purpose of educational research is to extend the knowledge

base for teaching and learning using best social science practice.... Educational research, if it is to be judged effective, must make a difference to the experience of participants in educational settings (Desforges 2000, p.1).

# CHAPTER 4

## Mapping Out A Transformative Agenda : Snooping Into Lives

*What he learns there is what his culture's ethos and his private sensibility (or, anyway, certain aspects of them) look alike when spelled externally in a collective text; that the two are near enough alike to be articulated in the symbolics of a single such text; and the disquieting part that the text in which this revelation is accomplished consists of a chicken hacking another to mindless bits (Geertz 1973, p. 6).*



*Sam is wearing his blue plastic overall. He leans forward and scrabbles his hand in the sand. He pauses, flexing his fingers as he feels the texture of the sand. Emma stands next to him. She reaches forward and picks up the plastic sand toy-a comb, and pulls it, two-handed across the sand. Sam pauses. His head back, his eyes focused on the sky. He reaches forward and scrambles again, erasing the marks left by Emma. Emma laughs and talks to Kay. 'Why did he do that?' 'He's playing a game'. 'Oh', Emma pulls the comb through the sand again. Sam flexes, pauses and scrabbles again. Emma laughs. Sam flaps his hands. (Bayliss, 2004, p.3).*

## 4.1 INTRODUCTION

This chapter has two main goals; that of presenting stories in an intelligible format and that of listening to the stories as narrated by the protagonists themselves. This chapter will bring in a very complex research question; in what way can the stories of people at the margins expose issues of "inclusion" and exclusion (*Figure 4.1*)? I will also engage with the discourse of narrative and its relevance to research. However, the core and heart of this chapter are the stories written by the people that matter.

Short life stories: These are more common and very different. They are usually gathered through in-depth interviews, with open-ended questionnaires, requiring gentle probes and taking somewhere between half an hour and three hours. Sometimes, they are first person documents found in autobiographical collections or letters. The stories here usually have to be more focused than the long life histories (Plummer 2001, p.24).

When I asked the people who contributed their stories, I focused on the aspect of "inclusion". The e-mail I had sent in this regard read:

As part of my own process to understand "inclusion" (in the widest sense and not only in the educational sense of the experience), I am

inviting you to write your own story of "inclusion" and sharing it with me. What I'm asking for is a little autobiography on what you have gone through in life; the challenges, the achievements, the disappointments, the dreams... (Andrew Azzopardi, "My Thesis" June 15, 2004).

**FIGURE 4.1: THE RESEARCH QUESTIONS**

EMPHASIS IN CHAPTER	ANALYSIS	RESEARCH QUESTION
4	<b>Analysis of autobiographies</b>	<b>In what way can the stories of people at the margins expose issue of "inclusion" and exclusion?</b>
5	Analysis of semi-fictional stories and focus group debates	What are the different perspectives of parent and disabled activists, teachers, university students, 'labelled' students and social workers in relation to presenting a transformative agenda for "inclusion"?
6	Analysis of auto-ethnography position	What practices enable "inclusion"?
7	Analysis of narrative research	To what extent does narrative research provide an adequate exposition of "inclusion"?

## 4.2 UNDERSTANDING THE SIGNS OF THE TIMES

Stories are an intelligible way of understanding the signs around us. Stories converge the strength of testimony with the vigour of outcome. The ability to read what the stories are telling us lies within the reader. It is then the capability of the reader to make the story a part of his/her social understanding. In a contextual scenario where diversity brings in the complexities of social relations, stories help the writer to design a collective identity. Social movements are '...expressions of collective identity, but they are also sites of contested identities' (Oliver and Barton 2002, p.86).

People with impairments whether they are physical, sensory or 'cognitive' have traditionally been oppressed by psychological research. This oppression is rooted in assumptions that view such impairments as violating individuals' very personhoods.... However, recent developments in research thinking have challenged these individualistic assumptions and, in contrast,



unearthed the ways in which people with impairments are disabled by societies that threaten to exclude them from mainstream activities. Two research approaches can be identified – narrative and discursive approaches to research – that promise much in terms of highlighting the social causes of disability (Goodley 2003, p.1).

It is the strength of narrative that manages to surface these profound, intense and complex stories of people that know exclusion in society as an acceptable part of their existence. It is my belief that reflection on "inclusion" and diversity is a manifestation on the culture which makes this whole thinking more interesting, productive and placed where emotions, passions and intuitions become part of a scientific method of understanding that reality. It is a method that allows the informant to be in control and present during the whole process.

#### **4.3 WHAT ARE THE STORIES?**

There are six stories that are written here. Five of the stories, as explained in Chapter 4 (Methodology), were collated following a request via e-mail (Murray and Sixsmith 1998). I thought this is the best option for this part of data collection for the following reasons:

- The people I have asked the stories from are in contact with me regularly via e-mail (Murray and Sixsmith, 1998).
- E-mailing is becoming an accepted method in research (Murray and Sixsmith 1998; Arksey and Knight 1999).
- All participants have access to the e-mail service, are comfortable using this system and have corresponded with them in the past.

The story of *Adam* I had to transcribe (and make some amendments to) because this student is semi-illiterate, has no knowledge on the use of e-mail and said that he finds it more comfortable to meet and discuss the issues in person.



I also know all six informants personally. I have met them on a number of occasions in the different roles I am engaged in. *Dean* is a critical friend and disabled activist. He works at the same social work office with me. He is involved in some work with me at the *University Of Malta*. On the other hand, *Jane* and her family are old friends. I have known this family for years especially in the context of parent activism when *Jane* was still very young. *Cynthia*, I have also known for years. She is currently one of my social work service users and closely involved with parent activism. *Sandra* I got to know in the UK. She is a teacher by profession and I could conceptualise that she would be able to identify with the work I was doing since she comes from an educational background and her disability developed later on in life. *Adam* is a student I taught for a whole scholastic year. Maybe the only success story in my relation to *Adam* was the fact that I managed to win his trust. *Conrad* I have known for some time as a service user in my social work role. He is also a passionate disabled activist. He is one of the most spirited people I have met in my life.

They all knew about my research and I had the opportunity to speak to them about what I was doing. Life stories in this sense are a way of fashioning identity, in both the private and public senses of the world. I endeavoured to link the public experience I had of these people and the private encounter I had with them. The following *Table* will give a summary of the characteristic features of the informants who shared their autobiography.

**FIGURE 4.2: THE PROTAGONISTS IN A 'NUT SHELL'**

NAMES	AGE (YEARS)	NAME OF STORY	IMPAIRMENT/ LABEL	EDUCATION	ROLE	DIMENSION
Dean	28	Resilience	Spina bifida	Mainstream grammar school <sup>6</sup> and Tertiary	Critical friend, friend and disabled activist	Life
Cynthia <sup>7</sup>	30	A parent's last gasp	Cerebral palsy (Physically and mentally)	Special school	Parent activist, social work service user	Parent activism and professionalisation
Conrad	25	A man on an island	Spinal injury	Secondary/ Technical	Disabled activist, social work service user	Service user
Adam	11	Once upon a time	Behavioural problems	Mainstream and secondary school	Student	Education
Jane	22	An untimely story	Cerebral palsy (Physically)	Mainstream grammar school	Disabled activist	Activism
Sandra	47	Contradiction in terms	Multiple sclerosis	Mainstream grammar school and Tertiary	Disabled activist	Identity

I felt that these stories deserve to be told by the persons themselves. I have carried out minimal editing to the stories. In truth they may at times not read to perfect *English* but are definitely stories told by the heart, by the mind and by a consistent trend of emotion that stems from a socially at times strained relationship with society. I have removed short extracts of what they wrote for no other but practical 'space' reasons. The analysis I leave for a later stage – for now let's just 'listen' to the stories!

<sup>6</sup> When we refer to grammar schools in Malta, we are referring to those State, Independent and Church schools that focus on the GCSE exams. We have a tripartite system in Malta where following the 11+ exam, you either go to a grammar school if you get the marks, an Area Secondary School, which has a nominal component of technical orientation or else what we refer to as ex-Opportunity Centres which are more or less schools that have a very weak level of academic constituent. Usually students in these schools are either illiterate or have serious numeracy/literacy problems.

<sup>7</sup> Her son has a 'learning disability' label. He is 16 years old.



## **4.4 THE STORIES**

### **4.4.1 STORY 1: RESILIENCE (DEAN)**

#### **Preamble**

This is the story of a 28-year-old physically disabled man. I have known *Dean* for years. He is also a distant relative. We have crossed paths a number of times in our lives. He was an informant for my Bachelor and Masters degree research projects. We also used to share the same secondary school. We presently work together at a social work service.

The story of *Dean* lies coated in pliability. His thinking is tremendously and excitingly elastic. He stands through with his principles, core values and beliefs. He does not compromise with his Christian values. He practices his faith ardently and enthusiastically. *Dean* would also attend prayer group and Bible study sessions. *Dean* is no exhibitionist. He is low profile, but 'everyone' seems to know him! He is a symbol of success to many, especially to other disabled people. He doesn't fit the super-crip mould although he has said that he feels that he has been used as a token disabled person in the past. This chap keeps strong and is unwavering in what he believes in. It seems that his inability to change physically in certain aspects has been transferred in his ability to adapt himself. On the other hand he loves an audience if it gives him the opportunity to debate on the social paraphernalia he is entrapped in. This may sound like a freedom story but in reality *Dean* makes the most complex of complexities, the most tough of harsh experiences sound simple and straightforward. He is one to reckon with. The story:

#### **New born baby**

I was born 28 years ago. I was my parents' first and only child after my mother had three miscarriages. Her gynaecologist suggested that she spends most of her pregnancy in absolute bed rest, which she did.



I was born by a caesarean section. Since my mother was still under the effect of the anaesthetic, my father was the first to know about my impairment, a medical condition known as Spina Bifida. He was also given the option to consent to an immediate surgical intervention, which I needed, without which I could not have survived for more than a couple of weeks. What was interesting (?!?! ) was the way he was 'advised' about this...although rather implicitly, he was encouraged to "let nature take its course" because..."anyway...with or without the operation, my life in the future will not be anything similar to what parents dream for their children...he would not be able to do this, that and the other". Thankfully, my father, in spite of this 'wise talk', consented to the surgery.

The surgery entailed, that I had to be transferred to another hospital. Before I was relocated to this other hospital, my father wanted my mother to see me and hold me at least a couple of minutes (this could have been the last time she had the opportunity to do so). As I already said, she was still under the effect of the anaesthetic, but she remembers seeing my feet a little bit bluish! This little incident was relevant, because when my father, eventually told her that I was transferred to the general hospital, he did not tell her immediately about my condition, but told her that I needed a little bit of oxygen. Having observed my bluish feet, she believed this story.

My mother had to stay in hospital for some more days. One fine day, she asked my father to bring her something to read. He went home to my grandma and asked one of my mother's sisters to give her some stuff to read. She had just bought a *Reader's Digest* edition, which she gave him to give it to my mum (without having read it herself yet).

When my mother was reading this *Reader's Digest*, she came across a story about a couple who had just had a baby with a 'strange condition' known as 'Spina Bifida'. This story was about the struggle with coming to terms with the fact that they did not consent for a surgery, which was required for their son's survival. Eventually, the baby died. This story set my mum thinking about what she would have done where she in their situation! She thought she would surely have given the baby the chance to live, to survive<sup>8</sup>.

That day, my father went to visit her as usual and she started discussing this story with him...one can imagine what my father felt when hearing this! Obviously, he could not tell her all this, there and then! When, eventually, it was time for her to leave hospital and she asked my father to take her to see me, he had to tell her that "something was wrong"...when she asked him what was it that I had, his answer was: "*Bhal tal-ktieb!* (The book's same story!)" Eventually, she interpreted the "*Reader's Digest*" incident as the way through which God prepared her for what was to come!

### **The patient**

It was obvious that I needed frequent medical attention, and my parents used to take me to hospital to visit various consultants, at least three times a week. In spite of this, my parents were never really told about my needs and most of the things they had to learn themselves. They could sense an almost total lack of support. I was very often quite sick, and when I was eleven months old, they could not take it any longer, and decided to seek consultation abroad. Obviously they needed some sort of referral, or

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<sup>8</sup> I was particularly intrigued by this part of the story. The illustration made by *Dean* is significant. The power of stories change people, affect their understanding and create a ripple affect not only on the person him/herself but the rest of the people that are intimately related. Stories change us.



at least some medical information about my condition. The consultant they sought advice from listened to their story and to their concerns, and eventually gave them his feedback: "Listen...he's got so many problems, it's just no use wasting money on him!" No need to comment further on this statement!

My parents persisted, and eventually I was taken to *Queen Mary's University Hospital*, in Roehampton, UK. What immediately struck my parents was the completely different approach adopted by the doctors and other professionals there...what was important was not that the 'glass was half empty', but that 'it was half full'. I was a human being who had a potential to lead a fulfilling life if only I had the necessary support, something which my parents were all for giving me!

I was taken to that same hospital one other time with my parents paying all the expenses. In 1977, I needed another urgent operation, and since the doctors in Malta were on industrial action, the government had no alternative other than to send me to have the operation abroad. I was taken to the same hospital I had been before. I remained their patient for the years to come, and the government used to send me for check-ups and/or interventions needed, at least once a year, up till 1992, when my condition was considered stable, and when the UK doctors decided that I could be adequately followed by doctors, surgeons, and other professionals locally.

### **Breaking a leg or two**

When it was time for me to start my schooling, my parents opted for mainstream schooling, again in spite of going against what was being suggested to them by some local professionals. The people at the first kindergarten school they went to, were not too keen to accept me (the



nun 'could not cope with my needs', even though my mother offered all her help and support). Another school in the vicinity was approached. This time the problem was that the class was already full, but I was accepted anyway. My mother used to come to school every single day during mid-day break to see to my needs. Although the concept was not at all known at the time, she was fulfilling the role of my facilitator<sup>9</sup>. A very good "working relationship" developed between my mother and the nun that was teaching me, so that my personal, social and educational needs could be addressed adequately.

After a scholastic year in this kindergarten school, it was time for me to move to a primary school. Again a school in the vicinity was chosen. Yet again, my mother went to the school before the beginning of the scholastic year to speak to the person who was to be my teacher. She was hesitant in the beginning because it was her first such experience, but seeing that my mother was willing to offer all her support, she decided to give me a chance. What was fascinating, was the fact that after about three weeks of me being in her class, my teacher felt that she had to apologise with my mother for being so hesitant initially. Again, even this time round, my mother used to come to school every single day during mid-day break to see to my personal needs. Moreover, I had absolutely no problem in participating in all the activities in class...my classmates did not only 'accept' me as one of them, it was simply natural for them to give me the support in those circumstances - I required it from them. What was sometimes annoying were the comments my mother used to indirectly hear from some of my classmates' mothers...concerns that my presence in their children's classroom could in a way hinder the fast and steady progress of their children's education.

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<sup>9</sup> 'Facilitator' in the Maltese educational context is the equivalent of 'Learning Support Assistant' in the UK.

Things proceeded well for the next two years. I was just a typical boy. I participated in class activities and always found ways to do things my own way. I once 'defended' myself from one of my classmates by almost running over his feet with my wheelchair, with all the strength I had. Were it not for the fact that my mother was watching, this poor fellow, would surely have ended with a broken leg or two!

Speaking of my mother, it is important for me to point out that both my parents never pitied me. They disciplined me whenever it was necessary (the above example was a case in point!). They always demanded from teachers that I be given the grades and marks that I deserved, no more, no less!

When I was to start my fourth year at primary school, the first major difficulty with physical accessibility arose. My classroom was to be in the second floor. There was no lift installed in the school. When my mother went to speak to the headmaster to see what support we could get, this guy was anything but helpful! His solution was for me to move to a 'special school' where I could have all the necessary support. Obviously, my mother was furious, but at the same time she felt helpless! Going out of the school after the meeting, she coincidentally met a friend of hers, who happened to have her husband who worked with the Education Department. She offered her help and later during the day phoned my mother to tell her that according to an Education Department official, it was my right that my classroom is moved to the ground floor in the same school. The headmaster had no option other than to accept this decision, and things proceeded smoothly from then on.



## **The Piano**

My life, even then, did not consist of just hospitals and schools. Through the constant encouragement I received from my parents to try and develop my potential as much as possible, I was always very eager to participate in extra-curricular activities.

One fine day, I announced to my mother that I wanted to play the piano. She said, "OK...fine!" She approached one music teacher:

*"My son wants to learn the piano. Would you teach him?"*

*"Can he make any use of his legs?"*

*"No"*

*"A piano has pedals...they are important! If he can't use them, I can't see how he'll be able to study the instrument formally".*

*"Oh...really!?! OK...thank you very much then!"*

Obviously, my mother being the way she is, was not to be discouraged so easily. She approached another teacher:

*"My son wants to learn the piano. Would you teach him?"*

*"Of course! Can he read the alphabet?"*

*"Not yet."*

*"When he is able to do so, please contact me".*

*"What about the pedals?"*

*"What about them?"*

*"He can't use his legs."*

*"Let's take things one step at a time. Pedals are important for higher grades...we'll see what we can do about them, when we get there!"*



Eventually, I learnt the alphabet, and eventually I started my piano lessons. When I reached the point where I was to use the pedals, my teacher wrote to the *Examining Board* abroad and explained the situation. Their reply was:

*"OK, no problem, he can sit for examinations just the same. The examiner will be informed about the situation and will examine him on other important aspects of piano playing".*

I managed to reach Grade 8 level, and had to stop only because of other commitments.

### **I want to play soccer!**

Piano lessons were not my only extra curricular activity. I was involved in quite a number of other things. This meant that I needed support especially from both my parents. My father was taking me here and there himself. The lack of an adequate transport service, which was accessible for my needs, proved to be a problem when I started schooling at another College after my first four years at a Government School.

My father used to take me to school himself, before he started work at 7:00 am. This meant that I usually had to be at school by about 6:40 am every single day. Thus at a young age, I had to get used to getting up really early so that my parents could help me get organised for school.

Life at secondary school was fun although not barrier-free. I had problems with accessibility. My classroom was situated in the second floor. However, this time, I had the support to make way there because older boys were given a roster to help me to get to wherever I needed to go. There were occasional problems. I remember being carried by one of my teachers single-handedly (a very frightening experience I must say!) down two

flights of stairs because the people who were supposed to come to help somehow did not turn up!

Apart from the accessibility issue, I had all the necessary support from all the teachers. Again, my mother used to come to school every day for the first four years I was at secondary school. This helped in building a relationship with my teachers, enabling problems to be sorted out as soon as they cropped up.

Again, I was actively involved in extra curricular activities. A particular experience is worth mentioning. It was my first year at secondary school and the PE teacher came in class to take the names of those boys who were interested in taking part in the soccer league. Obviously, I put up my hand! He started taking names and left me to the very end. When it was finally my turn, he looked at me perplexed! I read his mind and anticipated whatever he was going to say; "please sir, may I be the Team Coach?", irrespective of the fact that I hardly knew that a football is a round object made of leather, and that a soccer team is made up of eleven players. What was important for me was that I participate in as many activities as possible - which I did!

### **Writing like a hen!**

When I was in my second year at College, I needed to undergo a major surgery in my back. I had to be taken to the UK for this to be done, and we knew that our stay there would not have been a brief one.

I was almost eleven years old at the time and so I was to be admitted to a children's ward in the hospital. However, when I was to be admitted, there was a guy who had some sort of chicken pox or measles or whatever, and so they couldn't admit new patients there. I was placed in



the teenagers ward. It was a blessing in disguise! I was the youngest among them all, but I managed to integrate fully with all my fellow patients in the ward. The staff there was fantastic! We used to be given syringes to play with, which we used to fill with whatever liquid we had on our bed side, after which we all engaged in 'fierce' water fights!

What was important in the experience was the fact that the doctors and other professionals always and unfailingly explained to me clearly and with a language I could understand, whatever was going to happen to me. This gave me my dignity and helped me understand.

Although I have beautiful memories of the experience at Stanmore, it was not all plain sailing. During the operation, I had a cardiac arrest, which according to the doctors lasted for five-and-a-half minutes. When they finally managed to resuscitate me, the doctors were more than 100% positive that I had brain damage, considering the length of time that my brain was starved of oxygen. According to my parents, I did show signs of brain damage, but with their perseverance, and with them continuously talking to me not to let my brain go to sleep, I somehow managed to get over it in ten days. Even after that, my motor skills were affected (my handwriting looked more like the 'finger' printing of a hen left to roam about on a piece of paper). It required hard work and constant support to get back to almost the same point I was before.

### **Some teachers are good**

When we got back to Malta, I had to make up what I had lost in school. It is worth mentioning here, that while I was in the UK, one thing that helped me tremendously was the fact that some teachers used to write to me frequently, informing me what they were doing in class. This helped me tremendously both as a means of keeping in touch and my morale high!



When I was back in Malta, teachers used to come to us at home to help me make up for what I had lost. Although it was hard work, considering that it was a very hot summer and that I had a plaster jacket from neck to waist, we managed to get through as well.

Eventually, it was time for me to start preparing for my O-levels. One particular teacher offered to coach me through this "ordeal". He helped me prepare a plan so as not to sit for the examinations all in one setting. He helped me get the necessary support in the subjects I needed most. He also made me aware that I had a right for extra time during examinations to compensate for my slow handwriting. This proved to be very useful. Eventually, I sat for the examinations successfully. Often, other arrangements had to be made, especially when it came to choosing examination venues that were most accessible to me.

### **Chemical Dean**

My natural next step was to start studying for my A-levels. I chose the science subjects. I had decided to remain at the sixth form of the same school I was in. I must say I was a bit angry, because the sixth form complex had just been built, but it lacked necessary amenities for people with a physical disability. The biggest problem was the lack of a lift. I had to be carried one or two flights of steps two or three times a week because the laboratories and the library were in the upper floors. This time the problem of accessibility was a little bit more complex for me. At that age, I was becoming more self-conscious than when I was a child and the fact that I had to be carried in front of other students that also included girls, was sometimes a bit difficult to handle.

As I said, I had chosen to study the sciences. When it came to chemistry, the teachers taught that it would be too dangerous for me to handle certain chemicals because of my reduced manual dexterity. So, their solution to the problem, was for me to drop chemistry and choose another subject (for example religious studies or philosophy). They summoned my parents to tell them about their suggestion (without me knowing, even though I was sixteen years old!).

We refused to give in to their pressure and wrote to the examining board abroad. They replied saying that there was absolutely no ground for me to be asked to drop a subject I wanted to study. They suggested that I participate in all the practical sessions like other students with one of my classmates helping me to handle the chemicals, which could be dangerous for me, were they to make contact with my skin. They also granted me exemption from the practical sessions of the A-level examinations. The marks allotted for the practical sessions were distributed evenly among the other papers.

Eventually, I successfully obtained my A-levels in Maths, Physics, Chemistry and Biology.

### **Of ramps and revolving doors**

After Sixth Form, I wanted to go to University to study Physics and Computer Science. I knew that the place was not very accessible, and thus the summer before the commencement of the academic year, we went to meet the people responsible to see what arrangements needed to take place. This exercise proved to be very useful. I was given a power wheelchair, because the ramps were too steep to cope with because of the limitations imposed by the infrastructure.



We made sure that I had access to whatever I needed for my academic work. The apparatus I needed was transferred from a laboratory in an upper floor to another one in ground floor. My father, for the umpteenth time throughout my school years, made another desk, which was accessible and comfortable for me. Lecturers made themselves available to help me sort out any problems I might have encountered.

In spite of all this, there were some problems that remained with me till the very end. Access to the student house was non-existent and when a lift was finally installed, it was used as a service lift. This meant that to access it I had to use a back door, pass through an area where garbage bags were stacked, and when I finally made it to the lift, I often found myself accompanied by a tray or two of pizzas and Maltese pastries!

Another problem was the library. A revolving door had just been installed. There was no way I could pass through it with my wheelchair and so, every time I needed to go into the library, I had to wait for someone to go get the key to a side-door, a key which was very often misplaced. This meant that most often, I could not manage to get to do the work I needed to do because of the time wasted prior to my even getting into the library.

There were problems that were slightly beyond my control. For example, I often found myself blocked, because I needed to use a ramp, after having found that 'some kind-hearted' individual parked immediately in front of it; when I wanted to use the ATM, which was way too high for me; when I wanted to use a newly installed lift in which I barely managed to get in it being so narrow.



At University I also had my first formal *IEP*. Since the course I opted for was proving to be a bit too taxing on my physical stamina, I asked that something be done about it. I was eventually given the opportunity to finish the course in twice the amount of years, and also to be assessed by whatever the individual lecturer deemed fit, and not necessarily by test or examination. These arrangements proved to be very useful.

Eventually, I opted to change course, to study management and public policy, being able to get the degree after three years. The constant support I received from most of the lecturers was amazing. My graduation day was an important landmark, because it was my way of reaping the fruits of all the effort over the years, and my way of showing appreciation to my parents and to all those individuals who supported me in one way or another.

Another issue worth mentioning was the fact that by the time I started my University degree, an accessible transport service was set up, which proved to be crucial for me to be able to pursue my dream of getting the degree I was after. Even though I must say, the service was not completely hassle-free!

### **Saturday night fever**

Over the years, one thing that I always felt missing as I started growing up, was a group of peers, especially for Saturday night activities.

University life helped in this respect as well. One of my extra curricular activities at University was my involvement with the Catholic Movement. Through this involvement, I managed to build a circle of friends. This circle of friends is important to me up to this very day.

What I miss sometimes is a lack of close disabled friends. I have always grown up in an almost exclusively non-disabled environment. Although this had its positive aspect, it also had its negatives. I always 'competed' with non-disabled people, and my targets were those that were important for other non-disabled. As a consequence, such targets as being able to do certain important things (e.g. self-care) on my own, were never given importance, and I found myself lagging behind in these areas up to this very day.

### **Bridging the gap**

A very important landmark in my life was when eventually, about four months after I graduated, I found the job I am in now.

I must say that I am very lucky to be in this job. I enjoy the contact with the disability field; I greatly appreciate the constant support from my colleagues and friends; I am continuously challenged to work towards becoming a better, more efficient, more-capable-of-doing-it-on-my-own person; to develop my potential further. My colleagues understand the needs that arise from my physical condition and were/are willing to accommodate for them when this was/is necessary.

All this has helped me to eventually start thinking seriously about starting to develop further support systems, such as the recruitment of a personal assistant and getting my own transport organised.

### **Feelings**

Having a disability for me does not mean that one is condemned to a tragic life, as my parents were made to believe as soon as I was born. Challenges exist all the time, but every hurdle one manages to surpass, makes one stronger.



One hurdle I am working towards at the moment, is giving myself permission to feel. More importantly doing something about those 'feelings' - all the range of possible human emotions, be it anger, loneliness, sadness or love. I still have a long way to go, but I will get there - eventually!

#### **4.4.2 STORY 2: A PARENT'S LAST GASP (CYNTHIA)**

*Cynthia* is one of those persons who seems to keep going through life, meeting one challenge after the other. At one point I felt that she is the type of person to attract trouble! Well, I have changed that opinion, now I don't think – I'm sure! The reason is very simple, *Cynthia* has a sense of activism that is resistant and buoyant. This doesn't go unnoticed. She has a character where she manages to look straight into the eyes of whatever she does. She is not fearful or timid in front of the issues and the people.

This piece makes good reading especially for parents that in front of so much professionalisation find it difficult to keep facing the music. The story:

#### **Worn-out**

I was asked to share my life experience and what I think about inclusive education. I could not bring myself to write anything down before because I have been so let down by everything and everyone lately. It is already difficult for me to express my feelings, let alone when I am going through a whole period where everything you believe in and all that you put your energy into just crumples in front of you.



## Hope

I am not the type of person to expect that everything should be perfect in life - I think I gave up that dream way back! One dream I try to keep alive, where *disability* is concerned, is that of unity between all of us. Well I'm wrong. Very wrong! I keep meeting disabled people and parents of disabled persons that talk so much nonsense.

## In hindsight

I will not judge or criticise anyone, for I presume from a personal perspective I am pretty hurt and angry, first and foremost, at my ex-husband and his family. They have never tried to accept my son - their own flesh and blood. My son was born sixteen years ago. Like everyone I suppose, I always wanted a beautiful baby and never thought of anything else. At first it seemed that my wish was granted. When I saw my son, I thought he was the most gorgeous baby I ever saw. He was so delicate and blond, just perfect. He didn't cry so he wasn't handed to me. All of a sudden there was havoc. The mid-wife just ran off with him to put him in an incubator. I only got to see him the next day at the *Special Care Baby Unit* in hospital. It was a distressing experience. I was placed in a room with another mother, and when I asked about her son all they told me he was that he looked like a 'monster'. I had a glimpse at him later on when I was visiting my son. He was severely deformed. He only survived two days. My son stayed in hospital for another six weeks and I only got to hold him after about five weeks. I called him after my father, Wayne. I adored my dad and I always wanted my first born son to be called after my dad. My father was crazy about him. He would never go and see anyone at hospital but he used to visit his grandson regularly. It used to break his heart.

I lived in hospital both here and abroad for two years. I actually missed hospital food, when I left! Finally, I was given the news about Wayne being "handicapped" at *Great Ormond Street Hospital*, when he was six months old. I was told that he had cerebral palsy but they could not establish the severity of his condition except that it was serious. He had no reflexes and his immune system was weak. His body could not produce anti-bodies which resulted in Wayne being seriously ill very often.

After they gave me this news, I had no idea what this really meant. All I know is that the psychologist told me not to be discouraged because there were various famous musicians and scientists that have achieved a great deal even though they were disabled (she mentioned Beethoven, who was my favourite composer!). The question I kept asking myself was whether Wayne's disability was due to my husband's heavy drug abuse, a problem he was immersed in for over fifteen years. No-one would answer! I suppose I am glad today for not getting any answer. It wouldn't have changed anything really. I believe that my ex-husband and his family still carry the guilt and that is why they do not speak about this issue and refuse to have anything to do with my son. I see it differently. God sent me my son to make me the person I am today.

### **A young mother 'to be'**

Then I was very young, just turned nineteen. Everyone was really nice and people used to explain things to me. However, my life was in shambles. I used to cry myself to sleep every night. My father had just suffered a massive heart attack. My husband was in a mental hospital for rehabilitation and my son was in hospital fighting for his life. My 21<sup>st</sup> birthday I spent alone in the hospital in England eating a *Milkyway* chocolate bar!



The moments that were really painful, were every time we checked in hospital. My son and myself were always tested for Aids. This happened because of my husband's history, Wayne showed all the symptoms of Aids. He was very small for his age and was continuously being seriously ill. One thing that everybody remembers, is that Wayne was always smiling and laughing. I have seen him suffering so much but he would always give me a smile even if it was just a faint one. He had such a strong will to live.

### **An eventful life**

I used to borrow books from the nurses to learn about the medication Wayne was being given. I used to pinch the hospital files to get a second look. It was a struggle everyday, mostly fighting to keep him alive. I think the holy rites were read to him five or six times during those first two years. I was there struggling to keep my son alive and my husband and his family were thinking of how to get away from it all. I got no help from them. No support both financially and morally. They would come and visit and I could feel them thinking that this child is suffering a lot so why not let him die. On the other hand I thank God for my family who were always there. My friends helped too. They used to come in the middle of the night to visit. They always used to find a way to get into hospital.

After convincing the doctors that I knew enough, I was allowed to take Wayne home. I had to learn how to administer the rice-tube, work out the feeding pump, give the medication and so on and so on. My father helped me to take him for more tests in Sicily. We come from a little village in Sicily ourselves and the mentality is pretty backwards but I was always accepted and everyone wanted to help. Although they still sympathise with the, "oh poor thing" comments, they are genuinely interested as a community. Services were always available for the



disabled persons and their carers. The Government accepts the fact that it is better to make the life of the disabled easier by giving the proper financial services and support rather than placing these people away in institutions.

Anyway, in the middle of everything that was going on, I got pregnant with my daughter. No need to say I didn't want another child. It was only because I was forced by my husband to get pregnant after I handed him the papers for the separation. I was also too scared to have another child, not knowing the reason why Wayne was born with a disability. I also had such a strong bond with my son that I felt that another child would be intruding in my life. During the pregnancy I did everything imaginable that would assist in losing my baby - but nothing seemed to work. With Wayne I was so careful and took the best possible care of my health. With this child I wanted to rebel. Once my best friend brought me to my senses. She told me not to be ridiculous, "this child deserves to live, who better than a brother or sister to take care of Wayne?"

### **Holy Communion**

Some time after, my father died. My annulment was also going through. I was left with two children. My daughter started attending school and I was told about a special school where Wayne could attend. I cannot remember a lot about how Wayne got to that school, but all I knew was that we were too close to each other and we needed to go our separate ways. I used to go to visit the school. The horrendous smell that there was, would upset my stomach. I felt bad sending Wayne there but I had no other option. The staff and the headmaster were very nice and helpful people. However, all the students used to do was lie down in cots.

One good thing that had come out at that time was that Wayne could do his Holy Communion at school. So I got all dolled up and went to school and together with other disabled children Wayne had his Holy Communion. In the evening we held a party at a friend's house. Once again, when I told his paternal grandfather that Wayne did his communion all I got was Lm2 and a pair of shoes that were bought from the Lm1 store.

### **Troubles are over!**

In the meantime, I started dating a doctor and I thought that finally my troubles were over! Oh how wrong I was! He could not stand children left alone a child with disability. He never mistreated the children but he never went out of his way for them. I was fixated about this guy. On his part, he became possessive and domineering. I was so convinced that this guy was my dream man. He even managed to convince me that Wayne's place was in a residential institution. I actually visited the place and put Wayne down on the waiting list. Wayne spent some time there, because this guy wanted to go out on the boat on our own. The waiting list at this residential home was so extensive that Wayne was never called in, not even for an assessment. Thank God for that! I don't know what decision I would have made then. In the meantime I found out about respite services and again I was forced to apply by this bloke. This experience was different. I enjoyed the surroundings and also the fact that it provided for a small number of clients. My first experience was that Andrew Azzopardi who later became my social worker had organised a family weekend stay at this respite centre. We didn't spend the night unfortunately because my daughter had a convulsion but I remember feeling really good about this place.



## **Regular 'user'**

Eventually Wayne became a regular user of respite services. I would call and book him in, and most times I was given the days I need. I could leave Sebi and have my mind at rest that he is safe and sound. The most difficult periods were during the holiday period. It was always difficult to find a place then. That's when problems with this bloke used to arise. He always wanted us to be alone. So where would I leave the kids? He used to pay for a babysitter at times, and I also had to leave the kids with my family. My family at one point refused to look after them because they used to notice that this guy didn't care for me and my family. This caused more problems. I hated my husband and his family more by this time. They were never interested in the kids. Something happened which really hurt. My ex-husband's family had a family party and they asked me to pick the children up earlier. When I asked 'why' my ex-husband's father told me that one of the cousins was having a children's party and they were going for it. When I told him that my children should attend the children's parties he said that he agreed that my daughter could go but Wayne would make too much noise and everyone would be distracted. This was the last time they saw me and the kids.

Well with this doctor, it didn't work out, we're still good friends but today I look back and realise that even though he played an important role in my life and helped me become the person I am, this relationship couldn't work. He used to tell me that I would only stay with him because no one would want a woman with two kids, where one of them was disabled. I was going to start to believe that for some time but then my character made me challenge him. I started looking after my children with more intensity for who they were. I realised my son needed me because no one would look after him or give him the love and care I was able to give him.



## **Yet another white elephant**

When Wayne was about seven years old I heard about this new NGO. I made an appointment to speak to them. I explained the way my financial situation was and that I was going through court procedures and therefore I had no money to pay. I was told that it would be difficult to get Wayne in because of the money problem. I was really let down because there was no nowhere else to take my son. One day a friend of mine asked me to give her names of charities so that her boyfriend's company can donate some money. When I explained what had happened with *Eden Foundation*, she said that they will give the donation to this NGO as a sponsorship for Wayne. That's how Wayne made it to this organisation. Wayne attended those programmes for eight years. There I made many friends and I started seeing life with disability differently. I remember the first time Wayne had an assessment, I was told that children at *Eden* start walking. My mother was so happy that I had to tell her off and not make any false hopes. It was hard in the beginning I used to spend days there doing continuous therapy. That when I nearly broke down. I started speaking to some mothers and became quite friendly. We used to meet early so we could have some coffee and chat.

In this organisation we were involved in anything that concerned the children. This gave me a nice feeling of community. It didn't last for long. *Eden* started increasing their fees. Eventually we were only allowed to get the children in and out of the classroom. When *Eden* introduced the programme of "inclusion" in schools, I was one of the first people to be approached. A leading psychologist in Malta asked me what I think about sending Wayne to mainstream school. When I asked her about the care he required, she said that I would have to go and change his nappy, help with the feeding and take him and pick him up from school every day. I had heard the distress this was causing to other parents and I

definitely could not do it. I had to look after my other daughter and I also needed some time for myself during the day. I also felt that Wayne would be laughed at and the parents in the neighbourhood school would not accept him. I told this psychologist that I refuse and she got angry because she felt Wayne had potential and that I would be waisting an opportunity. I felt very strongly that I would not be able to cope. When I told her that Wayne will understand the fact that he would not be accepted in school by his peers she said that he had to learn that life was hard. That's when I freaked out and told her that she should be at the park and see Wayne's face when he sees all the other children playing and running around. It always caused him and me a lot of pain. But we coped and therefore I wanted to avoid more pain and hassle for both of us. From my experience with this Agency throughout those years I got mixed feelings. On one hand they did a great job regarding therapy and bringing the parents together. On the other hand, the fees kept on increasing and the services deteriorating.

### **Smile for pity**

We used to be asked by this organisation to go on television to speak about the services. The children at the *conductive programme* were always being filmed for charity. I did not agree with this anymore because I felt that our children's severe disabilities were being used to get sympathy from the public and nothing else. This goes on till this day. Wayne kept on growing and he needed more intensive therapy but there wasn't another student that was like Wayne. His communication had improved very much. He started feeding with little assistance and he participated in the activities fully. The last programme Wayne was doing at Eden was learning independent skills. Once a week, Eden used to take the children to the supermarket shopping. I could not afford Eden anymore. I owed them arrears and I was beginning to panic. They said



they will try and find me a sponsor. They promised that ever since I was there! It was a hard decision but I decided that I could not continue to make more sacrifices and pay for something that wasn't what my son needed. Actually Wayne had an operation and was never asked to return to Eden. I think one reason was that I always speak my mind and I learnt that I don't want to be cheated and taken advantage of. I have seen many parents being given false hopes.

### **A 'special' Special School**

The Headmaster at *San Miguel School* changed. I can't remember how I met him the first time. All I can remember is that he asked me to be part of the School Council because he had no parent representative. I asked another mother whether we should go for it. This opportunity was another important part of my life. I started attending the council meetings and started enjoying it. I learnt that I had a little power to speak my opinion and be listened too. I started thinking on what I wished to have and what sort of information I wanted and needed as a parent and so I started a newsletter with information on the meetings and current issues and other upcoming events. We got together and started organising talks for parents and became actively involved in the school.

### **Parent advocacy**

About three years ago, I was asked to join a parents self-advocacy group. Well actually as a member I had joined about five years before. But I was asked to join the committee. It's funny the way things work out in life. I was at the live-in weekend once and while I was there I met an old friend, well actually she was my brother's friend in the past. When we came face to face we were surprised to meet each other at such a place. I knew Sheila through my brother. I met her again when I gave birth to my daughter and when she came to the ward to see who was the woman giving birth



the night before she found me. She was very depressed then cause she had to decide about her daughter's operation. Her daughter had spina bifida. She asked me what she should do, whether to keep her daughter or not? I think she said she wanted to leave without her daughter because she couldn't cope. I told her about my son and that no matter what her feelings where at the moment she was still the mother of that child and that she had to take responsibility and look after her. It was her duty. I think she felt better then. I left hospital and didn't see *Sheila* for many years until we met again at a live-in weekend. We started meeting more often and went to each other's houses. *Sheila* had a different way of looking at life and we always managed to compliment each other. She became President of NPSPD and she said that she would accept if I accepted to be secretary. I said I didn't have a clue what a secretary was meant to do. Anyway, after *Sheila* promised she would help me we decided to go for it. This experience has given me another opportunity to understand life.

Because of the parent's association I have managed to get to know more people in the disability field. I have come to realise that parents love their disabled children dearly but most still perceive the inability of the person first. I understand my son's limitations but this does not mean that he shouldn't be treated as someone his age. For example, I cannot accept those parents that still dress their teenage daughters in pretty frilly dresses and ponytails. I think it automatically makes others around us perceive disabled children as babies. I try to make parents see this point but it is very hard to break through.

People who are disabled should talk about their needs. I feel that I am in a bit of a dilemma because I always have to interpret what is good for my son because of his severe disability. How do I know what is right? For

example I have met people with a visual impairment who where given the opportunity for an operation where they would improve themselves. Some of them would refuse because they are OK with the way they are. They don't know better and are content with how they are. I see this in many parents, and this is one reason why parents don't want to let their children speak for themselves. I am what I am today because of my son's disability. If someone had to take it away from me what would I do?

I see parents keeping back from fighting for the rights of their children and to find a better quality of life because they wouldn't know what to do if the disabled person had to move on another step in life towards independence. This would leave the parents with a sense of emptiness.

Wayne and me are very close but I wish him to have a life of his own. I remember my feelings clearly about how I felt when I had to let go when he started school, I thought my heart would break.

### **At long last**

To conclude I have seen many changes in my life and in the people around us. Persons with disability are learning how to speak for themselves and parents have learnt how to speak up and treat their children as people first. Some things don't seem to change, primarily, the attitude the medical staff have towards persons with disability. Disability is still regarded as a medical issue and therefore 'doctors' know best! In our case, up until last year when the orthopaedic surgeon said that Wayne needed an emergency operation to loosen his tendons, I was dead set against it, because Wayne was fine. He didn't use his legs but he could get by. The surgeon told me that he knows best and it has to be done. After a big discussion I was left with no option but to give in. I have no knowledge of medicine. The end result was that the operation went



wrong and it had to be done all over again, and Wayne is left with more difficulties in his legs. It was easier for me to lift him and carry him, and it is impossible for him to creep around like he used to. When I went to complain, the surgeon tried to make fun of me and call me a neurotic person. It's the typical attitude that people still face. After fifteen years it still gets to me that parents of a newborn child are sent home without any information and support.

I just want to say something about his sister's role in all this. I may have spoilt her, but I have always been conscious about the fact that her lifestyle is not within the norm and she needs the extra discipline as well. As much as possible I have always tried to involve her in her brother's life and activities and whether she had a choice or not, she always came along. Today she is a teenager and she seems to be very involved with the whole thing. She really loves her brother and looks after him. She is caring and sometimes she wants to look after her brother herself. I stop her because I want her to know that she doesn't have to, but she has to have choices. She argues with others regarding disability and at school she speaks up about disability rights. I am glad that the school she attends, are aware of her situation and give her the possibility to express herself. I was very pleased when she told me that one of her literature books narrates the story of a child with disability. She has really enjoyed preparing the project for the school about this book. It has given us the possibility for both of us to discuss her brother's experiences and what he went through when he was younger. Sometimes, we parents give too much attention to the disabled children and forget about the siblings.

#### **4.4.3 STORY 3: A MAN ON AN ISLAND (CONRAD)**

I have met hundreds of disabled people in my life. I have connected with a lot of different personalities. However, *Conrad* in my anthology of



memoirs stands amongst the most pronounced. *Conrad*, following the accident he had some years back had to go to *Stoke Mandeville* in the UK for rehabilitation. After that phase he came back to the country full of ideas, energy and eagerness on how to make his life. The outcome – ending up in a specialised medical ward for homeless spinally injured people because his immediate family rejected him. After a number of years he managed to make his way out – all on his own. He lived with a girl for six years. This couple is now separated. *Conrad* is once again institutionalised in a community home, but once more struggling to make his way out of this new institution. The story:

### **Swimming against the current**

My disability came about due to an accident some six years back. It was my eighteenth birthday and we had organised a beach party. It was a terrific summer evening. My lifestyle was super active before my accident; scouts, nightclubs, discos, movies, swimming, sports and dancing.

The least of my thoughts at that point in time was about society. As if I cared about the way certain people who had difficulties coped or not with their life. Life for me was cool. Being normal I could do anything I wanted without noticing how simple and straightforward life was for me.

### **School**

I went to primary school and after that I attended trade school till form five. I learned eight different trades. In Form Three I chose a three-year course in electronics, which I didn't complete. I left school to find a job because I needed money. I found work straight away in a factory that produces cane furniture.

## **Back to earth**

After the accident I started everything from the very beginning. It was like being born again. I had to ask for help on how to do my personal things again and every time to strangers. This time they were totally different and much more complicated boundaries that needed to be overcome.

I had to face the attitude from people towards me. The thought that crossed my mind was, how should I react? I knew by the look of their faces that nobody could or would understand me. I cannot remember how humiliated I was in the first couple of years as a disabled person. I used to get all the possible dumb questions:

How can you eat?

How can you hold the glass?

How are you going to shave?

How can you have a relationship?

What if somebody hits you with a car?

No one saw the *Conrad* as I was before. It was all in vain to try and keep this *Conrad* going. I had to adapt to the situation. Amongst the many barriers there are, we find the medical staff's attitudes, finding work, driving and accessibility in the everyday things I do. I cannot go to places I enjoy, due to the lack of accessibility for example, night clubs, discos, movies, beach, sports and so on. When it comes to the development of my career I could not do to any courses due to the ridiculous amount of money given to disabled persons. We are given enough money to remain poor. No employer gave me a chance to show my capability after the accident. It seems my accident didn't just change the fact that I couldn't walk but it changed me – that is not true.



Ten years after the accident - I am now employed and yet facing a crude reality of being homeless and institutionalised once again, dreaming of achieving my independence and personal space, which is normal for any man at twenty-five years, living in a western society in 2004. I await in silent anger.

#### **4.4.4 STORY 4: ONCE UPON A TIME (ADAM)**

This is an incredible story told by a young boy. It is the story that brings to the surface what education is really accomplishing or rather not achieving. *Adam* is a student gone bad! He will not listen to what teachers have to say. He wants to be liberated from the daftness of a lingo he doesn't recognise. I know this boy because I have tried to teach him, to talk to him, to play with him, to relate with him, to discipline him. I have failed in all. He is a street boy. He understands the culture he is engrossed in, full-stop. He will not take any 'shit' from teachers. He loves animals but at the same time will hurt an animal if he feels that this will satiate his need for control. He is a bully and at the same time I can remember him crying his eyes out because a boy hit him whilst he was buying at the tuck shop. A symbolic feature of this boy's experience is the way students 'celebrate' their status in school corridors. They do so by the amount of times they had a cock stab another cock! *Adam* stands out as being one of the school champions in this matter - it says it all! The way school organised 'differentiated' pupils into categories, which then 'polarised' into opposing 'pro' and 'anti' school subcultures. The 'anti' boys were thus not simply pathological deviants, as they were frequently considered, but victims of positive/negative school organisational practice. In this piece I assume that this student is deviant, but I wanted to have a look at the world from his perspective, giving 'him' a voice, and affording him a measure of temporary equality, something the school system is not too bothered with.



What the cockfight says, it says in a vocabulary of sentiment—the thrill of risk, the despair of loss, the pleasure of triumph. Yet what it says is not merely that risk is exciting, loss depressing, or triumph gratifying, banal tautologies of affect, but that it is of these emotions, thus exemplified, that society is built and individuals put together. ... it is a kind of sentimental education... (Geertz, 1973, p.6)<sup>10</sup>.

The story:

### **The Interview**

"Can you tell me a bit about your family?"

"I have three brothers. One of them is in prison for stealing. My father loves him a lot. He misses him and goes to see him almost every day.

Then I have another brother, the one that brings me to school. He doesn't work. You like his car?"

"Oh yes, it's a beautiful one"

"It's a Cosworth!" "My mother is always at home..."

"How do you feel at school?"

"I started badly, really badly. Now it's sort of better. I mean you get used to it. The thing is that I like the other school better. Here it's ok but at the other school we used to spend hours at the ground. On the other hand here it's good because I'm close to home."

"Do you feel accepted by the other students?"

"Of course, yes. Well in a way because some students still don't like me.

"I think they are jealous. Most of them like me."

"Do they actually like you or are they afraid of you?"

"I don't know. I don't think so. It shouldn't be. They don't have to."

"What are you planning to do when you've finished school?"

"Find a job obviously."

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<sup>10</sup> Extract retrieved on January 2, 2002 on the World Wide Web: <http://www.cs.auc.dk/~pera/travel/photoindex.html>

"This isn't simple I suppose."

"No but if you're careful you'll find it. Loads of students have come out of this school and they have found a job, no?"

"Yes but there are a lot of students who haven't found the job they are looking for either."

"Yes but if you're careful you will find a job."

"Do you think you're doing enough at school till now?"

"Well so far, I'm not working that hard. If I had to go out from school I wouldn't find a job. But I'm going to start studying and I'm sure I will manage to make it through. It is a question of getting the rhythm going"

"What job would you like to be doing?"

"I'll do the job that comes my way. There's no choice on this. The thing is that if I wanted to become a carpenter or a mechanic, I know that I won't make it. I don't know enough school, so it has to be the job that I find first. Even if I'm OK at school, I know that I will have a job that means a lot of suffering. I'm still young. Maybe in the future I will manage to find a better job."

"Do you think teachers understand you? You have a bit of a name for being naughty! Do you feel they are interested in you?"

"They don't understand the family problems I have. They don't know how much trouble I have at home. For example, I would have come from a fight at home with my family, I would be very irritable. The thing is that I cannot tell them what is going wrong. I cannot tell them about my problems. That is my personal life and teachers have a duty to be more sensitive. They see me as if I'm the devil in person. They are just not interested in understanding what I'm going through [Pause]. The teachers that know where my problems are coming from are OK. You have teachers that have known me before and so manage to understand my problems. Others do not know and are not very interested in me."



"But how do you expect teachers to understand what you are going through if you don't tell them anything?"

"Teachers are adults. They should understand what the problems of young people are. Something should click in their mind. A guy I used to speak with at the other school used to be really understanding. He understood what I used to go through. I would speak, he would listen and the fact that he was really interested in what I was saying made it easy for me to speak. We trusted each other. He said and promised that he won't speak to anyone about what we were talking about. We spent almost two years speaking regularly about my problems. Even though I haven't seen him for a long time, I still know that he wouldn't speak about this problem with anyone....with most teachers I wouldn't trust them the way I trusted *Daniel*. There are teachers that are OK and would be ready to keep a secret but I don't know if I need to speak to anyone about my problems. There are other teachers that don't understand what it means to have problems because their life is relaxed."

"What do you think school is for, just for teaching?"

"Teaching is not only teaching me to read and write. Teaching is more than that. Teachers should teach you about life. You know, if I have a car, that, they can take, but whatever there is in your head, that they can never take from you. Teachers should teach you education. I also think that teachers have to do their best. But then it's up to the students to make the best out of school. They have to learn. If you don't want to learn then it's up to them. I would really like to keep on with school. School is important. Then I will find a job and I will make it through to a good job. If you want to find a good job, then you need to have certificates to show for you."

"What do you think about the Head of School?"

"I don't like him. I liked the school more before. The other head of school was really good. He had a good attitude with us. He understood us. H



doesn't look things up well when there is a problem in the school. What he does is he picks out a student and whether it is his fault or not, he takes the blame. That's not fair."

"How do you get on outside school with your friends?"

"Oh they are really good and true friends. We're like brothers. We go out and talk and do things – and we enjoy ourselves."

"If you had the power to sort something out in the school, what would you arrange?" [Pause].

"I don't know. This is a difficult question. Well not a difficult question but you have to give time because school has just started. If you had asked me this question in the next term, I would be in a better position to answer."

"OK mate, thanks. I really appreciate the time you gave me."

#### **4.4.5 STORY 5: CONTRADICTION IN TERMS (SANDRA)**

Meeting *Sandra* was a splendid experience. I got in touch with her through a person I had met when I was in the UK to do some research. We meet at her house in Sheffield. We spoke at length about her ideas on inclusive education and the issue of finding her position within the disability field. I was impressed by her candour on the issues surrounding disability and education. One of *Sandra's* qualities lies in her ability to interpret both the disabled and non-disabled world. The story:

##### **The disability 'move'**

"You should be proud to be disabled." The group waited in silence for my response.

This was in May 1991 and was my first introduction to the *Disability Movement*. I was working as an education adviser in Leeds and my main role was to work with mainstream schools on issues related to disability. I

was attending a two-day conference organised by the NUT, focusing on disabled people's experience of schools. My daughter, who has a severe and enduring mental illness, accompanied me as a personal assistant. I needed her help because I was diagnosed as having multiple sclerosis six years previously and the condition had progressed to the stage where I used a wheelchair most of the time and had some difficulty using my hands.

I don't remember exactly what I said, but I think it was on the lines of "I am proud of myself not of being disabled." Since then, I have thought on many occasions about how I feel about being disabled and I can now make a much more reflective response. I am proud of myself and my achievements. Some of the elements that make up 'me' include being a woman and having a physical impairment. It seems to me that these are not choices, they are simply facts about 'me'. What I can choose, is how I react to my circumstances.

### **Shaping me**

I am not necessarily proud of having a physical impairment, but at the same time I do not wish it wasn't part of my life. Physical impairment has helped to shape what I am and I do not want to change what I am. In many ways I have learned a lot because I have MS. I am a very different person to the woman who for the first 38 years of life was not disabled. I think I have learned tolerance, patience and most importantly, to like myself as I am.

This has not been a quick or easy process and it was not just MS that made a difference. What it did was to give me and my partner an opportunity to consider ourselves and our relationship. I am fairly certain that if I was not disabled we would not still be living together and I would



not be happy. Of course life is frustrating and at times I become angry with my situation. But this is equally true of other people. Everyone meets difficulties and barriers in their lives and the way they deal with them is characteristic of their personality.

To return to the *Disability Movement* - I have not forgotten how depressing my experience was on those two days in 1991. I did not seem to be accepted as a disabled person because I had not been to special school and had more than 30 years experience as a non-disabled person. I was made to feel that I did not belong and was to some extent considered a traitor to the *Movement* because I wanted to work with non-disabled colleagues to bring disabled children into the mainstream. The argument went that only disabled people should play this role. I did not think it was possible for disabled people to do this without firm allies and I still believe this is true. Unless we work together there is little chance that the culture of our society will change.

I had gone to the conference expecting to find a group of people who would provide mutual support. This was far from the case and my daughter's position was even worse. A mental illness is not apparent and it did not occur to anyone that she could have a hidden impairment. She was even prevented from being a scribe in a small working group because the group felt she would not understand the barriers being discussed!

My life history showed two distinct strands: one of progress through the education system to positions of some status and responsibility, the other through increasingly severe physical impairment. What at first was an irritant rapidly became a determining factor in my life choices. When I started to need help I found myself being perpetually apologetic and



feeling I should be grateful to people. After all they didn't need to help me and it was all my fault for being such a nuisance!

This gradually began to change as I found out more about what it was like to be a disabled person in a non-disabled world. I found people's attitudes impossible to accept. There was the senior adviser who said in a reference that I had been an exceptional employee, but now I had MS and I should not be considered seriously for senior posts. Him I tackled head-on and he realised he had made a grave error of judgement!

### **Moving on-'my' way**

But while you can take on individuals, it is far more difficult to take on the world. As I became more disabled I seemed to become public property. People seem to believe that it is okay to ask me intimate questions simply because I use a wheelchair. I see people judge me by the wheelchair, not by the person I am. Every day of my life I face excluding barriers and while I work to dismantle these, often successfully, I do not manage to change the culture. Just because one barrier comes down it does not help to bring down others.

In 1993 I took early retirement from employment. This gave me the opportunity to embark on a different kind of life. I started a series of sessions with a psychotherapist and I took some university modules related to women's studies. These two activities were to bring about an enormous change in my way of thinking. From an initial six weeks the psychotherapy took place over two years and I learned about me and my behaviour. I learned to be truly proud of myself and to like myself for what I was. I come with my own baggage and my own set of faults, but I still have much to offer to my friends, family and community.

I believe in my own worth and this has nothing to do with impairment. I am neither better nor worse because of it. I believe passionately that we all have rights and that minority disadvantaged groups are prevented from achieving these by oppression and discrimination. I work hard but this is not altruistic, it is because I enjoy working with organisations and people. I enjoy bringing about change and seeing that I have made a difference.

I am fortunate because the jobs I had before I took retirement have provided sufficient financial resources to allow me to enjoy a good lifestyle and to purchase the technology I need to lead an ordinary life. This technology is very expensive. I would prefer to spend my money in other ways, but my quality of life is very important and without the technology things would be grim indeed.

### **Half empty**

All this gives a fairly rosy picture and of course there is another side. Not being able to move at all means that I must ask for everything I want, this makes it difficult to maintain my self-esteem. I cannot really be left alone and my private space is severely affected. I employ four people to meet my needs and the intrusion this brings about is rarely welcome. The organisational skills needed are considerable and much of my energy can be used to just to make my life work. Leisure time is difficult. The activities I used to enjoy are mainly physical and I can no longer take part. I can and do organise gardening, cooking, holidays, etc. But sometimes there is no substitute for doing it yourself!

I tend to spend more time working than I always want to, but sometimes it seems to be the only thing I can do. I can use word recognition to control my computer and this is much better than doing nothing. I find I am



unable to slip quietly into a world that does not require me to use my brain. Physical activity is a very acceptable alternative, but no longer possible.

I have come to the conclusion with my partner that retiring will never be an option. I simply cannot do things that will make it worthwhile. The worse thing that my partner can imagine is for me to be bored! I can be very difficult to live with, my standards are high, but can only be achieved through others and this makes considerable demands on them.

There are times when physical illness prevents me from taking part. Particularly the pain can be very difficult. At those times I accepted there is nothing I can do, but wait until it passes. I suppose to some people I lead an extraordinary life, but to me it is very ordinary. I just do what is right for me and I am sure I will continue to do so until my time for living comes to an end.

#### **4.4.6 STORY 6: AN UNTIMELY STORY (JANE)**

Jane's story in many ways can be seemingly a sad story. Nonetheless, what is inspiring about Jane is that her impairment which for many is interpreted as disabling and restrictive gave her the intensity to make something out of her life. I may not agree with some of the interpretations that Jane gives to the waffling of the disabled person's voice, but she surely inspires my thinking on how grassroots disabled people construe their life. The story:

##### **The very beginning**

My name is Jane and I am 26 years old. Here I am, telling my own story. I was born premature at seven months in 1976. My mum didn't know that she was expecting twins and she was surprised – to say the least! As soon as I was born, I was practically dying, fighting for my life. I spent three



months in hospital with my twin sister in hospital, in the incubator until we got strong enough to be taken home.

When we were just five months old, my parent's started to notice that I was different from my twin sister. My sister would sit down whilst I didn't manage to. My parents took me to the specialists and they found what's wrong with me. I am physically disabled. My disability is cerebral palsy, of the atetoid type, which means abnormal movements, stiff muscles and lack of co-ordination. In the meantime the specialists referred me to the physiotherapy to ease my muscles and improve physically. I continued to do this therapy for the next five years. I also made use of speech therapy to start speaking clearly as my voice sounds jerky. In the meantime I also attended occupational therapy, hydrotherapy to relax my muscles and I was also referred for some hearing tests because I have hearing problems when there are long distances.

### **Taking off**

First improvements were shown at age three when I started attending special school. With the help of the kindergarten assistants I started sitting down on my own, crawling and doing basic things like touching, playing with toys and exploring the things around me. Then I said my first words when I was four years old. At the age of six, my teachers at the special school noticed that this school wasn't good for me and I was wasting my time there because I was bright enough to learn like other kids in a normal school.

The next difficult step was how my mother was going to talk to the headmistress of our nearby school. I wasn't accepted immediately. There were problems for at least a week. They wanted to see how I was

going to react with the teachers and the other students. Everybody at school welcomed me including my classmates who integrated with me easily and I really co-operated with them too. From once a week, I finished going to school everyday. I saw a lot of improvement, I used to copy the kids and try to do things like them. This has changed me in a physically and mental way. I was quite intelligent at school and I got good results in exams. I had many friends who used to play with me during the breaks and help me in the schoolwork we used to have as I couldn't write on my own and the facilitators did not exist at the time. I also was awarded with some prizes for the effort I had done in the annual examinations. I took part in school activities, concerts, excursions and so on. I also wanted to do everything like most kids do.

My mother used to help me in everything be it schoolwork, homework, or just trying to cope with my needs. She tried to teach me everything I needed to do in my life. She never said no to me. She taught me how to be independent. She was the best mum in the world. Even Dad has been great too, he has done his best to see me happy and he really fought hard for my rights. He is still very closely involved with me. He does everything for me as my mum passed away three years ago. My family was brilliant with me, my sister and my brother were always close. They taught me a lot of things. We used to go out with neighbours either to parks or play in our street. My sister used to take care of me when my parents had some appointment. We used to talk like most sisters do and share our problems. I was also active in the 'girl guides' for four years, I attended camps, marched in parades. I love drama and always had a role part in the school plays and concerts. I got prizes from Grade 3 till Form 2. I had a very happy childhood.



As I grew up in my teenage years I started understanding more what's happening in my life. I started to understanding my disability. It was hard to accept the things that I can't do in my life because of my disability. At the time I started secondary school, which was quite tough on me. With the help of my family and friends, I managed to cope as well. I had new friends, new teachers, and a facilitator

I had been through hard times especially when I used to get bullied from some of my classmates. There were teachers who did not bother that I existed in their class. I also had a problem with transport. There was a driver who used to refuse to drive me back home. However, with the help of my parents he had to do it. There were times when I used to have a great time at school with my friends. We used to chat for long hours. Some of the teachers were proud of me when I did well in their subject.

### **Facts of life**

In the meantime, I began to understand more the facts of life. I started going out with friends in the weekends like most teenagers do. The subject of our main discussion was about guys. I realized that it wasn't easy for me because of my problems. It wasn't easy to accept the situation I was in. All the girls used to do the things that I couldn't do. It used to hurt a lot.

### **Long sighted**

I started to concentrate on my O' level exams. I really studied hard for them without attended any private lessons. I passed from seven subjects with the help of my facilitator at school. I was really proud of myself, so were my parents. After a year out of school, I found a job as a clerk with *Maltacom* and as usual I had to face the challenges.



Computer is a great gift from God as I can do anything I want. I use it for work and at home for my free time. When I did not have friends, after leaving school I was a bit lonely. Browsing the Internet, sending e-mails, chatting, listening and downloading MP3s, making new friends around the world kept me occupied during my free time.

### **Black clouds**

We discovered that my mum had a terminal illness. Once again I had another struggle to face. I did my best to cope in this situation. I started going to a *Christian Charismatic Group* and I found new friends there. In the meantime mom was getting worse. My family and close friends supported me through out this trauma. I did my best to find a personal assistant to be independent and not always depend on my sister because she has her life too. My mom died three years ago. However, life has to go on. It isn't that easy but I am coping for better or worst.

About a year ago I went out with a guy and I had a nice experience but it all ended after five weeks. Lately I am being involved in a number of NGO's. I am a member in the committee, *LAND – Living Ability Not Disability*, where I am the president of the group and other NGOs groups which I am a member to their activities.

Being a physically disabled person, I wanted to do something for others who have the same problems. I can understand their boundaries. Together with my friends we started a group called *LAND, Living Ability Not Disability* for youths. The group was set up seven months ago. The objective is to support physically disabled people from 18 to 35 years of age and are trying to live a normal life. The objective of this group is to

promote the independence of disabled people, make other people aware that they are like any other person. They have their same energy, their same ideals, their same eagerness to have fun but can't because they have certain limitations. Volunteers come out with us to bars, clubs, cinemas and karaoke. We are a group of people that are determined not to lose hope. In this group there are people who suffer from cerebral palsy, spina bifida, and people suffering from post accidental trauma.

My philosophy of life is that, if you want something in life, keep trying to get it, until one day you will attain it. All things are possible no matter what - never give up! I dream of travelling as much as I can, go with my present group on a youth exchange, have the opportunity to see a popular band overseas, have my own flat and maybe have a family of my own.

My message to the readers is first see the person than the disability. Give us a chance in society because we are all human beings, we feel, we laugh, we cry - like everyone else.

#### **4.5 EDUCATION AS A CONTRADICTION**

The stories that these people raise have some important dimensions with the main inconsistency being the concept of 'education'. *Jane, Conrad and Dean*, all speak about an education that is distant, detached and disinterested. These young people are disheartened by an educational system that is missing out on the core values that it has been designed for; holistic development, skills development, formal education and generalisation of skills. "Inclusion", is a fundamental principle to social understanding and respect. School as perceived by these three youngsters is to seek ways of creating a respectful community. These are stories about individual needs rather than individualism. Exclusion is in fact



a socio-political oppression and struggle. It appears that to opt for inclusive thinking is a process that engages people to swim against the tide.

*Sandra* sounds sceptical whether this educational process will actually change and transform people. On the other hand *Cynthia* sends a clear message against 'professionalisation'. She speaks positively about special schools! In a way *Cynthia* appears to struggle for acceptance of special schooling more as a justifiable situation for her own particular situation. She makes an argument whereby she interprets "inclusion" as a decision to overthrow and discard anything that is happening outside mainstream schooling. The fact seems to be rather different. "Inclusion" lies in the search for the processes of equity where excellence and choice are turned into positive influences rather than negative essentials.

*Adam* simply feels he does not belong to the system. It appears in many of the stories as a process where education is misshapen into an oppressive agent. On the one hand we construe education, as a process that is there to resolve and engage with the difficulties that are happening in time and others that are expected to come about. Education comes in handy as a major contributor to this social 'healing process'. In contrast we see an educational process that is drab, conservative, wary, suspicious and mistrustful, which make the much-needed changes increasingly difficult. Education needs to be regulated through policy and legislation. The people who have related their experience by writing their autobiographies are placing a great deal of emphasis on the regulation through policies and social institutions. Schooling needs to contribute towards adult citizenship rights whereby marginal groups in society collude with the development and upholding of those most distantly displaced. Disability studies need to be committed



not to a partial view of "inclusion" but to a contemporary society with a vision of a community conceived for all.

The use of narrative in educational research creates a new way of including subjects and where educational research in turn becomes restorative. In more than one way, the people I asked for their story may have found the process of telling their story therapeutic. *Dean* told me on a number of occasions that he loves to write and the writing is his own way of dealing with the complex and innumerable issues that are involved. Other people spoke about a story, their story, as if they were my service users, as if they were once again public 'knowledge-ing' their story. It feels like people are just bringing their story out of the cellars and onto the table for people to, chop, munch and devour (Bartolo 2001). *Sandra* and *Adam* felt that way. Then you had a third type of story-teller. They are the ones that wanted to tell this story as part of activism. They saw this story not as a cathartic process but as a way of actively engaging with a political discourse, an appeal, a plea to attract attention. People like *Jane* and *Conrad* are amongst this category. As *Bernard* (2000) is quoted as saying;

As a tool for emancipation, participatory research is one way to engage people in a process that aims to challenge oppressive structures that define and control their lives (p.185).

The people here who were telling their story recognise that they are 'different' but they seem to make clear that this difference, this diversity only becomes relevant at certain times and in particular contexts. These social frameworks that highlight their impairment identity is the way that society elucidates and expounds segregation. All these stories speak about a struggle. Some of the autobiographies feel as if their authors are at their last gasp, calling out and scuffling in anxiety (*Conrad* and *Jane*).

The stories also elicit a notion of difference that is not the product of impairment but a cultural structure that interferes with their identity. This brings them also to another attitude whereby disabled people's identity is constructed around distinctions on the basis of capability and behaviour (*Jane and Adam*). What I do find interesting though, is attitudes of people like *Conrad* and *Sandra* that are displaying a fluidity in claiming disability as part of their identity but at the same time are becoming their own agents of resistance to the dominant discourses that overtake their lifestyles and choices. They seem to be adopting an assertion for their own position in society. These people at the margins expose issues of exclusion and "inclusion" because they manage to string together their life story. Autobiography becomes a process of writing the 'self'. These stories became the vehicle through which the individuals concerned communicated the complexities of their lives, the experiences of exclusion and emargination were exposed, and where their existence is illuminated by past experiences of rejection and belittling.

#### **4.6 CONCLUSION**

The informants find themselves having to squeeze their life within a thinking process that is conditioned by a multitude of factors. The people who are narrating these stories are stating clearly that "inclusion" and exclusion lay at the foundation of the discourse on 'voice' and how their experiences, their struggles and their movement can obliterate disabling barriers. The past educational experiences of most of these people are in most cases testimony of education gone wrong. This is why the stories of 'people' at the margins contribute immensely to exposing issues of exclusion and "inclusion".

# CHAPTER 5

## Mapping Out A Transformative Agenda : Reading The Writing On The Wall

*Imran found an old lighter in my car. He asked if he could have it. I gave it to him with a patronising warning, "Now don't go burning down your mother's house will you?!" He looked at me with despair and retorted, "I'm not fucking stupid you know" (Goodley 2000, p.183).*



*'No need to hear your voice. Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my own. Re-writing you, I rewrite myself anew. I am still author, authority. I am still the coloniser, the speaking subject, and you are now the centre of my talk'.  
(Hooks 1990, p. 151-2 cited in Walmsley).*

## 5.1 INTRODUCTION

Stories are the way people seem to talk in all the time. There are stories that we are involved in during our recreation as we watch telly, as we read the papers and socialise at the bar.

People are saying stories at their place of work. News Portals are carrying headlines with stories of people that in some way or other have made an impact. What's more? Parents are teaching maths in story-sums! It's all about stories, how we say and listen to them.

In this chapter I will present the semi-fictitious stories that have come to life from my own ethnographic reflections and the four pilot interviews I had with some labelled students (Corker and French 1999; Goodley 2000). I then present a personal annotation of these stories. This chapter continues with the arduous tasks of presenting the main 'findings' following the discussions I had with the different focus groups. This part of the *Thesis* accounts for the process of bringing together stories and focus groups. It is also about presenting the stories and providing an analysis of the focus groups' response to the stories and how a transformative agenda for "inclusion" will be charted out. This chapter analyses the power of using stories in this kind of context.

The main debate centres on the following research question (Figure 5.1); what are the different perspectives of parent and disabled activists, teachers, university students, labelled students and social workers in relation to presenting a transformative agenda for "inclusion"?

Stories in themselves are a depository of data. It is in coming in contact with the familiar that enables a reader to make 'sociological material'. How can we start to understand the complex issues concerned with "inclusion" when we are unable to have a position as readers (Plummer 2001). Thomas and Znaniecki (1958) are cited by Plummer (2001) as saying that when 'one' is able to analyse the experience of the respective individual, there is data that can be generalised in the understanding of the complex issues that affect a similar context.

**FIGURE 5.1: THE RESEARCH QUESTIONS**

EMPHASIS IN CHAPTER	ANALYSIS	RESEARCH QUESTION
4	Analysis of autobiographies	In what way can the stories of people at the margin expose issue of "inclusion" and exclusion?
5	<b>Analysis of semi-fictional stories and Focus Group debates</b>	<b>What are the different perspectives of parent and disabled activists, teachers, university students, 'labelled' students and social workers in relation to presenting a transformative agenda for "inclusion"?</b>
6	Analysis of ethnography position	What practices enable "inclusion"?
7	Analysis of narrative research	To what extent does narrative research provide an adequate exposition of "inclusion"?

This chapter will attempt to scrutinise some important debates that encapsulate these varied debates surrounding "inclusion" and its transformative agenda seen primarily from the informants standpoint. The interpretation of the stories;



- The methodological consequences for informants in using stories;
- The rational interpretation of "inclusion";
- The main difficulties in the workings of "inclusion".

Figure 5.2 presents the four research layers that have informed my work.

**FIGURE 5.2: THE RESEARCH LAYERS**

RESEARCH LAYERS	DESCRIPTION
Layer 1: 'Me'	My own experiences deriving from the students I teach in an Area Secondary School and at University, my own social work practice, advise I give to a <i>Parents' Support Group</i> and my contact with disabled activists.
Layer 2: Autobiographies	I wanted to learn more about the way 'adults' see their experience of "inclusion" by collating a number of autobiographies, some of which I have reproduced in Chapter 4.
Layer 3: Auto-ethnography	I engaged with my own experiences and reflected on what is constituting my thinking on the issues of "inclusion".
Layer 4: Focus groups	I consulted and observed students to learn more what their perception on the whole issue of "inclusion" is. Their concerns, tensions and experiences, I transferred into five semi-fictional stories. I got together six focus groups, that I would say make up my professional DNA. In these focus groups I presented the semi-fictional stories for debate. The discussion took off according to the moods and frame of mind of the participants in this group.

The data I will be debating centres around material transcribed from six homogeneous focus groups that represent the different areas I am involved with in my professional life. For these focus groups I have put in writing five stories that represent the core experience of "inclusion". The semi-fictional stories are the common parameters I wanted to create to develop a discussion. These stories stemmed from four interviews I had with students at the school I work at and my own ethnographic experiences.

All these different and complex debates are interwoven within a methodology that is made up of four layers as seen in this diagram (Figure 5.2). The analysis of the data I have collated has basically four elements that make up the social enquiry (Clough and Nutbrown 2002);



- Persuasiveness: There is the use of 'voice' as being the crucial component in appealing to the major events in the lives of these people;
- Purpose of the project: Analysing the agenda for "inclusion" by engaging with the debates that are created by the protagonists;
- Positionality of the research: The clear correlation between findings and the literature review;
- Political role of the work: The very *Thesis* in itself is political because it is loaded with a large amount of stories, evidence, and testimonies. It is a work that is opinionated.

I wanted this research to be, influential, biased and positional (Clough and Nutbrown 2002). My argument lies in the fact that the work I am engaging with is first and foremost a process about 'me'. It had the target of helping me become visible and identify where I stand with the massive and composite tensions that govern this notion. Although this is one of the sections I dedicate to data analysis, the whole *Thesis* is in fact a *conclusion* in itself. This research is not after finding some blue print solutions but it is about answering the complex research questions by mapping out the different perspectives. Researchers have often claimed that research will only be valid when the public can connect to it (Clough and Nutbrown 2002), this is clearly my intention. Chapter 4 reported the autobiographies of a number of people who have helped me make up my thinking. The chapter was jam-packed with issues that ranged on a debate with every aspect of the "inclusion" process. I then moved on to Chapter 5 where I provide the background to the stories that informed my focus groups. This backbone chapter had the role of presenting the stories. I wanted to have the stories presented there because of the fact that these stories are semi-fictional and they held so much real facts as they held fiction, but either way they say the truth. I would refer to these

stories as taking a participatory ethnographic approach (Goodley et al 2004). It was participatory because people recognised the scenario and understood what is happening in a way that couldn't hide my identity.

Why focus groups? Focus groups are the hub of this research ...what I want to do is to observe and read through the issues ...at one point I said, what is the easiest thing to do, maybe get hold of "inclusion", define it, present some recommendations and that's it! I felt that that would not do justice to the issues. I wanted to illicit, even the obvious from the people who have a richness of experience because they live the "inclusion" debate, people like social workers... university students ...teachers who have to face the music... parents activists... disabled persons... I wanted to understand "inclusion", but I wanted to understand myself as well that's why I used narrative. I wanted to interact, to listen to stories, to reproduce a reality ... Now I would like your ideas first and foremost... general or specific, it doesn't matter... when you read these stories, what did they mean to you? (Andrew, Researcher to Social Workers).

However, they were very perceptive in understanding where I stood. This work was ethnographic, because I was deeply involved with whatever was happening (Denzin 1997). The stories I write, the focus groups I was facilitating, the interviews I was constructing were all immersed in a profound cultural experience of a social group that attempted to find the hidden possessions and submerged hostilities. In a way these writings take on a personal narrative which had a strange feeling especially when members of the focus groups (Anderson 1997) at one point said that it was practically obvious that I was there, fully present, in the stories. It comes to a stage when I started feeling that the territory lined around the academic 'me' and my personal life story open up to each other. Having grown in a research culture where the infamous cliché 'keeping boundaries' is practically *sacrosanct* was frightful. Practically in every one



of the focus group sessions I started out my introduction by saying that I am afraid where this research will take me, because if there is anything I'm in control of, 'me' does not stand as one of them. I wanted my work to be grounded in a reality that in itself could help me interpret the wider context (Plummer 2001). I wanted my stories or rather the stories I wrote to build up and illustrate a wider perspective.

...what we are now starting to see are social scientists who turn their studies into fiction. They tell the story as a story – drawing it is true upon their research, but making a major concern rest with its readability, its ability to enter a more popular imagination (Plummer 2001, p.200-1).

This chapter converges the data that has been collated and the subsequent analysis on that information. The complexities of the methodology I have brought into the scene made the analysis a very difficult and volatile process. The methods employed all had to lead towards having a methodology that is based on the values of emancipation and participation (Barnes and Mercer 1997). The scenario of all this was based on the narratology that I endeavoured to develop. The analysis will be split in two main components, a commentary that gives an overview of the main issues contended with in the focus groups, and a review of the matters that came out from the focus groups and the subsequent debates.

## **5.2 MAINSTREAM SCHOOLS REPRODUCING WHICH PARADIGMS?**

Before reproducing a number of comments and reflections that my focus group informants articulated, I would like to state that in the local context, here in Malta, the concept of "inclusion" is often referred to as being 'full mainstream presence' (Barton and Armstrong 1999). However, in the corridors, boardrooms and during socials, professionals and parents speak about "inclusion" as being a provision that can be qualified into layers of



systems, models and strategies (Salend 2003). It appears that the only way of achieving the right attitude is for the disabled to accept the professional as collaborator;

Molly has received little parenting support from the health and social services. Service delivery tends to be crisis-oriented: Molly has been left to cope as best she can until things go wrong. Her past experience has taught her to be wary of social workers who, in any case, tend to move on so frequently as to prevent the formation of a trusting relationship (Booth and Booth 1993, p.15).

Conversely, there is a big movement in the local scene to support having full "inclusion" of students in mainstream and it is not politically acceptable to speak about different models and alternatives! However, in unofficial settings one can see vibrant debates that take place around "inclusion". I have seen this during focus group meetings. I have also witnessed these debates with my colleagues at school, during lunch break or else in the staff room. I stumbled upon these 'hot' discussions with social workers and also with students at University. I recall various incidents when I spoke about "inclusion" during lectures and students would come up during lectures or after the session and tell me that they believe in the principle but find it increasingly hard to translate these notions to their teaching practice. These contributions that I have quoted from my focus group discussions address the various perceptions on disability and the workability of such a notion. The informants fling from a thinking where "inclusion" is possible to a framework where "inclusion" is not possible for all unless there are drastic changes to the system; varying from further professional development, to peer preparation programmes to a completely transformed school ethos.

...we have to create a sense of "inclusion". We have to include them... (*James, Teacher*).

...when he gets out of school, the children we take care of, are not going to have a facilitator with them when they are going around in the streets, and when they go to the village square... (Carmen, Facilitator).

...and we have, for example, another boy at school who uses his disability to get what he wants (Joanne, Teacher).

Either you don't let him play because he knows he can't be like others. At the same time, you have to make the others aware to include him, but how fair is it to let him win... (Joanne, Teacher).

But for example a child who cannot go up to Form 1 because there is a staircase in that case the Headmaster has to tackle that problem first and foremost because that child has to go to school, in that sense I was saying. It is for me the most obvious kind of thing (Elizabeth, Parent Activist).

I think that "inclusion" is a very complex issue. and there is no one answer. Like everything else you cannot put everyone into one basket, you need to have an ideal but you cannot become the slave of that deal. The ideal is there to help you achieve your targets (Richard, Disabled Activist).

I would like to emphasis this point. The norm is now "inclusion", "inclusion", "inclusion". But there is a percentage that understand that "inclusion" doesn't work for everyone. I had a case some time ago, an 18 year old girl.... I asked her how she did at school? She told me, not well. I told her, 'and you didn't repeat Form 5 or anything?' She said, 'no, I learnt nothing at school!' ...God knows how many children there are like her (Walter, Disabled Activist).

Because listen, you need to understand this. For example they put a severe disabled person with



challenging behaviour in the classroom. Now come on, if you were the father of another student, what would you do? Let's be frank here, we are all disabled here and we say we believe in "inclusion". But, it depends on which part of the fence you are. You can say that everyone has the right to be included but if there is a student that is all the time interrupting... what happens? (*Walter, Disabled Activist*).

### 5.3 UP CLOSE AND PERSONAL

I am always impressed by the disciplinary action that takes place in the schools vis-à-vis these children. Many a times instead of helping them they hurt them more. For example I remember the school I went to. When there where the girls that did not make part of the norm, they were excluded from school a week at a time, just to get rid of them. Instead of helping them out, they threw them out of school (*Ann Marie, Social Worker*).

The same stories revealed sentiments and internal complex emotions of the informants. They spoke about "inclusion" and how this whole debate was affecting them as they recall events which manifest how experiences they have gone through in the past have been revisited through their engagement with these semi-fictious stories. They delved into the personal. The narratives touched them deeply enough to get them to speak their thoughts about themselves.

That's why... and you have to work with that person and tell him, 'listen this is your condition, accept it'. There will be someone who will not accept you – it's not a negative thing, because even though they say I'm normal, there are some persons who don't accept me – should I get offended? But they don't accept me even though I don't have any outside defects, but you have to see the person, 'listen, this is how you are, accept who you are, be thankful, you go with the friends who like you and accept you,



those who don't accept you, it's their problem. Don't get offended yourself because there are people who don't have any disability and still they are not accepted (Karen, *Psychology Student*).

Informants have identified with the stories, bringing in a repertoire of intense generalisations. This brings to mind the power of stories. I well recall reading Moore's participatory, ethnographic story (Goodley et al 2004) and immediately linking it to a friendship I have with a disabled person whom I work with in my social work relations (Clough 2002). Stories take on a dimension that is beyond space and time. Whilst tragic, it converges a different reality. It is a marvellous cross-fertilisation of understanding reality. Whilst Moore's story has an ending, 'mine' has yet to be concluded. These stories are self-revealing (Goodson and Sikes 2001).

These are films going around that are purposely about either "inclusion" or racism, where they show the emotions ... you're seeing a black person and a white person, they're getting along together, one gets hurt, they both cry together, they go through emotional things together, and you start saying: 'that person has feelings just like I do or that's like...' as soon as they see how we are alike, it brings the barriers down (Karen, *Psychology Student*).

#### **5.4 MAKING THE RIGHT METHODOLOGICAL CHOICE**

When I was reborn in that hospital I was 31 years old I had no idea that the most important work I could do would be to become a storyteller about living with a disability. But from my own stories to the history of disability rights to the creation and work of the Institute on Disability Culture, it is the stories of our people – disabled people, people with disabilities – that people want to hear, want to read, want to write, want to know their role, want to know what part they

have played and continue to play (Brown 1995, p.106).

An important debate in the focus groups centred on the methodological aspect, where the use of stories was discussed and analysed as having a place in practice and policy. It is interesting that most participants who came from different perspectives assert their position in relation to presenting an agenda for debate. 'They' found these semi fictious narratives useful in a number of ways;

- These stories had the responsibility of informing the people in the focus groups.
- The focus group discussion was coated with a particular flavour. Each story was understood depending on the background where informants 'came from' (Clough 2002).
- The homogeneity that characterised the focus group is an issue that may have created some innate tensions and nervousness. The stories themselves have a dimension of curiosity within an auto-ethnographic framework (Clough 2002).

I have reproduced the ideas of these stories as they have been said to me and regurgitated to the different people that have shared this debate. The notion of the 'real me', points to the unity of the self which, once dislocated, poses disturbing questions of identity.

Maybe we need to get used to living with fragmentation rather than eternally searching for the self and accept that the self will be invented and re-invented.

Because the question that comes to my mind as well is "Diversity in itself" – it continues with what Omar said – "diversity in itself is rejection of conformity?" ...this research is a reflection of what I feel is happening around me, like you said

Anna, it's as if at higher levels and at policy level, everyone is clear on what they want – an inclusive culture, inclusive schools... All right, good, we agree on all this, a nice book is published, full of "National Curriculum", it makes a lot of sense, .... but in the end? Later when you come to the real – the 'yes and no', to the every day life, Monday morning at 9:15 am, lesson 2, understand? There you find circumstances that you say, now I am either going to have a go at everyone: with the Head, with that one, with the other one, or otherwise I'm going to try and conform and make compromises (*Andrew, Researcher*).

The informants, in this piece of work, repeatedly sought ways how the research can become their own. There was a continuous engagement with the need to be present in this work. They recognised the cruciality of methodology or as Goodley *et al* (2004), describes method/ology as a sympathetic tool that allows the people involved to be in control. This discourse would be in tune when the theoretical dialogue is done within a debate that is governed by a syntax of theory. It is useless emphasising the importance that lies in the social model thinking. Disabled activists have repeatedly seen the validity of method if it brings them in line with the control and the struggle they have engaged with; moving from the personal to the social oppression theory, recognize expertise as part of the experience, affirming a position rather than being pushed around to adjustment and making politics rather than fancy strategy clichés (Oliver 1996). The social model does not lie above the echelons of practice. The social model has provided enormous inroads for people who have struggled to have citizenship rights. This model, has re-positioned the emphasis from one of fault finding to a shifting of responsibility, from a society that has created mainstream values to a struggle that has seen the most basic of assumptions faced up to (UPIAS 1976; Oliver 1996; Barnes



and Mercer 2003). Taking words from Goodley's (2000) Acknowledgment page, "They are the real disability experts and may they continue to change their worlds" (p.1).

## **5.5 THE STORIES**

Stories and story-telling has been a neglected part of educational research. However, a number of researchers have thankfully realised that "stories are oral literature whose meanings, forms and functions are situationally rooted in cultural contexts, scenes and events that give meaning to action (Cohen, Manion and Morrison 2000, p.302). Stories have been known to carry affluent, valid and reputable information which has made the mainstay of my research. The following five semi-fictional stories ensue with a commentary. These have made the mainstay of my research.

1. Chris and the Blade
2. Dustin and the Counsellor
3. Clint and the Porter
4. The Circus is in Town
5. The little Nationals

### **5.5.1 STORY 1: CHRIS AND THE BLADE**

Chris is waiting in front of his home, his face pressed between his two hands, his eyes sticky after a good nights sleep. He's as still as most things in *St. Thomas Street*, a narrow lane in the centre of a clamped up town with the gantry and tower cranes at one end and the fifty-year old slums at the other. It's a dark path, leading to hell - some would say. The nauseating smell of humidity, mixed with the stanching odour of vegetable soup - a mix up to make it feel like you're at the end of a day in a discounted restaurant kitchen. Piles of rubbish at one corner of the road, all muddled up with a colony of kittens struggling their way into this

overload of rubbish. From somewhere you could hear a baby crying out from the brown lazy walls. Walking up the lane was what looked like a very normal eleven-year-old, haversack neatly stacked on his back, wearing a freshly washed and ironed white school shirt moving with a steady pace as if he doesn't want to arrive late for his next appointment.

*Rick:* Hey mate what's up?

*Chris:* W-h-a-t-'-s u-p?

*Rick:* Yeah, you look as if you're off to the dungeons. It's school time man. I was looking forward to school. It was so boring these last two weeks.

*Chris:* Oh shit, we're late.

*Rick:* Oh it's ok. The Head's a twat, he won't notice.

*Chris:* Well my mother will!

*Rick:* Come on quick, we can get the bay-blades after...

*Chris:* After what? I'm on transport this year...

*Rick:* Oh don't tell me...

*Chris:* Yeah, don't tell me! She said it's too much for my scoliosis, too much for my arms, too much for my back and the....

*Rick:* Oh I suppose it's fair enough...

*Chris:* No mate it's just crap. My back is fine, I want to play ball and all my mother keeps saying is 'watch out love, watch for love, watch them love....' Oh look there's Mark... Hey Mark quick we're late...

*Rick:* Mark, look at my blade!

*Mark:* Cool man... com' on guys let's go... what about the team, we have a game with 2A tomorrow?

*Chris:* Can I play?

*[Mark and Rick look at each other puzzled]*

*Mark:* Quick guys we're late....

### 5.5.2 STORY 2: DUSTIN AND THE COUNSELLOR

*Counsellor:* Hi son! How's it doing at school?

*Dustin:* Oh it's fine Sir!

*Counsellor:* You're sure? Been hearing about you quite a lot lately!

*Dustin:* Oh really! No, I'm cool! Well some of the teachers are litter, junk... I get blamed for everything with them!

*Counsellor:* Yes? But why?

*Dustin:* Oh they just see me as their shark bait... I'm sincere, I'm open, so I always own up... the other kids don't ... they [*the teachers*] just keep bragging until I'm told that I either say who it is or I'm in shit! That's not fair! I would never talk about my friends. Some teachers are bums...

*Counsellor:* You know I've heard things being said about you?

*Dustin:* Teachers are always telling tales, saying things that are not true...

*Counsellor:* How are you feeling after being away from this school for these two years? [*Dustin has been to a residential school*]

*Dustin:* Ok. I like this school better...

*Counsellor:* Why?

*Dustin:* The teachers are much better! They talk to us as if we are their friends...

*Counsellor:* But you said you don't like the teachers...

*Dustin:* Well, not all of them! Most teachers are OK! I like this school cause I have loads of friends... I've been away for two years, but at *St. Andrew's*, well it wasn't the same.... Too much discipline... Too much pressure. If you don't do well, they beat you... they treat you like a pig...

*Counsellors:* Who?

*Dustin:* Some of the teachers...

*Counsellors:* All of them?



Dustin: No...

Counsellor: Most of them?

Dustin: No just some of them... the drama teacher I hated most. It was a good excuse for him to hit us... he would say it's drama, we need discipline here, we need to... and he hits at us... the fuckin' cunt... I hated him, the bastard...

Counsellor: Did you speak to the Head?

Dustin: Oh the Head was one kind of a dick head. He was an ass hole, a real damn bastard. I used to tell him about this at first. Then once the drama teacher, we used to call him the Caterpillar because he walked the corridor in zigzag, had a really small head and was always wearing a coat bigger than him. [Counsellor and Dustin laugh] ...well the Caterpillar told me that the Head had told him what I had said about him. I ended up not doing drama and just getting extra work, more like a copy it was. The ass hole... and the Head was always telling us to go to Mass. I really hate them all. They suck.

Counsellor: Ok, I know this irritates you but easy with the language...

Dustin: Sorry sir. I used to like our social worker - I used to! We talked a lot. At first I didn't trust him. Then I started telling it all. He was cool. He loved the same team I side with, Manchester. He told me he went to see them once in England. Then all of a sudden he didn't work there anymore. Never heard from him again.

Since then Dustin has been told off by the Head of school. He said that he does like school but he always gets the blame, whatever happens. The Counsellor asked for a case conference. His mother and Aunty came. His mother is rapt in a depression, has a history of domestic violence and is now a single parent with three other children who are

younger than Dustin. Dustin spends most of his time with his Aunty. She is the one that takes care of him. The Head said that Dustin is about to be dismissed from school if things stay as they are. His Aunty asked what is going to happen to him if he is sent away from this school?

Counsellor: You know you're risking being sent away?

Dustin: Why?

Counsellor: Your behaviour...

Head: You've gone wild Dustin... you keep telling lies. Dustin, you keep calling teachers names, you got a flick knife to school the other day and said it's for the fruit...

Dustin: It was for the fruit...

Head: So why did you tell me it wasn't for the fruit then?

Dustin: Uff, come on...

Counsellor: You're in trouble mate...

Dustin: Why?

Aunty: What are we going to do Dustin?

Mum: This is crazy? Why didn't they keep him at St. Andrew's?

Head: Yes, what happened there? Do you know? They told us nothing?

Counsellor: Dustin, you're in trouble...

Dustin: But why? What did I do?

Head: You shout all the time, I hear you from my office... don't forget my office is just right by your classroom...

Dustin: Is it me that shouts only?

Head: I hear YOU mostly...

Dustin; But yesterday, I was trying to keep them calm during the History lesson, *Paninu* [The nick name of the History teacher... meaning 'bun'] keeps trying to do a lesson and Joshua kept shooting pins at his face....



**Head:** It's not just yesterday Dustin... Dustin you're in trouble...

**Counsellor:** What do you suggest...? *[Looks at relatives]*...

**Aunty:** Please, give him another chance *[Both are in tears]*.

**Mum:** Be a good boy Dustin...

**Dustin:** Yes mum, do you have money?

**Mum:** No...

**Dustin:** *[Goes to look in her bag]* You see you have – you're a liar!

**Head:** That's being rude...

**Dustin:** But she lied...

**Head:** You see, talking with Dustin is useless...

### 5.5.3 STORY 3: CLINT AND THE PORTER

A lot of hullabaloo outside his office...

**Counsellor:** Ok Paul, see you then... Quick, quick off to class...

**Paul:** But....

**Counsellor:** Quick boy quick...

**Paul:** Can I have a note sir please?

**Counsellor:** *[Irritated and snappy]* What note son?

**Paul:** Well to say I've been here...

**Counsellor:** *Oh it's ok... tell the teacher you were here. With whom is your lesson? [Before Paul could answer]... Oh she's ok... she won't tell you anything... [Jostles Paul out].*

By this time the Counsellor jammed between Paul's exasperating desire to have a note and a wooden door that is about to smack their backs. The scene at that time was made up of a loaded foyer with about twenty students going off to their lesson in a buoyant rhythm. Charles the Porter and a flabbergasted Clint with a helpless look like a puppy about to be whacked by his master. The Counsellor is grappling to find the right words.



**Charles:** You sod. Pick that fucking God damn can from the floor. I saw you throw it away, you know, I saw you! [*Clint still hanging on to his puppy look*]. Now don't you play the handicapped with me, you fuckin' ass hole... I saw you do that... you pick up that tin or I'll flick your silly face mate. [*The Porter had his hand raised to the highest level possible, as if he wanted to make sure the slap would be heard all over the school*].

**Counsellor:** Charles, calm down...

**Charles:** I fucking what?! You know he stepped on my feet? He just did it... yeah he stepped on my Goddamn feet... the ass hole. I'm not afraid of this idiot. He just wants to look silly. He's not silly you know, he's just a bastard... I clean, he dirties [*Still with his hand raised but now with the Counsellors hand squeezing his elbow in earnest*].

**Counsellor:** Charles he has a shunt...

**Charles:** A fucking what?

**Counsellor:** He has a shunt... if you hit it he's dead... - you can K-I-L-L- H-I-M.... you know, it's one of those things in his brain to keep the liquid flowing... [*Charles starts to cool down, coming out of his angry stint. The Counsellor keeps at it seeing that Charles seems to start realising what is happening*]. He's been operated there a number of times. Got some sort of pipes.....

**Charles:** Oh shit... oh thanks man... oh God...I, I lost my temper...I, I, I just couldn't, oh my God....

**Counsellor:** It's ok Charles.

**Charles:** Oh my God...

**Counsellor:** Ok, off to class Clint.... off, off, off...



Clint with a dazzled look, moving on with his unsteady gait, confused look, and with an air of victory stoops off to his next lesson, giving a quick glimpse every ten paces he makes, still feeling the threat of Charles hanging over his head, and a twinkle in his eyes sitting lazily in his twisted specs telling it all. From the end of the corridor you could see his facilitator walking towards the victor.

*Facilitator:* Time for math Clint. Had a good break?

[Some days later:]

*Counsellor:* Hey Pete, did you realise what Charles did?

*Pete:* Did what?

*Counsellor:* Well the thingy with Clint.

*Pete:* Oh damn, that was bad. You know what? I spoke to the bugger?

*Counsellor:* What bugger?

*Pete:* Clint... he told me it was his fault...

Counsellor opened his eyes with the white showing all around the pupil.

*Counsellor:* What?

*Pete:* Yes, Clint threw the can on the floor and he stepped on Charles's feet on purpose...

*Counsellor:* Oh fuck! Goddamn son of a bitch... but he was going to hit him...oh and I was about to be slapped myself.

*Pete:* Oh yes, he's a bugger that Charles. He loses it. Fuckin' hell. I mean Clint is handicapped. Not sure these kids should be around. Aren't there special schools for kids like him?

The Counsellor went out feeling confused, awkward and tongue-tied....

#### 5.5.4 STORY 4: THE CIRCUS IS IN TOWN

A total hustle bustle. A compeer plods in whilst the jugglers are still at their games. Others are on the ropes. Some are working the Still Trapeze. Headstand specialists and acrobats. Life-daring stilt walkers. The bars, the poles, the fire-eaters. Clowns, lion-tamers, flying trapeze specialists, make-up, props, costumes and other... This is what it looks like as I pass the science class. No idea of balance or symmetry, discipline or method or order. Down with the pedagogy and up with the restraint! Oh gosh, hang on, this is not it. This shouldn't be it. This is not a Circus we are in – it's the science class – I keep reminding myself!

*Teacher 1:* Ok Johnny, I've had enough. Bring your bloody arse back in here. Come down from that window I said! Hey Tom, get that toilet paper roll in here. Get it! Ah what was that – Oh God! Ok, who threw that?

*Peter:* Ron miss...

*Teacher 1:* Ron, off to the Head.

*Ron:* No. It wasn't me... Mark you're a cock face and you look just like the Iguana at Harry's Pet Shop...

*Teacher 1:* Who's the class prefect here? Bring the Head [no one moves]. Who's thrown that olive....? Now... *Screams*] Now, somebody has to own up – or you're all grounded for your next football match. [*Students expressing their dissent at the top of their voices. Some hanging on to windows, others throwing things at each other and others playing around with the toilet Thesis roll*].

*Ron:* Hey they're lying... Paul you're a fucker!

*Teacher 1:* Ron, you're a damn stupid idiot. The more time passes the more rude you become. You suck. ✂



Ron: Hey Teacher, stop the rude words. You cannot call me names.

Teacher 1: Oh yeah! Says who? Did you hear me say anything rude boys? *[Some students nod, others gaze away – none say no].* Ok Ron, you know you did wrong. You have been throwing chairs, walking on tables, disturbing other students. You know this isn't fair. This is just not fair and you have to admit *[Teacher starts getting angry].* You've really piss... got at my nerves. *[Screams outside the classroom - Teacher is now shoving Ron out of the classroom. In the meantime another Teacher walks in to help out. Teacher grabs Ron from the elbows and takes him to a quiet and sheltered corner in the school lobby].* Now it's the two of us Ron. You stop the fucking shit with me. You better behave or I'll kick your ugly face. Now in class we rule – and you go with our rules. *[Patting him gently]* and keep this in mind – stop the shit or I'll smack your silly face out of the window. Oh you couldn't say anything about this little conversation eh? It's just us – no one will believe you.

Ron: I'm not afraid of you – you're bullying me.

Teacher 2: I'm not, I'm just teaching you the rules of this school. You're new – so you need the help.

Ron: I hate school, I hate Teachers. I'm not afraid of you. You cannot touch me.....

*[Screaming heard from the science room... Teacher1 runs out of the room].*

Teacher 1: Call an ambulance someone. Paul has a concussion. He's been knocked down by Darren. Oh my God, Oh my God.... I just had to leave for two minutes to get the handouts. *[Ron*

*looks flabbergasted, as if somebody had really smacked his grin out of the door].*

Teacher 2: You'll be ok. I'll tell them you don't usually leave your classroom...

*[45 minutes later. Health and Safety Teacher comes in the room].*

Teacher 3: Paul is ok. He just has a bad headache. I guess going for a check up to hospital will be routine. You'd better go write up an incident report.

Mathew: Hey Miss...

Teacher 3: Yes...

Mathew: ... my nose Miss... it bloody hurts. Shit miss don't touch it.

Teacher 3: I need to have a look Mat.

Mathew: I knocked it against Paul. He was about to fall. Oh shit – it hurts.

### **5.5.5 STORY 5: THE LITTLE NATIONALS**

Stairs. Loads of stairs. Dark and smelly. A handful of shadows and more stairs. I walked up wearing my tie – feeling uncomfortable, confused and a bit scared. 'God', I kept asking myself, 'do these slums still exist'? I don't usually 'dress up' for work. I was coming from a meeting, an important meeting at school – a case conference it was. One of our students wasn't behaving well. I told them, 'I know what he has!' They all seemed to stop at once. I never managed to have so much eye contact at the same time! 'He's got ADHD!' Some lips, some eyes, some cheeks started to quiver and shudder as if they wanted to say, 'Oh thank God, now we can start doing something'. On the other hand they knew, we knew, well I knew, that there wasn't much to do with this boy – he had to be sent away.... to a special school. They all seemed to agree that a special school 'is the most appropriate school for him'. The population of the school is just ten students. 'The Headmaster is a good man bless him' they



said. 'Oh and what is the name of the school?' I dared to ask. 'St. John's EBD' I was told. I could notice a grin under our Head's hand rippling down to his big unsymmetrical belly. He seems to cover his mouth all the time as if he's too shy to show his missing teeth or was he too ashamed of failing to take care of little 'Dennis the Menace'? Or is it fear he is engrossed in? And then the.....

*Myself:* Oh sorry – do you know a family called Zyneb?

*Small boy:* No.

*Small boy's mum:* Oh keep walking up, turn left, walk straight, then turn right and you'll find it. There's a little *Madonna* in a niche' close by.

*Myself:* Oh thank you... [*Still confused and struggling hard to get into the social work mode*].

I remember once at school I had a friend of mine, Abdul. He told me to ask the Arabic Language teacher to make a translation for me. I asked why. 'Oh you tell her' he told me, 'you'll make us all laugh'. I remember asking the teacher, 'Misses, can I have the translation of 'butter in the nest'?'. Well it didn't sound too bad too me, just silly. 'Ok darling you're out of class, straight to the Rector and don't come back to this class without your mother'. Well I remember asking her 'What did I say wrong? Abdul asked me to ask you this', I continued. She told Abdul to walk out of class with me. I remember being kicked and slapped by Abdul as we walked to the Rector's office. I soon got to know that the literal translation of that phrase to Arabic sounded like 'drop the penis down the fanny!'

Back to this day and age. I caught sight of the *Madonna* incubated in a glass coffin standing to attention, waiting for the next pilgrim. I arrived at the top of the stairs. Felt like the stairs would never end. The family I



found. All wrapped up in their North African culture, seemingly afraid of the questions I was going to ask, before they actually came to mind. A little Down's syndrome girl looking at me with compassion as if she understood that my heartbeat with all the stairs had shot up the pace. We talked.

As I left the house, I remembered a conversation I had with some students I teach at University some weeks back. We spoke about diversity, about "inclusion", about people coming from a different culture, about Malta being just at the right point to converge these different cultures. At that time I thought it was a good academic reflection of what is happening – but now it all sounded silly – there's no converging I saw in the slums I'm in! And then my mind shifted to Tarik, a student I teach who was helping me write my *Thesis*.

- Myself:* Hi Tarik!
- Tarik:* Hi Sir!
- Myself:* You know I had to speak to you. I told you about this at the end of the scholastic year last June.
- Tarik:* Yes, you had to contact me.... You never did! [*Looking disappointed*]
- Myself:* Yes [*embarrassed*] I was busy, well I tried to call, but couldn't get through. Hemm... anyway, you remember what I talked to you about...
- Tarik:* Yes, you said that you'll be writing a book, a big book and you're going to write about me in this book! [*Looking proud*]
- Myself:* Ok Tarik... how are feeling at this school?
- Tarik:* Ok.
- Myself:* Do you feel bullied?

- Tarik: No.
- Myself: Ehm.... Do you like school and....?
- Tarik: Oh yes.
- Myself: ...and the teachers [now looking puzzled]?
- Tarik: Yes they're ok.
- Myself: Do students bully you?
- Tarik: No Sir, no.
- Myself: Ehm.... not even because of your surname?
- Tarik: No.
- Myself: But Tarik, last scholastic year you said that you had problems with the other students.
- Tarik: No, I am happy at school. They didn't bully me, they were just joking.
- Myself: But Tarik you cried and you were very angry.
- Tarik: Yes, but now it's ok [*Using an irritated tone*].
- Myself: No it's not ok! If you were bullied, you were. If your friends picked on you it's not ok. If they called you names its bad. Look, the other children were treating you badly ok...badly...there is no question about that. I want to know who was treating you badly. Speak up Tarik, come on speak up. What was wrong?
- Tarik: But sir now it's different.
- Myself: No son it's not.
- Tarik: But my father was an Arab. He lived in Tunis. My mother lived here alone.

By this time I had arrived outside the slums. The air felt fresh even if bursting with pollution and car fumes. I breathed two, three times to make sure my lungs were full to capacity. I was off to my meeting on

policy. We were going to discuss how *Principle 4* of the *National Minimum Curriculum* could be implemented in schools. Masses of reflections to write to-night in my research diary!

## **5.6 QUESTIONING THE UN-ANALYSABLE**

### **5.6.1 INTRODUCTION**

This work is an attempt to connect with the readers and to animate the ideas that are being raised. This is no frivolous task especially when one keeps in mind the vast number of people that were involved in this process of consultation. Rather than creating a debate that brings such a complex discourse to read clearly, I went to a debate that reads critically.

The datum becomes, then, not the consequence of a way of seeing even, but that act itself (and as such, must be intentionally opposed to the thing in itself). And in just this way are 'social practices' produced by research. For there are no instruments, no methods prior to the function of consciousness, and all instruments and measures depend for their very existence on the way they serve this function (Goodley *et al* 2004, p.68).

My viewpoints converged with the perspectives of the informants that were involved in the focus group sessions. These analytical debates include the importance of allowing the informants to say what the stories have meant to them.

### **5.6.2 WHAT DO THESE STORIES TELL US?**

One of the key concepts that seemed to emerge in the debate was that stories were telling 'them' something about 'them'. During this process people were basically getting to know themselves. These stories carry a great deal of notions and thinking points that informants have managed to see through. The principle analysis on these stories are the following;



- 'Difference', as a negative interpretation of social construction (Thomas and Loxely 2001);
- 'Injustice', interpreted as a breach of human rights (Armstrong, Armstrong and Barton 2000);
- 'Balancing power', as a conditioning factor that downplays the forcefulness of disability issues (Clough 1998).

I believe that difference is difficult to accept...  
(Gloria, Social Worker).

There are loads of things to say about the stories, but what stands out is the sense of injustice these kids go through (Jenny, Social Worker).

There are a lot of 'power' related issues. For example there are moments when the students have the power. Than there are moments when the staff has the power. It seems that there is never a balance.... This is what I felt mostly.... issues of power... (Ann Marie, Social Worker).

The first semi-fictional story, *Chris And The Blade*, is about this physically disabled boy, *Chris*. He is a young student coming from a particular part of the country, a region where I work at as a teacher (I also had some social work visits in this region). It is a geographical area I know well, a part of the Country characterised by poverty and limited resources. In reality, all of the stories have characters that are native to this region.

The Cottonera district is caught in a degenerate and viscous circle... Uneducated couples (legally married or otherwise), generally living in sub-standard conditions, bear children with little or no possibility of ever being responsible or productive citizens. In all probability, each new generation is more numerous and culturally worse than its preceding one. Is there a way of breaking this viciousness and degeneration, thus pledging the right of socially disadvantaged children to the future.... Strange as it might seem, most of these children do not attend

school for long periods or none at all. In various parts of Cottonera.... gangs of children roam the streets on weekdays in the mornings, and even late at night. Their ill breeding is thus further intensified by the uncouth neighbourhood surroundings, which accepts their misdemeanour with complacency (Montebello 1999, p.1-2).

This manifestation and the bringing together of this collective experience contributes to the weaving of a tapestry where the occurrences and the informants are brought together to deliver a message (Azzopardi 2000). These people have their own way of protecting a culture that the rest of the Island would want to eradicate and remove. It is a culture where *The Balinese Cockfights* of Clifford Geertz (1973) come to life. The narrative of Geertz (1973) and his *Notes on the Balinese Cockfights* is a scenario I recognise very well. It is a state that characterises this region. Within this situation, we can understand better the way people live and think, and the form interaction takes.

What the cockfight says, it says in a vocabulary of sentiment-the thrill of risk, the despair of loss, the pleasure of triumph. Yet what it says is not merely that risk is exciting, loss depressing, or triumph gratifying, banal tautologies of affect, but that it is of these emotions, thus exemplified, that society is built and individuals put together. ... it is a kind of sentimental education... (Geertz 1973,p.6).<sup>11</sup>

It is a discourse, which takes us well into what is being engaged with in our daily interactions. These students know interaction through the pain of exclusion.

I think that what brings them together is something that is a matter of culture. The culture that what's different is to be kept different (*Omar, Teacher*).

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<sup>11</sup> Extract retrieved on January 2, 2002 on the World Wide Web: <http://www.cs.auc.dk/~pera/travel/photoindex.html>.

Chris is a 'typical' in his area. He hardly has a 'voice' but still struggles to position himself within a school context that is 'a completely different planet' from where he comes from, from parents that treat him as if he's still in hospital coming out of surgery and students that are more sensible than adults think they are. It is a context where one gets confused what the real impairment is, the social constructions of society, the perceptions of the people around this person or the physical impairment *per se*? Amongst the issues that stand out is the understanding of "inclusion" tensions as taught out by the boy's at school, the normality debate, the restrictive environment, the selectivity that starts even from the cult of play, the anxiety of parents, the condescending way culture decides for 'him' as being 'abled' or 'disabled' depending on the social mood. The struggles that such individuals have to endure bring into play the way disabling barriers are designed and an attitude cultivated by isolation. Lack of confidence amongst the disabled community.

Injustice and oppression I would say.... For example in the first story, the mother ... is always telling him to be careful... and if he does what is mother tells him, he'll probably feel afraid to include him.... (*Frances, Social Worker*).

*Dustin And The Counsellor* is a story that brings into play a key role in Maltese schools, that of the counsellor, a role elaborated within the vocational guidance teacher's job description. Teachers in Malta are interviewed from central administration and then they are placed according to the vacancies created in schools. There is no consideration for the assortment of cultures and social baggage that teachers and students carry. This, as indicated even during the focus group sessions is one of the factors that informants believe influences negatively school practices. Parents seem to be afraid to face the reality of mainstream school that seem to be failing them miserably. This could also be seen in the contributions by people during the focus group sessions;



It sounded to me like conspiracy. They just wanted him out of school, out of school, out off his school. It didn't look like a meeting to see the interest of the child, but a plan by a group of people to justify his moving out of school and send him to special school. This mentality of clustering these 'different' students is rampant in our system, run by the *Education Division*. A policy of "inclusion" and a culture of exclusion – that is our Education Division! However, there are a number of teachers... that in their heart of hearts do not wish to have "inclusion" (*Carmel, Disabled Activist*).

My child is in a secondary school in a specialized unit in the mainstream. I keep thinking whether I am taking the right decision to send my child to mainstream school after all (*Donnha, Parent Activist*).

I believe that it is lack of education, fear and lack of exposure, fear of change, lack of motivation, just leaving things be ... Jenny, Social Worker.

But fear of what? What are students afraid of? (*Andrew, Researcher*).

Unpredictable behaviour, something they don't know ... they don't understand (*Gloria, Social Worker*).

This story also invokes a debate on the role of social workers and how they always tend to remain at the peripheries of the 'real' social issues.

'Helping professions' can turn into statutory oppressive structures if we are not careful. Professionals tend to feel they have a right to make part of someone's life, dip into that experience, make some money and move on when the time is ripe for that professional (Finkelstein 1987; Oliver 1991; Olive and Sapey 1999).

George talked away as he washed me. Maybe he was trying to keep my mind off the ordeal? I was stripped naked, cleaned and dried, and rolled flat on my back. I was so nervous I did not even notice that he forgot to return the urinal

bottle to its place between my legs. Completely paralysed from the armpits down, incontinent and still very unfamiliar with the techniques of shifting immobile flesh around, I lay still, feeling helpless and very dependent (Finkelstein 1987, p. 1).

*The Little Nationals* raises the squandering of our ability to listen to what people at the margins have to say. The principle of active listening however is not enough. The informants in my focus group also came up with a need to draw a list of all the things that need to be done so that disabling barriers can be eradicated; a more prominent students voice, a national policy on "inclusion", more professional training for teachers, smaller but autonomous schools, a school ethos that positions the students at the centre of all decision making process, additional parent involvement, less impairment based strategies, a more positive school environment, a managerial group of administrators that are able to map out an effective strategy with the resources they have, better support systems, a stronger grassroots movement, more motivated teachers and more training at University level (*Focus groups*).

Disabled people have become increasingly critical of the role of professionals in their lives, in that such encounters have been viewed as essentially demeaning and oppressive. Part of the criticism is that they have a voice but it is not being listened to, and the perspective is undervalued. The concerns they raise are fundamental and include the extent to which they control their own bodies and lives. They demand the opportunity to make their own decisions and exercise choices, and thus the question of empowerment is central to their objectives (Barton 1998, p.1).

This narrative tells us about the systems in school that don't seem to be functioning, structures that are intended to make students feel 'at home' but in reality make them feel 'far from home'. Students are thrown out of

schools, justified by the rhetoric of professionals and an inability to cope with the diversity that miscellany brings with it. The mechanisms that professionals are so proud of, such as, case conferences, are at the end of the day oppressive tools that dish up the barricade of professionalisation (Goodley *et al* 2004).

Of course, and when they are receiving the message continually that they are failures and that they don't fit in, isn't that serious? (*Gloria, Social Worker*).

But did this child have the right support systems? Was there adequate support for him? Why do we always have to speak of success stories? What's wrong with us? Why don't we really ask why these students have been failed by the system, and there are loads of them you know? (*Ann Marie, Social Worker*).

Adults seem to have this ascribed power from society to take decisions for children, without any consultation whatsoever. .... and when they are professionals, it's even worse. We are adults and we are professionals, than we have the power (*Gloria, Social Worker*).

Their attitude is influenced by the Head of School. Many a times the teachers speak so much about the behaviour of the students that it becomes a self-fulfilling prophecy on certain students. I think this is bad, really bad (*Frances, Social Worker*).

Here it shows the power of the Head of School. He wanted the student out of there at all cost...and it seemed to have happened! (*Frances, Social Worker*).

What is interestingly worrying in *Clint And The Porter* is the inability of the system to protect the vulnerable members in society, 'weak' not as in physical health, but as in our way of poking these persons through our (non-disabled) wrongful attitudes, value impositions, outdated pedagogy



and a thinking process that materialises the failings of the person. The institution becomes an oppressive organisation at all levels. It leaves little opportunity for initiative and protection. *Clint* in the focus group discussions is interpreted as ending up being protected by luck and pushed around by destiny. Like other students he has his own way of being naughty. Disabled people, most of the time seem to be exempt of waywardness. Another issue that comes out of this story is the requisite disciplinary methods. This thinking point comes out from the disputes in focus group meetings. One wonders whether being physical with the students is a foregone problem in our schools – I don't think so.

I'm especially disturbed by the scenes that involve the school .... of Dustin, of Clint... it's like you feel a lot of frustration on the way that structures are designed and if labelled people do not fit within them 'they' become the problem and we have to see what to do about them!  
*(Gloria, Social Worker)*.

Yes, what came out of the story, the story of the social worker, you know the story off Dustin. It hasn't got anything to do with what we said before but it's so true, yes it really hit me, in the sense that for once he said that he had found a social worker that suits his needs and he developed a good relationship ... it was a relationship built on trust and not just problem based. All of a sudden, all the relationship collapsed – the social worker did not work there anymore *(Anthony, Social Worker)*.

Occasionally, people tend to listen to what is happening in the classroom. Our classrooms are void of initiative, of space. You have children that sound as if they are in a maximum-security prison. Some years back I did some work with the correctional facilities and also worked with drug addicts in one of the residential therapeutic programmes. There is an uncomfortable similarity in all of these three contexts; rigidity of regime,

humiliation, lack of citizenship, lack of voice, a culture immersed in fear and rebellion, submission and belligerence (Ballard and McDonald 1999; Clough 2002).

Difficult or 'delinquent' youngsters need and are entitled to appropriate education, and the general public expects them to be suitably engaged and cared for rather than having the chance to offend. Adequate resources need to be made available in the early stages of breakdown of schooling to prevent growing numbers from being on the streets for lengthening periods of time. It will take far more determination...to change the situation. Are we not failing in our legal and moral duty towards children who are excluded from school? (Stirling 1992, p.130).

The *Circus Is In Town*, is a story that I write to manifest the increasingly undermining of students and the removal of their identity, distinctiveness and uniqueness (Barton and Armstrong 1999). The informants in my focus groups expressed their concern that people will not listen to students. They are screaming (at times literally) their heads off trying to find their position and space within society and their communities. Another crucial engagement with the focus group led me to reflect on the violence that is taking place in our schools. This violence is reaching schools from three directions. Firstly, students are somehow seeing teachers as being representatives of oppressive measures. I have noted earlier on that the way schools are designed allow little or no space for initiative, expression and self-realisation. Secondly, there is violence that is coming from the teachers who want to enforce and protect their profession and rank. I've had innumerable conversations with colleagues in my staff room, where we spoke about the need to transform some of our schools into boot camps, re-introducing corporal punishment and removing students who do not abide with regulation and send to EBD or similar schools. I cannot

forget a new teacher who turned up at the staff room saying that these kids are animals and deserve to be treated as such! I thought that he would be flying out of the window in a second, because one of the teachers who was listening to this 'profound philosophical analysis' had a son who attends that same school! Another experience I recall was when a teacher who had just been there for a month or so, came one day during break saying that he had just punched a kid out of his trajectory after this same student called him names. "He's been respecting me since this happened you know!" he told us. This event reminds me of a couple of the stories I presented further on. Another stratum of violence is on the divesting of personality and culture. These students are made to undo their cultural paraphernalia at the school door. Schools for these students who carry some diversity label are encapsulated in this establishment, which somehow 'throws them up', making them feel that their difference doesn't suit the society they make 'part of'. The agony is that this whole notion of violence is no rarity. This is what the focus group informants said:

Let me tell you, sincerely, I stay in the classroom and I meet many different teachers. The only thing there is ...you start thinking is it possible that a teacher says these kind of words? Yes a teacher uses those words. And is it possible that a teacher doesn't realise that he is hurting the person in question? ... the children come and expect care from the teachers, because maybe they are lacking care from home and then a teacher talks to a child in this manner, I'd say 'that's it', the child has lost every aim of coming to school. Some of these kids don't come to school to learn. They come to school because they have another family, kind of, and then we talk to them like that... and there are teachers who talk to them like that. I'm sure there are... I've heard them myself... *(Carmen, Facilitator)*.  
The common theme that I saw is that either they are children that no one pays attention, in the



sense that they (the children) talk but no one is really listening. Or people look at them like – pitying them and letting them do whatever they want (*Karen, Psychology Student*).

Justin of Form 3D, I would like you to remember him when you are assigning merit certificates, or something similar, because if it wasn't for him he [Rick] would have thrown the chair at me. From a whole class, he was the only one who had enough courage to stand up to Rick....that boy swears really bad. And try to understand me, I cannot show him that I'm afraid of him... "OK throw it", I told him, I don't know what to do in such a situation (*Linda, Teacher*).

...the children are still bullying her in the classroom, and they say 'come on Miss because I'll grab you from your neck and lift you up' (*Carmen, Facilitator*).

The students also said their own about how they feel in class. What is particularly worrying in this context is the violence there is, the aggression that exists and has been mentioned even by teachers.

*Louis:* We are split in class. There are two groups. The nerds are always given chances – we're not.

*Researcher:* Why don't you stay quiet in class? What's wrong? You're always in detention.

*Charlie:* The thing is that I hate being in class. I try to do everything possible to get out of class.

*Researcher:* So you don't behave well on purpose?

*Charlie:* Yes!

*Ryan:* I feel as if I'm chocking in class.

*Researcher:* So you ask to go out?

*Ryan:* No, I just go out.

*(Focus Group, Labelled Students)*

There were times I used to be with the kids all on my own in my social work pre-placement. It was ok, but you have to see they don't hurt, if they want to drink, to eat, to go to the toilet. They were literally, like monkeys, hanging all over the place. Even if one had to be the most docile person in the world, they take out the devil in you. You need to shout with them because they drive you bananas. I really can identify with this story (*Jenny, Social Worker*).

When my daughter went to mainstream Government school, I mean she was put in a corner, not allowed to go with the others, beaten with a ruler, that's not "inclusion" that's isolation. If they [teachers] are not good enough they should be sent away (*Elizabeth, Parent Activist*).

The issue of 'violence' is a complex and multifaceted debate, which is mingled with the lack of voice that children experience, an inner identity that is left concealed (Clough 1998).

...the underlying reality of an educational system unable or unwilling to meet the needs of all children remains the same (Oliver 1988, p.20).

*The Little Nationals*, is a story that converges a number of realities in flashbacks. In this story I touch upon various experiences I come across in my professional life (if I can really separate it from my personal). I speak about a visit I made as a social worker to a family that lives in a downtown household. In the process, I recall work I had done at school, my role as a researcher and the whole miscellany that makes up the person I am. I end up reflecting whether my responsibilities are taken over by what I am to gain in this process (mainly money and authority) rather than participating as a supporting actor in this livid and discoloured 'reality show' I am engrossed in from morning till night. Unfortunately negativity tarnished this discussion because students and disabled persons are constantly struggling for respect, autonomy and their own personal

pliability. We are positioned within a culture that disallows variability and changeability.

What impressed me was that last year he said that he was being bullied, and now he changed his words completely. ... when I was in senior school, I was bullied myself. I would say the same thing to the teachers if they asked, 'no they were joking'.... I really saw it as something big to tell about the experience of bullying. I mean the researcher was going into his life, asking questions and then leaving again. This is reality. That's what we do as professionals (*Anthony, Social Worker*).

...the kids in question, ... they are crying inside somehow, in the sense that they were not seen for who they are, they don't have the opportunity to express themselves or they don't know how to express themselves so they end up using bad language.... (*Jane, Psychology Student*).

Other issues of policy are brought into the scene because of the story's mention of the *National Minimum Curriculum* (Ministry Of Education 1999), a document that has been interpreted by many as a very rich document in ideas and notions but is motionless when it comes to implementation (*Armstrong, Armstrong and Barton 2000*).

...the policy is idealistic and we have to keep our feet anchored to the ground... (*Andrew, Researcher*).

The issue that frustrated me most and that created in me a bit of aggravation, is the fact that teachers are not so supportive for the students, in the sense that we are... policies are being made outside, up there somewhere, and then the teachers, the Headmistress, the Headmaster, the social workers, the counsellors... where are they implementing what is being written? This story reminds me that we are good



at writing but, in reality what happens? (Anna,  
Social Worker).

## 5.7 MAKING THE PERSONAL PUBLIC

The data for the study is being collected through a combination of focus groups, interviews, biographies and personal reflections. The sample has been drawn from a personal engagement I had with the different experiences I came across. One key argument I bring in at this stage is the visibility or rather invisibility of the children in this "inclusion" debate. In what way can the stories of children portray these issues? What are the different perspectives of the people I am in contact with daily in relation to presenting a transformative agenda for inclusion? What are the practices that facilitate inclusion? To what extent does narrative research provide an adequate exposition of inclusion? These stories helped me realise the imposed silence of these students, an 'omerta'<sup>12</sup>, and at the same time the interpretation that the professionals give to what is then referred to as blaring pain (Clough and Barton 1998).

The effectiveness of story-telling lies in the way this research paradigm is making a contribution to combating the oppression of people who are at the limits of society out of no choice of their own. These stories are useful as they describe the experience and the way we are connecting with that debate in the face of academics who tend to distort and manipulate data according to what 'they' feel is the experience of disability. Stories also re-define disability and challenge the ideology and methodology of the dominant research paradigm. The methodology matches the emancipator research paradigm. This whole debate brings in a description of collective experience in the face of academics who

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<sup>12</sup> "Omerta", is a practice whereby everyone would know a secret but at the same time everyone is afraid to speak about that fact.

are not really interested in engaging with the social model discourse and the values propagated by the disability movement.

My central struggle with policy then was this: if knowledge is constitutive of power, as Foucault has argued, and if welfare and social policy are constitutive of both power and 'the social' (as Hewitt, 1983, argues of Foucault's account), then research, which seeks to provide knowledge in both policy areas, its nature, is crucial (Fulcher 1995, p.9).

## 5.8 THE THINKING THAT LIES IN STORIES

I keep asking myself, but what will stories tell me that I cannot see for myself? What will stories represent that I cannot describe? Well, the fact lies in the ability to read the stories not that have been written but that can be perceived in between the conversations, metaphors and the discourses that are taking place. It is not passively listening to an orchestra at work but,

Stories are more than individual tales. They are the product of complicated research relationships. They are imbued with theory, with practice and policy implications and with humanity.... What is the point of storytelling? The points are in the telling of stories (Goodley *et al* 2004, p.195).

There is a very contentious issue that is being detected here. These stories say a great deal about 'me' but aligned with the scenario where different perspectives of parents and disabled activists and teachers, university students, labelled students and social workers present a transformative agenda for "inclusion". An outstanding issue in the debate of narratives lies in the ability of the narrator to help the 'audience' experience the biography of the speaker, the circumstances that surround the narration, the credibility of the issues that emerge and the narrators view of shaping the narrative. I wanted the stories to contribute to the revelation of the

cultural norms that are at the forefront of the debate in question. This discussion is influenced by the language that is used, the weaving of arguments, the interactions that are taking place and the metaphor that we engage with (Booth and Ainscow 1998; Plummer 2001). In a way I feel that the narrative has been a way of preserving my identity, of looking at the conservation of what I represent in the stories. These stories, these narratives, are an affirmation of cultural norms enmeshed in interactional approaches and the telling of events. They are also political narratives that connect with the various tensions that are created in the search for truth and in the expression of policy (Denzin 1997).

To assess the effects of any policy we must first understand the nature of policy as a general category of action and intervention in social life: we need to conceptualise policy clearly and then theorise it adequately, meaning we need to put it in a wider theory of social relations, rather than treat it as something different from other actions (Fulcher 1999, p.14).

## **5.9 MAIN FINDINGS FROM FOCUS GROUP DISCUSSIONS**

I have been presenting the main findings in these five different categories. I am splitting up the responses for clarity sake. Most of the themes discussed were in reality an overlap of the various perspectives we were debating; personal experiences on "inclusion", interpreting/philosophising "inclusion", defining "inclusion", impact of stories and methodological perspectives.

### **5.9.1 METHODOLOGICAL PERSPECTIVES**

This research had a primary role of debating the methodology as part of this research process. We need to understand to what extent narrative surfaces the issues of "inclusion". The stories in themselves as a methodology had to be a means of justifying emancipatory research, of giving control to the informants. My understanding at this point is that the



use of stories in whatever context, being research, media or case conferences can be a means where narrative gives the space to the persons concerned to have control and informed choices. The following are key notions presented by the informants which underline the methodological arena which in their majority express a liking for this method as a way of understanding the issues, understanding the self and trying to make the context 'one' that is engaged with more effectively. This aspect during my focus group discussion emerged from the following questions:

- Does storytelling have a place in practice and policy?
- Did you find the stories useful? In what ways?

... I enjoyed reading them (*Jack, Teacher*).

I think that they were very true. The stories trigger different thoughts to the people that read them (*Donnha, Parent Activist*).

I liked the stories because we are living them all the time... We witness these things on television regularly and you end up putting the sound off. But the way they did it, it was really great (*Maria, Parent Activist*).

I preferred this style (*Walter, Disabled Activist*).

Why do you think they are an effective means of research? (*Andrew, Researcher*).

Because they give a realistic picture of the situation (*Carmel, Disabled Activist*).

They are also food for thought (*Sandra, Disabled Activist*).

I've read the stories and they are real... For example the issue of over-protection in the first story, where a person with a disability isn't even allowed to play. Most of the times, in research, things are done out of good intention but that lack of consultation gets at me (*Richard, Disabled Activist*).

These are some positions that I took up as I debated the issue of research methods with the informants in my focus groups. It was a stance that was primarily delineated within the following boundaries; a personal involvement in the process of research, a participatory commitment of the informants, a yearning to live the stories and finally the risks taken so that research speaks to the reader. It was interesting to note how receptive informants were to this. Their involvement helped to shape our collective position as we grew in the process of "inclusion". The more I was immersed in this debate, the more clear it became that "inclusion" has no straightforward instantaneous solutions.

Yes true, and I have experienced a bit of a situation where I was a dropout at school, and I have lots of negative thoughts on my educational experience... I was lucky and the question of luck is a big question because otherwise these people wouldn't have got into your life at, or almost at, the right time. (*Andrew, Researcher to Disabled Activists*).

### **5.9.2 HOW HAVE THE STORIES TOUCHED THE RESPONDENTS?**

The research also provided an opportunity for the informants to speak about themselves and their own personal experience of exclusion. Stories in themselves seem to generate more stories, more thinking and more reflections that a one dimensional form of research like questionnaire is able to. I am referring to questionnaires and other forms of research that disallow initiative and unpredictable thinking styles.

I've seen things change from my youth to now I mean I'm 46. I'm doing my first degree now. I feel that if I were born 20 years later I'd probably have done my first degree earlier. Things have definitely changed – I was a very difficult and excluded student as a child. I think things have changed and they are changing, and what's happening here today is also important (*Jane, Psychology Student*).

It's like then you put our work in a different light now, because we are realising how much we are being faced with things that we have become immune to... *(Lorna, Teacher)*.

I'm an adult now, I'm sort of out of it... I never spoke about it, that is the way I dealt with it. Nobody knew about it, not even my parents, not even my sister. For my sister I was always the one that had to protect her and that I am strong enough to deal with all the issues that I am faced with. I spoke with no one, with no one, with no one! *(Ann Marie, Social Worker)*.

It is not just statistics, you are talking about statistics. The medical profession, at times is not able to identify the disability at birth. I don't know what they told me, the first thing they told me was put him in the corner and he will stay there for the rest of his life. Is that the prognosis you want for your child? *(Lorna, Parent Activist)*.

We asked permission to be present and provide support to the parents after the birth of their children. Do you know what the midwife told me? She told me you discourage them rather than help them. I told her do you have a child with Down Syndrome? I told her do you know what you are saying? Do you know the injustice of what you are doing? And she still insisted that she does not want us around. So you don't give support to these parents and these parents are being lost *(Lorna, Parent Activist)*.

In fact maybe stories... let's take one of them that we lived a good part of it, you don't see it so bad as when you read about it again. When you read it again you start to realise how serious it is. Sometimes you get so used to being in these circumstances that you let them go by. But when faced with the stories you tend to stop and think, 'what happened was really bad!' *(Carmen, Facilitator)*.



This quote by *Ann-Marie*, brings out a variety of complex and interesting debates wandering whether students in our schools fit within these social structures that contain them. Students feel mislaid and incongruous with the experiences they are rapt up in.

I was one of them you know. There were very few exams I managed to finish on time for example. If you give me one hour and you expect me to finish an exam paper in one hour, then I'm doomed, cause I never finish it on time. There are so many students who go through this experience. It's only one of the problems in the way schooling is done. OK, whoever has a wheelchair can be seen, whoever has a visible impairment can be seen, but there are loads of students that their needs cannot be identified. These children need help as well (*Ann Marie, Social Worker*).

I feel strongly about this. I was bullied when I was still at school at the Primary School, not in my secondary school... it gets so painful to speak about these issues at times, it hurts, it really does (*Janica, Social Worker*).

In the previous chapter, I presented a number of autobiographies that provided the basis that constructed my thinking about this issue. The interviews I had with the focus groups emerged some alarming debates. They show that practically on all fronts; teachers, students, social workers, parent activists and (most startling) disabled activists perceive "inclusion" as not working out for a multitude of reasons, ranging from a need for commitment to limited training opportunities, from a lack of resources to an option to use segregated education because the needs of the 'individual' are met. "Inclusion" may not be interpreted as being the final solution.

## 5.10 CONCLUSION

The most important data that I have gathered on narrative is not drawn from the observation of speech production or controlled experiments, but from the reactions of audiences to the narratives as I have retold them. In a regular and predictable fashion, certain narratives produce in the audience a profound concentration of attention that creates uninterrupted silence and immobility, an effect that continues long after the ending is reached. It is the effort to understand the compelling power of such narratives... (Labov 1997, p. 1).

The notion of normality, of people wanting to live their life and just get 'on with it' ends up being a major hurdle in the life of people labelled as having a disability or are excluded for some reason or other. The concept of achievement, success and accomplishment ends up being really difficult to define. The social structures that encompass us are difficult and knotty.

In general we talk of inclusive education but first we have to start of with inclusive society. We don't have an inclusive society. It is useless to talk about inclusive education if the man in the street does not have any clue about what "inclusion" is all about. By "inclusion" I don't mean accessibility only, because every time I hear the news it only refers to accessibility. I mean one never mentions mentally impaired people. It is as if they are non-existent, they are 3<sup>rd</sup> class citizens in our society and it hurts like mad. So if we don't have an inclusive society we cannot have inclusive education. We have to start of from there (*Elizabeth, Parent Activist*).

"Inclusion" is as broad as ever. This *Thesis* is concerned with learning about a particular social reality, "inclusion" as understood and experienced by a group of people with different values, emphasis and

beliefs. The means of enquiry had to be open-ended. However, the informant's contributions helped immensely to converge the varied and tantalizing debates that were being analysed. The different perspectives of my informants have managed to open the debate on what the action has to be to transform the agenda of "inclusion" in a lively debate with vigorous strategies centred around the involvement of the major stakeholders.

This involves the researcher taking the voice of disabled people seriously, listening to them, exploring their lived experience in particular contexts. Getting beneath the surface to the personal feelings and experiences of participants is a significant aspect of this form of research (Barton and Clough 1995, p.143).

This section endeavoured to analyse some crucial debates that abridge the varied debates surrounding "inclusion". This transformative schedule is understood primarily from the informants point of view, different perspectives that convey a transformative agenda for "inclusion".



# CHAPTER 6

## Mapping Out A Transformative Agenda : Coming Out

*Three weeks I've wallowed  
in this deep place  
this underplace  
this grieving place  
getting heavier and heavier  
sleeping by day creeping out at night*

*Nothing I can do  
Nothing I want to do  
But stay small and still in the dark...  
(Anazuldua 1987, p.186-7).*

*And this is where I think I have benefited, from psychology in prison, because I've watched people, because the people are watching me... And you get a much better response from a person if you allow them to be themselves, and to express themselves. Of course, at the end of the day, they are... It's truth. It tells you. That's why you've done so much research – because you want to bring the truth out. (Jepson and Parker 2002, p.82).*

## 6.1 INTRODUCTION

It gets at me when people in management and policy-makers decide the policy from behind desks and in boardrooms. Today I had a similar experience. People in an advisory committee want to decide the faith of a service-user simply through their political agenda. This is not fair. It is an unjust assessment, which leaves me bitter and unmotivated (*Research Diary, 17/3/2003*).

The previous data analysis chapter focused on how stories of people at the margins can expose issues of "inclusion" and exclusion. The other data analysis chapter engaged with the different perspectives of the people I work with and how they think about the complex debates in relation to enabling a transformative agenda (Barnes and Mercer 1997). This chapter will bring into contention another component that was crucial in this research, 'the researcher'. It is a section about 'the letting go' process that I have gone through myself (Barnes and Mercer 1997). The debate surrounding this intricate discussion centres around capacity building rather than about shaping our arguments on deficiencies. We keep speaking about schools and other services as being havens of mistrust, weariness and suspicion (Finkelstein 1987; 2002). The research question focuses around the processes that facilitate "inclusion"; 'what practices enable inclusion?' A Head of School I met in one of my regular visits to State Schools said:

We don't know how to implement "inclusion" –  
we need help (*Research Diary, 7/3/2003*).

There are two arguments that inform this debate and will feature the  
practices that enabled "inclusion";

- We need to move towards a mentality where debates are directed  
towards interdependence rather than dependency or  
independency, which is a focal module in self-realisation (Goodley  
2000).
- This work blends collective and individual debates as part of a  
comprehensive solution to this elaborate discussion (Goodley 2000).  
Finding solutions is not about isolated decisions, disconnected  
struggles, tangential involvement of the disabled community and  
marginal strategies. We need to make "inclusion" happen on a  
variety of fronts, tap-in allies, look for resources in existing structures  
and challenge the rhetoric that oozes from boardroom debates.

I've just been to a meeting on how we can make  
"inclusion" function in our schools. There were so  
many different ideas (that not necessarily match)  
– they all sounded fine. Some of the ideas were:

1. We need to work to give parents a 'voice'.  
They need to be involved in these choices  
for their children.
2. "Inclusion" is not good for everyone;
3. Special schools should be transformed into  
resource centres for all schools;
4. We need to give priority to IEP's;
5. Students do not know what is best for them;
6. The "inclusion" discourse applies to all.

(*Research Diary, 15/5/2004*).

From my own personal observations and involvement in this field through  
my teacher, social worker and other roles, I have come to appreciate the  
sophisticated discussion and the overload of discords in the highest  
echelons of decision making. The institutional spaces that I make use of  
are predominantly the school I teach at and the social work agency I am  
attached to. However, the debates I have stem also from my link with the



University and my teaching there, to the Education Division and the policy work I am involved in and also my consistent involvement with the disabled and parent activists in their groups, fora and assemblies. It is here that I brought together the complex reflections I needed to make in lieu of my ethnographic contribution to this project.

These conflicts seep through the 'supporters' of "inclusion" and those of special education (Thomas, Walker and Webb 1998; Farrell and Ainscow 2002). This debate has even been extended from one organisation to another. Furthermore, there are two NGO's, namely the *Eden Foundation* and the *Equal Partners Foundation* that are persistently focused on the training of disabled students as part of their educational services remit. However, one organisation is more steadfast in its mission statement that advocates inclusive education at all costs and in all circumstances, whilst the other organisation is more resolute to find a balance that in some situations can lead to including students entirely and in other circumstances engaged with different provisions tailored around what 'they' think are the needs of that particular student. The main parent's 'society', on the other hand, doesn't have a position on inclusive/special education and disabled persons (Ballard 1999). They have never issued a position paper and apart from that there where always conflicting opinions even at committee level, where I attend regularly. Then there is the position of the Church and Independent schools who are very selective on who is to attend their schools but somehow making exclusion and selectivity sound very politically correct! (Research Diary, 15/9/2004). Notwithstanding all these divergences, locally, in these last years we have made colossal progress in the field of inclusive/special education (Farrell and Ainscow 2000; Thomas and Loxely 2001) that compares well to other countries that have many more resources and capital (Research Diary,

21/3/2003). We need to keep engaging with a discourse where policies enable "inclusion" and the disabled community entice this agenda. The data I have gathered in my ethnographic dimension of my research compares well with my focus groups (Anderson 1997) and the 'autobiographic' findings I assembled from disabled adults and a disabled student. In ethnography, there may not be any concrete data by some researcher's standards but the information is gathered out of a very personal agenda when it collides with the reader (Clough and Nutbrown 2002). To help me administer and manage my research I have referred to the social model to provide for my analytical framework, which hinges on an individual engagement - this avoids social barrenness. (Corbett 1996).

**FIGURE 6.1: THE RESEARCH QUESTIONS**

EMPHASIS IN CHAPTER	ANALYSIS	RESEARCH QUESTION
4	Analysis of autobiographies	In what way can the stories of people at the margins expose issue of "inclusion" and exclusion?
5	Analysis of semi-fictional stories and focus group debates	What are the different perspectives of parent and disabled activists, teachers, university students, 'labelled' students and social workers in relation to presenting a transformative agenda for "inclusion"?
6	<b>Analysis of ethnography position</b>	<b>What practices enable "inclusion"?</b>
7	Analysis of narrative research	To what extent does narrative research provide an adequate exposition of "inclusion"?

## 6.2 I Became Aware

### 6.2.1 I BECAME AWARE OF: 'ME'

Ethnography turned out to be my own personal odyssey and discovery (Denzin 1997). This work has been based on a number of important components; stories, listening to people and reading literature. However, the crucial point of my research lies within the fact that this was a process

of self-exploration (Plummer 2001). It is an analysis of this whole complex debate of "inclusion" from my own point of view as well on what enables this agenda. I sought to give my work an ethnographic dimension through participatory observation and focus group interviews that were highly unstructured. As a participant in the engagement of the processes were involved, I sought validation and representation. Ethnography was complimented and enriched with the use of different research methods (Bell 1999).

### **6.2.2 I BECAME AWARE OF: PARENTS**

According to my own observation, most parents in the region where my school is positioned feel that their child benefited to some degree or other. They also appear to feel that their children had to struggle to achieve appropriate "inclusion" (Daniels 1995; Thomas 1995). A number of parents still feel that they were prevented from being fully involved in their children's education (Booth & Booth 1997). Other parents emerged with a distinct experience. They were able to work in partnership with the school systems to find the best way to support their child's education (DFEE 1997). When speaking with professionals, it become apparent that parents in their own distinctive cultural discourse are trying to interpret the complex debate that is taking place in the disability discourse. They bring to light the following;

- The importance of an "open school" with two-way communication.
- The need for consultation and personal involvement in the development of the school policies and school development plans. Schools are not simply the end of the implementation line. Policy also needs to be developed in schools (Slee 1993; Clark, Dyson and Millward 1995).
- The experience of parents and their disabled children reflects a marginalised institutional struggle involving professionals, academics



and bureaucrats. Parents are at times confused where their allies and allegiances lie.

- Parents feel disorientated about the whole debate of "inclusion" and how this discourse is being chased by a standards mentality (Brown 1999; Ware 1999).

I know of facilitators who put hyperactive children in the corner and shout at them because teachers they don't know what to do (*Sharon, Parent Activist*).

I have just experienced discrimination against my son at school. He could not go to school because the facilitator was out on long sick leave. I mean I fought and fought but what do I get - nothing! (*Donnha, Parent Activist*).

I don't think the teachers really know what they are dealing with. From the feedback I get from the teachers, teachers tell us because we don't know what we should do, no one tells us anything (*Tanya, Parent Activist*).

My son has autism. When he went to school for the first time his teacher spent a whole week learning his sounds (*Donnha, Parent Activist*).

Apart from supervision, I believe that there should be SENCO's in schools. To a certain degree your school [Church school] is doing fine (*Maria, Parent Activist*).

There were also debates that may not have sounded as being very politically correct, especially when it came to the debate on having or not special schools on the "inclusion" continuum of services (Thomas and Loxely 2001; Farrell and Ainscow 2002).

Please do not close special schools (*Maria, Parent Activist*).

In a paper I had published in *Disability and Society* in 2000, I tried to examine the concepts of "inclusion" and exclusion as part of a complex

interaction with notions governed by professionalisation. Parents are increasingly dissatisfied with the way provision is regulated. There is a tendency to interpret professional involvement as a shared negative experience. This may be the same conduct I may be imposing on others.

This quote emanates from a research diary I was keeping as part of my work on this paper;

Today we had the Parents' Society Annual General Meeting. Everything went on really well.... Following the AGM as I was going home, a parent accused me that what I said during the committee meetings was considered important whilst in her case she felt that she had to struggle to be understood. To say the truth I got rather upset at her comments, however, I kept asking myself whether somewhere along the way she was right. Maybe I was considered an ally to some and an adversary to others (Azzopardi 2000, p.1066).

### **6.2.3 I BECAME AWARE OF: SCHOOL COMMUNITY**

From my own observations, I could note that the responsibility of having an inclusive school community lies primarily with having a school administration that is vigorous (Busher 1998). Schools are being expected to create an inclusive culture within an atmosphere that is increasingly demanding and competitive (Farrell and Ainscow 2002). When disabled students are included in regular programs, these tasks need to be attuned to their specific requirements. Leadership ultimately rests with the Head of School, who has to understand, interpret and react to the school climate and attitudes of staff towards change. The task of developing "inclusion" strategies will be best facilitated with a knowledgeable administrator that believes that inclusive education is in the best interests of the whole school community (O' Hanolon 1995).

The current emphasis in schools... is upon academic achievement, high standards of behaviour and consistency of curricular approach. Whilst this can be praised as an equality of opportunity model, it reinforces an individualised, competitive attitude which rests uneasily with the emphasis on community values, co-operation and social learning which form integral elements of inclusive education (Corbette & Slee 2000, p.137).

School communities are there to include the facility of speaking up for one's own right, designing options based on informed choices, having the facility to listen to and be taken seriously, developing new skills, helping, supporting and representing others, getting adequate information, having their children treated for what they are rather than for what they are not, influencing the fabrication of services and finally having social contact based on a process of citizenship (Azzopardi 2000). School community will not just happen. Our society is selective, secretive and reticent. Parents want a 'voice'.

#### **6.2.4 I BECAME AWARE OF: CULTURE**

The way that schools are structured reflects the culture and experience of a community and the curriculum is to take account of this reality rather than just accounting for a traditional chase for credentials. A school institution can bring about an "ideological intent" of oppressing students in already oppressed contexts (Freire 1970; Brown 1999).

Inclusive education is not by any stretch of the imagination a problem-free experience even with the best possible scenario. My ethnographic reflections were very explicit on two features that condition "inclusion" (Riddell and Watson 2003);



- Schools should have the right climate and opportunity to talk issues through. No organisation can function without a culture of talking and debate.
- Schools should bring together the community, educationalists, professionals, service-recipients and bureaucrats to engage with the discourse of "inclusion". This is no ones remit. Schools need to explore possibilities in a spirit of constructive dialogue in which all parties, especially students are free to voice (Davis 1998) their fears and dreams.

This process has been accompanied by a new managerialism in which 'quality' and 'standards' and 'targets' have become the *mots d'ordre*... In this context, the allocation of students to particular schools is influenced, if not entirely decided, by considerations relating to visible academic success rewarded by financial advantages and status in the community... 'Failing' schools are subjected to public scrutiny through 'naming and shaming' (Armstrong 1999, p.85-86).

The school is a communal location. It is the crossroad that for a moment brings in-line all stakeholders. Parents in this region are not after insularity, but keen to explore possibilities and opportunities for their disabled children. Teachers and other professionals within the education system are to keep an open mind about the potential of every child has to learn and grow. One cannot presume there is a distinct group of "special" children defined solely by professionals on their deficits or by the culture they derive from.

In a region that is already marginalised, it is even more complex for disabled students to be able to penetrate such a difficult context (Oliver & Barnes, 1998). Bringing together these fundamental experiences help 'us' reiterate the research question we are engaging with at this stage on

the practices that enable "inclusion". These are two exclusionary notions; firstly, inclusive education is a clear political statement that needs a context for interpretation. We cannot rebuff the processes that differentiate a community and a minority. Bringing these two realities together is further complicated and intermingled by the struggle for standards and accreditation. Secondly, difference and diversity have a place in education especially in the experience of this region. Education has the primary role of breeding tolerance rather than hijacking this experience with trepidation over standards.

Schools need to develop a new teaching culture. We have to move away from anti-pedagogic teaching approaches. Regional schools where cultural characteristics stand-out, require the necessary support provisions to adapt a curriculum that is respectful to diversity, "pupil context-based content" and to scrutinise existing teaching methods (Bonal & Rambla 1999) – I have seen this for myself.

The region I am drawing from for my research is a very elaborate context to comprehend because of the social stratification and political circumstances, lifestyle and values all enmeshed into one, of this particular group (Boswell 1994). The right assortment of research approaches will scrutinise the outcomes and achievements of the students in this school experience. In the process of analysing the effectiveness of schools, student outcomes are a decisive concern.

### **6.3 A SOCIAL MODEL PRACTICE BASE**

The starting point of the social model of disability is the separation of the two terms, 'impairment' and 'disability'. In contrast to the medical model, the social model of disability does not use the term 'disability' to mean impairment but to refer

instead to the disabling barriers of prejudice, discrimination and social exclusion. The following definitions are therefore used:

*Disability* is the disadvantage or restriction of activity caused by a society which takes little or no account of people who have impairments and thus excludes them from mainstream activity....

*Impairment* is a characteristic, feature or attribute within an individual which is long term and may or may not be the result of disease or injury....

*Disabled people* are those people with impairments who are disabled by society (Morris 2002, p.18).

This work pivoted around the social model principles and standards. The social model is in a privileged position. All other ideas, concepts, theories are seemingly seen as subordinate to it, and everything must fit within the social model (Corbett 1996)). The reason for this is that this model has a very broad consensus and has been adapted across cultures as a collective and individual experience (Riddell and Watson 2003). We need to get away from pathologising disability and perceiving it as a welfare dilemma. The most elaborate and important debate that has governed my study are the following (Oliver 1996; Barnes and Mercer 1997; Barton and Oliver 1997; Oliver and Barnes 1998; Finkelstein in Shakespeare 1998):

Disability is an experience of social oppression through political and economic factors that seem to be influenced by a capitalist paradigm. Disability is interpreted as being a symptom of social oppression and impairment is the physical representation of this dimension. This social construction is not about or caused by the body (or some impairment), but it collides on the body. Both impairment and discrimination have a massive impact on the life of this minority - in different proportions at different times. The social model contributes to acknowledging the



complexities that are taking place behind the scenes. The social model brings to mind the detail that disability is not noticeable to the majority world. Oppression tends to indicate something 'we feel' and are aware of, disability is about invisibility in these public discourses. It is in no way a transient situation that can enter and leave one's consciousness at the whim of 'how other people see us and how we therefore see ourselves'. It does not become a disability when it is recognised or constructed as such by others. It could be argued that the notion of 'quality of life' is part of the medical model and has no place in the social model. An important research notion that comes into debate in the disability discourse that relates to research is 'quality of life' which always tends to go back to the idea that one life is better than another. While it may be valid for a person to feel they have a limited quality of life than they feel another person has. It should not be the responsibility of researchers to compare different lives as this inevitably leads to value judgements. The social model could possibly be employed and applied as an epistemology. Whenever I come across a theory I ask, 'could it be customized to help further disability theory? Does it help explain the situation I am analysing?' The social model is ultimately an ideology but is fundamentally a strategy instigator that can lure "inclusion" practices in schools. The groups who feel excluded are the groups for whom the 'physical' versions of the social model didn't work, even if they hadn't articulated it in quite that way. They talk about "inclusion" into the social model without really considering whether the social model is or can be inclusive to the extent that everyone wants. This model has laid the fundamentals of the social world we live in now. This model has also developed a human rights and self-control agenda. It has encouraged more disabled people to speak out. Vociferous activists become more likely to engage in a culture conflict over which version of their lives prevails in the public domain. This model is also a culture on the politics of protest that is starting to emerge even

locally, instigated and conditioned by the fundamental principles that guide this conceptual framework. Previously, disabled people preferred to be submissive. By having a 'condition' where disabled people are tagged, the consequence is then around how society interprets these people. The notion of 'visibility' is brought in at this stage. The social model discussion tends to be multifaceted and complex. It is organic in that its boundaries are constantly revisited as disabled people continue to ask what it should mean for them. I would ascertain that the social model blends perfectly well with pain and fatigue as they are an integral part of 'impairment'.

The social model in Malta has been seeping through the varied and diverse contexts. One needs to keep in mind that the parent activist movement (although veiled) is very strong in Malta. This makes it sound as if the whole theoretical and practical application of the social model will not fit within this scenario. Parent activists however are starting to realise that this debate is under construction and they need to re-position their discourse within a broader 'disability agenda'. Accepting entirely that organisations of disabled people do not represent all disabled people (perhaps not even most), they have always been viewed as being of democratic representation. This may not always be the situation in Malta (Azzopardi 2000). The social model is a tool for change amongst a politicised disability community.

Despite criticisms from some quarters that social model ideas are too abstract to be of much practical use in the real world, I wish to argue that actually its focus on removing structural barriers makes it a far more logical and achievable strategy for "inclusion" than do traditional individual model approaches. (Tregaskis 2003, p. 4).

The social model is about focusing on the social barriers within the environment, culture and economy (Barnes and Mercer 2003). The social model can be used to understand this reality and the veracity they are immersed in. This model can be affianced to appreciate the family lives and the personal relationships of disabled people. The services that are there to support the disabled person end up constructing barriers and devalue the person and his/her lifestyle (Finkelstein 2003). This model has conditioned and affected my own thinking drastically (UPIAS 1976).

#### **6.4 THE REFLECTIVE SELF THROUGH NARRATIVE**

“Inclusion” works if students are in class all the time.... if students are absent for part of the day, then its no “inclusion”...“inclusion” is a whole school/life experience (Research Diary, 2/4/2003).

This research started years back really (Halliday 2002). It was already happening in my mind as I glided from one experience to another. The traditional thinking of “inclusion” as a process whereby all students, whatever their impairment, are in mainstream schools in Malta has not been around for a long time. I always believed in this concept of “inclusion” because I personally felt excluded at school (even though I have never been traditionally stamented/labelled). In actual fact, one of the reasons I wanted to get into this field of study was so that I could come up with some quick-fix solution/s. I looked into texts that spoke about a solution-oriented approach to “inclusion” (Slee 1993; Clark, Dyson and Millward 1995; Ainscow 1999). Whilst having their own valid and interesting conceptions;

- Slee (1993) focuses on “inclusion” as needing a fundamental strength in policy analysis and puts forward some very motivating notions of pedagogy, programmes and school organisation techniques;



- Clark, Dyson and Millward (1995), propose developments in the area of policy, organisation, teacher's professional maturity, resources, pedagogy, curriculum and values;
- Ainscow (1999), sets out a series of challenges and emphasises on the need to design various types of programmes that can meet up with the culture and needs of the student. He also brings in the *Index*, which is intended to lead to effective processes of school audit and "inclusion".

What it boils down to, I have said it for the past 18 years and I said it to the Minister of Education... is lack of planning. Let's talk about our country; if the education authorities sit down round a table together with the medical authorities, they have statistics right, overseas that is what they do. They have statistics about how many children were born this year with a disability and they know the various disabilities. These children in 5 years time are going to be in school age. So in 5 years time I need 300 people doing this, this and this. So when the things happen in 5 years time I will be prepared and I don't need to make use of people without training (*Elizabeth, Parent Activist*).

Conversely, my initial belief whereby I wanted to provide a solution based on ten, twelve or whatever strategies that will make "inclusion" work for all, was not probable (Nind *et al* 2003). One reason for this was because I started to realise that my personal and private persona started leaking into the debate. I was no longer, or rather, I was unwilling to detach myself from this discourse where an intimate bonding was developing (Bayliss 2004). However, I started finding myself moving from being sure of one thing to being confident in a completely different notion. This whole plethora and superfluity of debate was getting at me. Those of us who are struggling to make "inclusion" look for help anywhere! I have been pugnacious with this most important question, 'what practices enable

"inclusion"?' most of my professional life. For example, every year I am faced with a group of 100 student teachers in lecture rooms at University with eyes wide open, ready to ask an imperative, soul searching question, but what is "inclusion"? (Barton 2000). How does "inclusion" happen? This same struggle I meet when I am involved in the design and implementation of policy and consultancy. I am once again faced with this issue when doing social work, when parents are seeking the best schooling option for their children.

A parent came to the office this morning. He was infuriated. He kept telling me that he is just 27 years old and feels like he's 60 with all the worries he has to face. He said that he has a three year old child with autistic traits and the nuns at the school he was about to be sent to, had asked him to take the money they had deposited for the new school uniform because they weren't going to accept Cain at school. He couldn't believe his ears. He asked me to help him start the legal procedures against the school. (Research Diary, 22/9/2004).

It is all a vicious circle that leads to one basic reality – finding the way to make "inclusion" work. I have been through loads of literature, had discussions with people in the dozens, went through all the theoretical accounts I could lay my hands on and 'you' keep getting all sorts of different opinions, strategies and options on how to make this concept workable. This is not an easy task especially if one is trying to work within epistemological principles. "Inclusion" cannot become an end in itself. The process of 'means' and 'ends' is strictly interdependent. "Inclusion" becomes one part of a complex process that is intertwined with facing to the reality of students in schools as 'their' first test in social "inclusion" or exclusion. It is no simple chore to try and present practical pedagogical, curricular and technical applications, especially when we read of

particular schools positioned in specific cultures with exacting characteristics (Slee 1993; Knight 1999).

I am meeting the Headmistress of a private school tomorrow. It seems that she is interested in implementing a more inclusive policy in her school, however, it appears that she is finding it difficult. Most probably she has pressure coming from the school governors and from the demands of parents to make good grades when it comes to the 11+ and the common entrance examination. My dilemma is that my own son and daughter happen to go to that same school, and whilst I believe earnestly in the concept of "inclusion" I am in a bit of a dilemma because I wouldn't want my children to drop behind and not manage good grades following their 11+. Wow this is a catch-22... playing the policy-maker, the school advisor and the parent at the same time (Research Diary, 9/3/2003).

## **6.5 THE SPACIOUS SILENCE**

A first important statement at this point is that ethnography is not an objective-led, clear-cut, unambiguous and straightforward approach. As a researcher I had to find my way about this whole muddle of dynamics, personal feelings, political positions and roles I had (Rubin and Babbie 1993). Ethnography focuses on life as it is lived, situations as they occur and are constructed in the everyday course of events. Though ethnographers seek lived experiences in real situations. In my commitment to ethnography I have sought to discover the meanings that participants attach to their behaviour. This is no simple process. Whilst as a researcher I needed to be sensitive to what the people were saying, it was also important that I value the inconsistencies, ambiguities and contradictions in my own and my informants behaviour. As a research with an ethnographic stance, I was not adamant to start with a 'theory' and try to prove that 'theory' but I wanted to establish 'theory' from what people had to say about their own life (Goodley *et al* 2004). The



applicability and expression of what people were verbalising converged into the social model of disability. The annotations I made in my work led towards conceptualising disability as a form of social construction that was being utilised by society to impede inclusivity. Another annotation was that disabled people were labelled, segregated, homogenised and left to wander and find their own place within society. The people I worked with medicalised the experience of disabled people and sought to find the ways that make their position more exclusive and dependent. People felt that they had to fix themselves, change, do away with what distinguishes them because they felt that they do not make part. There was also a strong argument about compromises, an argument based on survival rather than reasonableness.

"Inclusion" has an assortment of meanings and values (Bayliss 2004). It is useless trying to find a 'one fit all' solution. I have tried to keep away from finding an absolute in this whole debate – which tends to lead me to nowhere. The values that set up this whole discourse construct "inclusion" as primarily engaging with the exploration and the nature of difference. "Inclusion" ends up being the preamble to a discussion about social woes, that see society based on the principles of exclusion, selectivity and homogeneity – that does not allow unity. We end up interpreting the whole notion of "inclusion" within the discourse of impairment as being centred on a debate that focuses on 'defectology' (Bayliss 2004).

## **6.6 THE STORY THUS FAR**

The research 'self' is practically internalised within my identity now that I was so immersed in this whole project. The reason I engaged with stories that make up my 'professional genetic blue print' was because stories are vivid. Stories can be read and embraced. Stories can say something to everyone (Goodson and Sikes 2001). It almost seems as if 'you' knew

these people. The stories in my own ethnographic reflections feature primarily as residing in the system and not in the students. The students have no fault. They are helpless in a situation that is tragic in many senses because children are often seen as if they are the problem (Clough 2002).

To-day I had a heated debate with a teacher colleague of mine. He kept insisting that it is the students' fault that things are the way they are in our school. I kept challenging this idea. How would his son, my son react if they were in this school? Would they be any different? This is tragic. The school as an establishment seems to have turned against the children. At times it feels like a battleground. I'm confused. I love my job. The thing is that people are perceiving me as if I'm playing the students 'Champion'. I'm not. I'm just trying to practice what I preach. (*Research Diary, 2/3/2004*).

## 6.7 MAKING PRACTICAL-SENSE OF THEORY

When I tried to explore with my informants what are the issues that in their thinking enable "inclusion" (Clark, Dyson and Millard 1995), they came up with the following argumentation, which is a manifestation of their anger, irritability and frustration at the people who are managing the schools;

*Teacher:* If you had to change something in the school, what would you change to have a better school?

*Larkin:* The Head of School.

*Teacher:* What?

*Charlston:* Yes the head of school.

*Teacher:* But you'll get another Head just the same.

*Larkin:* Oh come on sir. Don't you see a difference between the Head we had and the Head we have now? ....he doesn't speak with us. It's either what he says or nothing.

*Teacher:* Any other ideas?

- Mathew:** Yes, change the teachers, I mean change some of the teachers.....
- Teacher:** What needs to change as well?
- Matthew:** The ground, we need more space where to play.
- Charlston:** The time of the break.
- Ryan:** Teachers hit us. This should stop. They don't speak to us but they hit us. It's ridiculous. The Craft teacher hits us. If he does it to me I'll kick him back.
- Tony:** It also happened when we had Maths. He banged Paul's head against the wall. Crazy man.
- Teacher:** But don't you tell these things to the Head?
- Tony:** It's all for nothing. They never believe us.
- Charlston:** We speak for nothing because nothing is going to change.
- Teacher:** Why? Because.
- Larkin:** If the Head of School doesn't change nothing will change.
- Kevin:** I find the Head ok. I just want the Math's lesson to change.
- Martin:** He's OK? Are you joking?
- Teacher:** So do you think the punishments work on you? The fact that you are left in at break for detention or else made to stay after school or else left in a room for a whole day on your own.... Does this help to change your behaviour?
- Charlston:** No.
- Matthew:** Definitely not. I end up being more naughty.... So what I do now is that I keep my behaviour 'reasonably bad' so I still do wrong but I don't do bad things too much so that I won't get big punishments. Teachers love to give us big punishments.

The perspective of disabled activists was also very valuable and it surfaced a number of thrilling debates that describe the tensions that exist



in such a discourse. The impression I get is that there is a dearth for discussion amongst all the stakeholders, which would contribute considerably to the 'opinionating' of these issues according to the perception, perspective and persuasion of disabled people. Structures that are being set up at the moment such as the *Malta Council Of Disabled People (2003)* and the *Malta Disability Studies Group (2004)* are still at a very early stage to make the impact and dictate the agenda that this context so fiercely needs. So, debate remains sporadic, isolated and fragmented, which is convenient for policy-makers, professionals and politicians not allies to the 'cause' (Campbell and Oliver 1997). These debates include, argumentation on the way disabled people experienced and think about schooling;

No, I mean until they accepted me, it wasn't that difficult as I saw it. Obviously, I had a facilitator but my colleagues accepted me a lot you know. Even the teachers accepted me (*Sandra, Disabled Activist*).

No, as far as I am concerned, wherever possible I believe in total "inclusion", I insist on it but this is what worries me, the fact that you have full "inclusion" a lot of children that can be helped are not being helped (*Walter, Disabled Activist*).

Carmel, it very much depends on the type of parents there are. ...it depends on the background of the parents. ... a great deal of borderline cases that are not coping in mainstream education (*Walter, Disabled Activist*).

There is also a discussion on the need to provide the necessary resources to activate a successful schooling system;

As we have been saying, unless we have good support services, "inclusion" will not work. (*Richard, Disabled Activist*).

Maybe for "inclusion" to work completely, we need to create new structures that can meet this

need, systems that do not even exist as yet.  
(Richard, Disabled Activist).

From the contacts I've had in schools, schools were really feeling helpless, they just do not know how to work with this student. They were really looking forward to meeting me because I was a social worker who works with disabled children. They said, 'come, because you can tell us what to do'. Now, I'm not that involved in education but the fact that I told them that I know something gave them courage to work with the child. In fact I told them not to keep him isolated in a classroom. I gave them information about existing services and they seemed to start reflecting on what they were doing (Anthony, Social Worker).

A contribution by a facilitator spoke about his understanding of "inclusion" as a school community process that involves all in its sum;

A facilitator for the school and not for the child'.... (Kevin, Facilitator).

Then there are some concerning factors deriving from a sense of helplessness and a lack of belief;

...you can never bring them equal [the students] whatever you do and however hard you try...  
(Linda, Teacher).

...there's nothing to do unless you don't invest in a school, with a suitable syllabus, lots of physical training and lots of games (Jack, Teacher).

Andrew: If I am not mistaken MCAST was set up to give opportunities to those who lack educational skills.

Laura: Have you read the prospectus of MCAST?

Andrew: Do they have exclusion criteria?

Laura: Yes, mentally impaired are discriminated against wholeheartedly. Not only mentally

impaired but also those who have  
behavioural difficulties.

*(Focus Group, Teachers)*

My research started from a very precise geographical location, at the school I work at. The research questions then evolved from a concern with products and outcomes to a situation of process and ethos. These questions were answered in the on-going debate and analysis that has drawn from my own exposure to the stories that I was engaging with. To understand this notion I looked at what I am doing in different times of the day with the diverse hats I had to wear. This whole thrill and stimulation brought about a concern even in the methodological sense of the word. As a consequence, the relevant research tools changed from interviewing to ethnographic work in the schools and the other experiences I was immersed in. Research gave way to ethnographic work in the varied contexts I am involved in and an introspective 'storying' of all my experiences. The interactions, dynamics and stories that were being told were of immense richness. I would listen to what is happening around me in a more intelligible way (Plummer 2001).

Formal and informal education though designed to facilitate learning, also included a range of barriers to learning and participation. These barricades can take a variety of forms, structural, pedagogical, conceptual, epistemological, professional and financial. But above all the most difficult barrier to surmount is the attitudinal. These barriers manifested themselves when learning breaks down and when learners drop out of the system. Equally important is to recognise the existing strengths and harness support in order to transform systems from lesser to higher levels of "inclusion". Many a times, the educational system is unable to respond to the lifestyle of the community. Barriers in learning thus arise (Oliver 1996). Inclusive education is more than including the



disabled but it is often taking away people from examining the many exclusionary pressures within society and its schools (Booth and Ainscow 1998). The issue of "inclusion" is not concerned with how a relatively small group of pupils might learn along with others but it lays the foundation for an approach that could lead to the transformation of the system and of society.

The way in which you are talking it's like the responsibility of disabled children lies only in the facilitator's hands, right? *(Kevin, Facilitator)*.

The problem Andrew is not with the students, it's with the adults. This summer I had the opportunity to go and visit the schools and there were a number of heads of schools that were saying that 'we agree with "inclusion" but I have loads of problems with the parents of the other children' *(Carmel, Disabled Activist)*.

"Inclusion" is fundamentally cultural politics (Riddell and Watson 2003). It is unrealistic to assume that schools were made for everyone (Clough 1998). In spite of a genuine effort to make schools accessible, the demands on these institutions to continually reflect and mould themselves to the requirements portrayed by the citizens is not an easy task. Sometime ago as I was speaking to a colleague at my school, he told me that schools are designed around the needs and abilities of only 15% of the school. I asked him what he meant by this. He said that the way schools function, the type of pedagogy employed, the personal and professional qualities of teachers, the thinking put into schools, the physical structures, only appeal to a very small portion of the school population. Then you get a percentage of students who compensate for the fact that they do not feel part of the school because they get support from their parents or because of sheer luck. The rest of the students would feel out of place. Whilst the analysis of this teacher lacks in depth of analysis this discussion in passing makes one reflect and ask questions. Ultimately, all schools will be

guarded by electronic gates that, "bars entry to those children who do not metaphorically hold the correct pin-number" (Slee 1999, p.206).

Children's ill breeding and uncouth surroundings cause severe damage to their morale, development, and maturity (Montebello 1999, p. 2).

In these last years teaching has become an "increasingly explicit politicisation of educational structures and processes" (Clough 1998, p.1). The experience of education will succeed if it becomes a liberating force that would help students transcend into new social dimensions. The processes of education are strongly governed by legislation, regulation and the marketisation of schools (Clough 1998; Giordmaina 2001). This responsibility entails a great deal of liability on the whole school institution to respond to the particular demands of society. The struggle is hijacked by converging all our efforts on standards. "Inclusion" and cultural diversity become elements of contention and at times are perceived as a waste of energy and lack productivity.

## **6.8 CONCLUSION**

In working through this project, I have identified the main contentious debates that answer to the research question I presented at the beginning of this chapter. This debate is centred around the fact that I am immersed in all these dynamics. I have used this work so that I can further conceptualise the influences that have conditioned my thinking and my personal and professional development. Practices that enable "inclusion" are broad and complex. The engagement with ethnography gave me another window to have a glimpse from. These debates have started from the contexts I am already immersed in (Clough and Barton 1995). For me this research has enabled me to come out of the preconceived, fixed and inflexible thinking that has governed my involvement in this field. We tell our stories all the time. We restructure our

notions and thinking patterns. This *Thesis* is organised first by explaining the lenses through which we have filtered our experience. These are methodological and theoretical. Methodologically because we make use of ideas about positionality, participation, emancipation and reflexivity. We shall then locate our project within the plethora of official routes to improving teaching and the culture of diversity. A critical analysis of what actually happened as we attempted to fulfil the aims of the research provided the 'close-up'.

I have come to realise in this *Thesis* that ethnography is a complex activity which draws on a range of epistemological positions (Denzin 1997; Clough 2002). It is by engaging with these different perspectives that we are able to chart out strategies. One position that I take following my interaction with this field is to have an updated "inclusion" policy that sends out a clear and radical strategy for change, that takes place at school level. The *National Commission Person With Disability* (NCPD) in 1993 and the *Education Division* (2000) proposed a policy on "inclusion" with a great deal of 'ifs' and 'buts'. This is an extract of the policy by the NCPD;

...to the maximum extent appropriate, children with disabilities are educated with children, who are not disabled and that special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disabled is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily (p.5).

Ethnography is multifaceted and composite both as a process and as a product. I have used ethnography because as most ethnographers today would agree the term ethnography can be applied to any social research that is carried out in everyday settings. Additionally,



ethnography is perceived as being both contextual and reflexive, another very important component in my research. It gives importance to the context in understanding events and meanings. Ethnography merges the perspectives of both the researcher and the researched.

As new ways of capturing voice are sought, it may be necessary for qualitative researchers to momentarily suspend their preoccupation with the field interview and the carefully transcribed voice of the other. If there is a warrant to the narrative turn in the human disciplines.... then this warrant directs researchers to the study and collection of the personal experience and self stories people tell.... These narratives will work outward from the researcher's biography, entangling his or her tales with the stories told by others (Denzin 1997, p.47).

# CHAPTER 7

## Mapping Out A Transformative Agenda : It's All About 'Me'

*All the World's a stage,  
And all the men and women merely players,  
They have their exits and their entrances,  
And one man in his time plays many parts...  
W. Shakespere  
As you like it  
Act 11 Scene 7*

*I didn't like school, I would see it as the first, sort of, prison I was in. I saw it as an institution full of all the rules and regulations, I wouldn't go there. I learned nothing from school. (Jepson and Parker 2002, p.70).*

## 7.1 INTRODUCTION

We have, each of us, a life story, an inner narrative – whose continuity, whose sense, is our lives. It might be said that each of us constructs and lives, a 'narrative', and that this narrative is us, our identities.

If we wish to know about a man (sic), we ask 'what is his story – his real, inmost story?' - for each of us is a biography, a story. Each of us is a singular narrative, which is constructed continually, unconsciously, by, through, and in us – through our perceptions, our feelings, our thoughts, our actions; and not least our discourse, our spoken narrations. Biologically, physiologically, we are not so different from each other; historically, as narratives we are each of us unique (Sacks 1984, p.105).

This chapter will focus primarily on the fourth research question I have presented in my research; to what extent does narrative research provide an adequate exposition of "inclusion" (Figure 7.1)? The narrative both as a method and methodology, has been dealt with throughout this Thesis especially in Chapter 3. I have incessantly argued about the validity of research not only for its ability to help people read into their situation but also as a way of realising what is going on in life, a process of catharsis, an understanding of the social constructions and a strategy building system. This type of research has created copious debates, self-reflection and surfaced complex tensions (Plummer 2001).

My own professional and intellectual interest led me to consider the social, cultural and political context of this experience I have been researching. In effect, I became an ethnographer in my own social and



professional world. The debate I wanted to engage with was construed around narrative stories. As a matter of fact the work that I did was supported within the stories that people told me, stories I premeditated following my own personal connection and debate with informants and the focus groups that drew from those semi-fictional stories.

My focus in this research is inclusive education. That's pretty obvious, but that is the only thing I'm really sure of. I want to get to know the reality from the horse's mouth, teachers, students, aspiring professionals and social workers (Andrew, *Researcher to Social Workers*).

That is one of the big risks that I have in my research.... in reality what I'm saying is, now I'm starting to reveal even myself to me (Andrew, *Researcher to Teachers*).

The exciting event about "inclusion" is that it is an academic field of enquiry but also an area of political activity. This could be seen from the contributions that disabled and parent activists made. Their main line of argument was the schooling process, but there were also other contributions that were dealing with political issues that the concept of "inclusion" drags in with it (Thomas and Loxely 2001). In every culture, Malta being no exception, education is perceived as the cornerstone of all debates and the beginning of social life. This debate is linked to every aspect of citizenship; legislation, employment, economy, spirituality, leisure and relationships. This debate is undoubtedly governed by social justice. Disability is socially constructed and inclusive/segregated education is conceptualised through a debate that is amply loaded with rhetoric. Industrialisation and disability have not yet converged. The educational programmes that disabled people are engaging with are simply not meeting the needs of industry, making disabled people feel useless and getting this minority set on the poverty line. This is manifested locally primarily through the distribution of pensions, lumping of people in *Adult*

*Training Centres*, high unemployment/unemployability rate amongst disabled persons and *Segregated Schools* that mean absolutely nothing to 'their' future development, citizenship and social contribution. Disability cannot be interpreted as being objective. A basic notion in disability is "inclusion" and if "inclusion" starts compromising, than it means that the whole rationale behind "inclusion" starts taking on a new function. A precise and on-going assessment of the individual and the educational process must take place and how these two realities are congregating. Inclusive education needs to assume co-ordination of the educational process in consultation with all the parties concerned, because "inclusion" instils changes (Salend 1998). Each training programme should work towards interdependency and skill development to maximise on future self-reliance.

Traditionally researchers in the field of disability studies have worked with disabled people to uncover their experiences, and to place them within a social model context in which, in capitalist societies, disability is shown to be an artificial and exclusionary social construction which penalises those people with impairments who do not conform to mainstream expectations of appearance, behaviour, and/or economic performance (UPIAS, 1976, pp.3-4; Finkelstein, 1980; Oliver, 1990, p.11). .....

The social model of disability has been an emancipatory concept in the lives of many disabled people, in helping us to make sense of our experience... (Tregaskis 2000, p.343).

The stories need to be told and others need to listen. It is up to us to decide what is true and what is bogus or counterfeit in these stories. There seemed to be agreement that, what constitutes a story is a matter of debate, rather than of fact. These stories are first and foremost taught starters. They are a way of engaging with a reality that is extremely complex with tensions that are running high. The limit of a story lies within

the reader. Story-telling is considered as the new way of doing knowledge. Stories are imprinted in the backbone of storytellers, their knowledge, values, and emotions (Plummer 2001). They bring together an active rather than a flabby state. They are an interactive discipline. Allowing narrations to surface entails that we are able to be alienated from the original modus but then allow the access to second order observations (Clough 2002).

## **7.2 THE CREATION OF NARRATIVES**

Narratives are not so much created by the mind but by 'what', 'how', 'when' and 'where' people listen. Narratives are useful tools in the construction of the 'self'. Meaning comes about through our ability to listen. It is difficult to imagine oneself as a realist in life: there is no such thing as "life in itself" with no interpretation (p.11-12). It is impossible to grasp the "self" without externalising through narrative. The individual in turn evaluates the narrative in view of his or her experiences to check its veracity. That is why I engage with the stories of these people. I wanted 'them' to speak to me because of the recognition that I have nothing to say but what 'these people' have to say – so what better way is there than to let 'them' say it?

Narrative identity is closely related to the view that identity comes about through a conversation between 'me' and the environment. In order for a narrative to come about, there has to be a true dialogue between participants who speak and listen and recognise each other (Syrjala and Estola 1999). This dialogue will create; simultaneous reflection on the self and a better understanding of identity. The attitude of the audience towards the narrative also affects the narrator's identity and finally the self-knowledge of both the narrator and the listener/reader are enhanced.



Whilst telling a story, the individual constructs the 'story line' with a narrative tension and plot. The story sets in an understanding of whether the experience is a tragedy, a comedy, or 'a story of possibilities that never came true'. This sense making may be directed to several audiences, first of course being the storyteller. Most stories, however, are addressed also to an interviewer or to the larger audience. Even though these stories came to me through e-mail, I had already met with these informants. I have known them personally and communicated with them in the past (Murray and Sixsmith 1998; Arksey and Knight 1999).

Narrative identity can be described as a constantly evolving story, which compounds the past experiences of human life. A person constantly renews his/her narrative by re-creating mental experiences in the form of words and sentences that connect with readers in the stories. What is intriguing is that when you are reading narrative you tend to start placing in doubt what is true and what is fictitious, what is proper and what is illusive. Life is a cycle, implying that experienced life and narrative life intertwine and can be weaved into a clear tapestry of understanding. Life is a long process of narrative interpretation. The significance of existence cannot be differentiated from the stories that are told of it. The relationship between experience and narrative is reciprocal. The narrative is a continuous interpretation of life, which is used by people to organise their experiences and thus create meaning for them. Existence, in turn, is a novel version of the tale being told. Whilst on one hand it is good to have a 'cut off point' and thus contextualise the stories in time, as a reader the validity of that story will read against the interpretation, experiences and constructions that as a society we are involved with. For example, being a teacher is part of my identity besides my distinctiveness as a professional researcher. Probably, the most intricate and complex

role of any teacher is to help the students connect with their identity, individuality, uniqueness, and exceptionality. Listening and engaging with their stories is a key move towards discovering this identity.

Your research was great, it was different..... This is what bothers us a lot, and I confirm this, when people come to do their research, use our experiences, get their projects done and their Doctorates and then one realises that we weren't really consulted and given a voice but talked to (*Walter, Disabled Activist*).

Narratives are the meaning-making tools that help people recognize this identity. The human being is continually asking: Who am I? Where do I come from? Where am I going?. Sometime back I came across a poetical representation that points to the value of perception. Chuang Tzu, a spiritual ancient philosopher says;

When an archer is shooting for nothing  
He has all the skill.  
If he shoots for a brass buckle  
He is already nervous.  
If he shoots for a prize of gold  
He goes blind  
Or sees two targets –

He is out of his mind!  
His skill has not changed. But the prize  
Divides him. He cares.  
He thinks more of winning  
Than of shooting –  
And the need to win  
Drains him of power (*Wicks 1998 p.21*).

In order to make sense of the self, the person grasps life through a narrative. People have different experiences of what their position is in relation to what they are aiming at. It is also a question of what the person has within, and how that 'persona' is interacting with the environment he or she is engrossed in. The weight of these experiences is only understandable in view of the meanings they acquire in the whole-

life narrative. We must move around to be able to make an adequate evaluation of these circumstances and forcibly relate to a biographical approach. These stories take on a format that is similar to oral history (Plummer 2001). It is the recording of people's memories and a living history of everyone's unique life experiences. It is a vital tool for our understanding of the past. In a way this type of collating of thoughts would have been hidden from history and never to be heard. This type of engagement is in a way innovative, especially in the local scene of research, and its value lies in being interactive. Stories preserve everyone's past for the future.

First when I said that the problem is the difference.... What I wanted to say was that difference is beautiful. The fact is that "inclusion" is not about making everyone the same (*Omar, Student Teacher*).

**FIGURE 7.1: THE RESEARCH QUESTIONS**

EMPHASIS IN CHAPTER	ANALYSIS	RESEARCH QUESTION
4	Analysis of autobiographies	In what way can the stories of people at the margins expose issue of "inclusion" and exclusion?
5	Analysis of semi-fictional stories and focus group debates	What are the different perspectives of parent and disabled activists, teachers, university students, 'labelled' students and social workers in relation to presenting a transformative agenda for "inclusion"?
6	Analysis of ethnography position	What practices enable "inclusion"?
7	<b>Analysis of narrative research</b>	<b>To what extent does narrative research provide an adequate exposition of "inclusion"?</b>

Narrative fiction was utilised for a number of reasons (Plummer 2001). Firstly, at times it was too difficult for me to face the issues. I was embarrassed and uncomfortable to admit I make part of a context that is littered with conflicts, aggressiveness and wrong doings. The most difficult part of it all was to admit that at times, to cope, I played in tune with the



system rather than fighting every battle. I must disclose that in these last twenty-four months the reality of the secondary school I teach at was undone. For some years we had managed to contain the conflicts, pain and anguish there was. We managed to speak the language of the students for a period, but now all was let loose. Secondly, I wanted to represent this reality through creative writing to help the people involved in the process read them without fear and inhibition. The people I engaged with in the focus groups know all about my story and I wanted to make sure that there is no deterrent for me or them that will interrupt the thinking flow.

### **7.3 VISIBILITY**

I took on the role of a visible narrator and I used myself as a fieldwork tool, drawing on self-knowledge and personal, professional experience in making interpretations and analysis. My own 'positionality' and familiarity with the context can inhibit insight, at the same time, every ethnographic 'telling is interpretative' and the 'outside within' position can be particularly informative. Generally, our interest is in better alternative futures – for ourselves, our colleagues and our students, and we believe that revealing our own agenda strengthens our validity and sincerity claims in this matter. As long as the telling is derived from the "uncompromising origin" of fieldwork, it can be considered an authorial voice as "middle ground" (p.194) between "deference to subjects' views" and "systematic and reasoned discourse" (*ibid.*). This is, partly, how we endeavoured to make our arguments convincing.

Why focus groups? Focus groups are the hub of this research ...what I want to do is to observe and read through the issues ...at one point I said, what is the easiest thing to do, maybe get hold of "inclusion", define it, present some recommendations and that's it! I felt that that would do justice to the issues. I wanted to elicit,

even the obvious from the people who have a richness of experience because they live the "inclusion" debate, people like social workers... university students ....teachers who have to face the music... parents activists... disabled persons... I wanted to understand "inclusion", but I wanted to understand myself as well that's why I used narrative. I wanted to interact, to listen to stories, to reproduce a reality ... Now I would like your ideas first and foremost... general or specific, it doesn't matter... when you read these stories, what did they mean to you? *(Andrew, Researcher to Social Workers).*

Narrative research provides an adequate exposition of "inclusion" for a number of reasons. It seems that through this type of research the people who were saying their stories, or the stories that were re-written from the experiences of people helped them learn new things about their environment, and the personalities of the people that surround them. This was an excellent opportunity for the disabled students to analyse the people that make up their life. Another reflection is based on the fact that this work proved to be an opportunity to reflect on what people are aiming for in life. Unfortunately, students who have been stigmatised or else labelled as being different are often unable to cope with school experiences because they lose a lot due to hospital visits, lack of adequate support systems and 'professionalisation'. The interview process was also a means of people widening their horizon. There was also a situation where there was a re-construction of the narrator's identity because the work helped me mirror my own individuality. People who were listening to the narratives also managed to reflect and interpret their own situation.

If we had to go one by one through the stories I think it would take us longer than midnight to sort them out... there's so much to say... *(Carrie, Student Teacher).*

Stories give us the opportunity to discuss rather than to listen (*Ann Marie, Social Work Student*).

I never thought I would do it myself, you understand how it is? But it was very much better for me than if you gave me for example, a theory for me to read and we come here to discuss it – that fact that we went around... look at how many things we went around, you understand? I liked this method a lot (*Omar, Student Teacher*).

In this work I engaged with my 'self', my experiences, my way of seeing and interpreting this broad agenda of "inclusion". In more than one way this work serves as a 'jump-start'.

Here, the researcher is supporting a process of change by challenging stereotypes and legitimising the different life experience of disabled people. Corker (1999c), drawing upon Bakhtin's ideas about 'heteroglossia' and 'speech genres' (1986), talks very specifically about the disabled author being reborn as a speaker, in a social context, who produces narratives that embrace both an individual and collective perspective (Davis 2000, p.197).

#### **7.4 "INCLUSION" IS REALISTIC**

There are concepts that will help make "inclusion" a realistic and practical issue, a vision propagated by the use of narrative research.

Firstly, education is a mainstream environment which can encapsulate the fundamental principle of 'schools for all'. Inclusive education must guarantee quality life expectations and should offer lifelong and equality for access to all the echelons of society. Inclusive education has to adapt to the needs of the student and not vice-versa. Early intervention also supports re-education and autonomy. Parents are the prime educators of their children and key partners in the educational process, however they cannot and must not isolate themselves from the politicisation of this



debate, an agenda tailored by disabled persons (Clough and Corbett 2000).

Rather than seeking to fix people and to separate them from mainstream society we need to address the complex issues that will enhance society. The solution therefore lies not in the person as an individual but within society. It is in breaking down barriers and people will be able to read into a community that is inclusive.

"Inclusion" policy is about treating the students equally and not the same. The narratives that I have come to use depict a reality where there is a need for disabled children to be included rather than existing in educational institutions that segregate and exclude them. Bullying and isolation are another two components that are grounded in mainstream schools (Morris 2002). Lack of flexibility in the provision of mainstream school often leads the parents and the disabled child to opt for special schools. Another issue that narratives bring to the surface is the barrier of friendships. Friendship is the biggest gap there is with their non-disabled peers. Any "inclusion" policy and strategy will be a letdown if the issue of mixing up of disabled and non-disabled children does not happen. Disabled children do not seem to fit in mainstream schools and special schools (Salend 1998).

...until, we get it right, parents and children will continue to make compromises even though the consequent segregation is a high price to pay. We must respect these choices while at the same time striving to make them unnecessary (Morris 2002 p.14).

Narratives situate self-determination in the life course (Denzin 1997).

Bolton has summarised the value of narrative fiction in terms of:

- its capacity to offer "an intelligible research summary of the huge body of data which qualitative research tends to provide";
- its capacity to enable people to explore a professional problem that is "inaccessible or problematic by any other means";
- its capacity to convey "the ambiguities, complexities and ironic relationships that exist between multiple viewpoints"; and
- its tendency to "leave gaps for the reader to fill in and raise questions through the unresolved plurality of its meanings" (Bolton, 1994, p. 56 cited in Bridges 1999, p.1).

## 7.5 THE APPEAL OF NARRATIVE

The twist towards having narrative and story telling methods in social sciences is yielding rich harvest of research conclusions (Goodson and Sikes 2001; Goodley *et al* 2004). It is also a way of vitalizing the relationship between policy and practice. This method provides a more meaningful and creative practitioner – service-user relationship and a better understanding of professional sound practices. Research becomes the process of not only identifying the complexities, dynamics and snags we are engrossed in but also to find the ways and means to get back on track and to come up with solutions.

Stories lie in the blue print of narrators. Empirical narrative work in the study of diversity typically values narratives and story telling as a form of emancipation, of 'giving a voice' to otherwise silenced groups. This is very much in line with the work of the disabled activist and academic Mike Oliver (1990a). In emancipatory research, the central purpose of research is seen as supporting the empowerment of service users, and the making of broader social change.

I believe that the core of narrative luxuriates in story telling and remains bound to a partiality of perspective and rejects any form of abstract universalism. Narrative can take different forms; historiography, oral life story, myth, novel or film as their point of departure (Plummer 2001). Within social action, there are issues of social, cultural, and political belonging. I believe that the core of narrative and its social and political importance lies in the fact that narrative and storytelling remain bound to a particularity of perspective, and thus rejecting any form of abstract universalism. At first, this seems to contrast 'theory', 'concept' and 'narrative', but we also insist on exploring the possibilities of narrative theorising. The argument always seems to bring it all down to a key notion; can we feature storytelling as a powerless form of universalism? Can we find commonality in this method to the world of "inclusion", exclusion, and diversity? We need to look at narrative research with three key concepts in mind;

- The nature of collaboration and how it is going to be analysed;
- The function of story in research and its writing;
- The implications of using a disjointed rather than linear mode of presentation.

How can research in the form of narrative be validated? We need to create a dialogue within ourselves to start engaging with such a discourse: 'I' need to study myself doing. How can I do this without destroying the story I am listening to? All I need to do is to position the story into perspective without criticising it out of existence. I want to show that it is an account, an anecdote, a story, which has many layers, many explanations and a great deal of indecisive conclusions.



## 7.6 STORIES - A CONTRADICTION TO REAL LIFE?

What can a story tell us about reality? What can we read in such a story? What reality will this story narrate about the social dilemmas, the social dynamics and the tensions that there are raised in this arena? We speak about research as if it is a dimension beyond us. We speak about research as if we are speaking about a conscious that doesn't belong to the informants, to my students. But, what is research? What makes research valid and true? What can be defined as facts and fictitious data? What makes research creative and effective? What I am proposing is that we start engaging with research as a process of creative reflection and suppress the traditional qualms. We need to see qualitative research not as a distinct position away from us but a reality that each researcher needs to connect with. If we were to focus on educational research than this becomes even more critical. Research in itself has become a 'trend setter'. It is research that moves people to think about something and this is a new function of research that goes side by side with the interpretation of facts and circumstances.

*The Polish Peasant In Europe And America – A Classic Work In Immigration History* by Thomas and Znaniecki (Zaretsky [ed.] 1996) is a classic when it comes to understanding this whole debate. Prior to a decision taken by the notorious *Chicago School of Sociology*, the only way that information was gathered was through 'social surveys'. This style collated data without providing the capacity to analyse the causes of these notions. "Thomas and Znaniecki, by contrast, sought to explain social problems by examining the relation between individuals and their surrounding society" (p. xii). Quote;

The meanings of narrative arise out of the interaction of story, storyteller and audience (Reason and Hawkins, 1998, p. 86). What

audiences do with stories is often unclear  
(Goodley 2000, p.57).

The focal point of this *Thesis* is that life stories as a research tool gives control to the informants. Understanding experience as lived and told stories, also known as narrative inquiry, has gained popularity and credence in qualitative research. As a research method, narrative inquiry can reveal or capture political, ethical, and moral dimensions of life, experience, and professional practice that other research methodologies cannot. While well-crafted and documented stories can serve as primary data in formal academic research, they can also serve as powerful teaching and organizing tools and sources of wisdom and inspiration in action-oriented community development and collaborative inquiry projects.

Using such a technique in educational research creates a new way of including informants. It helps individuals acquire knowledge about the historical context of narrative research and 'social surveys'. It also introduces opportunities to safeguard ethical boundaries. The shortcomings of such a research technique can be described in the following questions:

- What can reasonably be described as a 'story'?
- What is the relationship between stories and endings?
- What is the value of an ending?
- Can we have a story with multiple endings or without any ending at all?
- Without closure to our stories, are we not left with a deep feeling of unease? And if so, what does this tell us about ourselves?
- Is critical reflection just another form of privileged rationality?

If we are not to accept every splinter of speech as a story, every awkward description as storytelling; if we are not to be content with a lack of endings, plots and characters, then it is time to carefully consider the limits of storytelling. Using narrative in educational research is another way of creating a new way of indulging in the theme under consideration with the informants involved in the whole process. Research has become one way of identifying the causes of certain changes, dilemmas and tensions that are taking place in our school community. Education is the panacea of all social woes. The evidence I read through the stories people tell are in harmony with what is happening and what will be happening. The story lies in the crystal ball – the narrative.

The twist towards having narrative and story telling methods in social sciences is yielding rich harvest of research conclusions (Zaretsky 1996; Goodson and Sikes, 2001; Plummer 2001; Goodley *et al* 2004). This method is a way of vitalizing the relationship between policy and practice. This technique provides a more meaningful and creative practitioner–service-user relationship and a better understanding of professional sound practices.

Being an ocular-centred community, we need to see what is happening and to read stories that are close to the reality we are succumbed in, even if they are stories that we are not usually directly involved in. These are stories that transcend from the people to the people, rather than from the researchers/academics to researchers/academics. This work is based on the power of stories. Stories and narratives are often intersected by multiple allegiances ranging from a historical context to political conformity, from grass-root struggles to social constructions and cultural hagemonisation, from researcher consent to economic agendas. Maybe the most complex of all issues is not the presentation of stories but to figure



out and recognise what constitutes a story, defining story limits, recognizing the usefulness of narration and finally reflecting whether the morale of narratives is context-bound. The core of my research lies in the stories that have been written and relocated back to the varied locations. Conversely, this scenario is complemented by stories I collated from disabled activists and parents of disabled people. This brought me to the enmeshment of auto-ethnography, focus group debates (via semi-fictional stories) and narrative enquiry. I have sought "inclusion" not in a fixed and resolute facet but I wanted to engage with the various experiences that are shaping my own views on "inclusion" in an assortment of perspectives.

In reciting the story of "inclusion" and inclusivity, I attempted to cover six fascinating and knotty years of fieldwork, reflection and research I have been wrapped in during my *Masters and Doctoral Studies*, entangled with a career that has taken me to the highs and lows of this complex debate. This experience has changed 'me' from the roots.

The use of narratives and fictions in social science research makes it possible to render the lives of others in such a way that others might access something of the raw truths of their lives. Conventional research reports (often) effectively render out the personal. ... Lives and difficulties are disinfected and presented 'steam-cleaned', and though creased and worn – they are offered up to the reader in a relatively painless way (Goodley *et al* 2004, p.184).

Let's not forget that we all hold together by 'social-ties' (Thomas and Znaniecki 1996). What better way than the narration of stories to assist us in this process? The value of narrative fiction, in terms of its capability to propose an intelligible research summary of the huge body of data which qualitative research tends to provide, connects with and explores a professional problem that is inaccessible or problematic by any other

means. It expresses the ambiguities, complexities and ironic relationships that exist between multiple viewpoints.

## 7.7 CONCLUSION

These findings suggest that the dynamics that ensue between the researcher and the informant are recreating the tensions and debates that such a notion as "inclusion" garners into play. The debate of "inclusion" is difficult because of its complexity and contradiction. We need to speak about "inclusion" because it still is an unrecognised notion that distances a person from the roots of all that is happening in this debate. The interaction becomes a medium in which the participant is able to connect with his/her reality (Slee 1993).

This work has contributed to exposing "inclusion" matters via the narrative method. This research contributes to an understanding of social life and the creative analytic practices opens up the text and invites interpretive responses. At the same time this work is imaginative, it illustrates reality and is satisfying even though very composite. This research provided a personified sense of lived experience. It impacts my informants and 'me' emotionally and intellectually, it generated new problems and it has moved 'me' to use a new research practice that lies within the informant rather than within the researcher come academic. This has also been a process of reflexivity (Plummer 2001). I personally was cognisant of epistemology and wrote the text, remaining accountable to the standards of knowing and telling as delineated by the people I was working with. In this work I was concerned with a range of innovative methods in particular those that find a 'voice' and a 'story' for social clusters who remain without such voices. Narrative gives richness to the writing and research and it does provide an adequate exposition of "inclusion" (Shakespeare 1997, p.182).

A narrative approach to research places the onus on the researcher to create an environment in which the respondent can begin to tell his or her story. The approach recognises that people live their lives and construct their identities in narrative terms (Taylor, 1989), and that makes sense of their experiences as events that contribute to their own script(s), the plots that constitute their lives. Unless one is able to 'employ' events within a broader life history and life story they have little meaning (Rioux, Crawford, Ticoll and Bach 1997, p.197).



# CHAPTER 8

## Conclusion and Commitments: From Here To Where?

*"... education... lies in its drive  
towards reconciliation" (Freire 1993,  
p. 53).*

*Education is a practice of freedom, a way of life that leads to liberation. It is a process of humanization, a process of becoming more fully human. It is a process of transformation, a process of changing the world. It is a process of hope, a process of believing in a better future. It is a process of love, a process of caring for others. It is a process of justice, a process of fighting against oppression. It is a process of peace, a process of building a better world. It is a process of life, a process of growing and learning. It is a process of death, a process of letting go. It is a process of resurrection, a process of rising again. It is a process of eternal life, a process of living forever. It is a process of love, a process of caring for others. It is a process of justice, a process of fighting against oppression. It is a process of peace, a process of building a better world. It is a process of life, a process of growing and learning. It is a process of death, a process of letting go. It is a process of resurrection, a process of rising again. It is a process of eternal life, a process of living forever.*

*All those people trying so hard to help me: the nurses, the doctors, the volunteers...All of them hoping for me to get better and do well, all wanting to be kind and useful, all feeling how important helping me was, yet never did any one of them ask me what I wanted for myself. They never asked me if I wanted their help.  
(Marsha in Saxton and Howe, 1988, p.55).*

## 8.1 INTRODUCING THE END

Fundamental principles to which we are both in agreement: disability is a situation, caused by social conditions, which requires for its elimination, (a) that one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting social control by disabled people. (UPIAS 1976, p. 3).

This *Thesis* has examined a number of important facts from a range of miscellaneous viewpoints in relation to "inclusion". In this final chapter I will engage with several of these important notions towards a consideration of the development of forthcoming agendas relating to stories of children, the different perspectives I have engaged with, the enabling practices and the adequateness of the method/ology I betrothed (Goodley *et al* 2004). This complex and difficult agenda relates to each other in different ways, establishing intricate associations with stories of "inclusion" (Barton and Armstrong 1999). This isn't and wasn't a straight forward 'presentation of facts-finding solutions' discourse, but a debate that is influenced by an analysis of the prevailing discourses and the values and practices that besiege this complex debate. A great deal of ideas have been presented especially through the literature review and the informants direct contributions. It is a starting point from which policies can be relocated to reproduce new strategies at local and

school level (Fulcher 1999; Ministry of Education 1999). Maybe a hidden but important reference lies in permeating, infusing and reproducing a more righteous schooling system. School clusters or individual establishments can create their own policies on how to make structures that weaken a hypersensitive and defensive pedagogy, which does not distribute the 'energies' proportionately. This work invited the main stakeholders; teachers, administrators, professionals, parents and students to be revolutionary and subversion because the transformation that needs to take place in schools starts to happen in our whole interpretation of the term "inclusion" (Barton and Armstrong 1999; Finkelstein 2001). "...it's not disabled people who need to change but actually the non-disabled world that needs to change, this was called revolutionary!" (Finkelstein 2001, p.1).

## **8.2 A PAUSE FOR REFLECTION**

This *Conclusion and Commitments* chapter brings to mind the many years I have worked on this area during my EdD research. It is true that at times my connection to disability theory has created a lot of pain and frustration because of the many unfinished business it leaves in 'you'. The debates are endless and the issues are complex. Who knows, maybe in this case, "was ignorance was bliss?"

The hegemony of the medical model still lies in command of disabled people's lives in the local context especially in the field of education. This *Thesis* has demonstrated that in applying the social model we have identified a number of ideologies within mainstream education that make this *Thesis* vital, visible, relevant and applicable outside its specialist domain. Reading this *Thesis* brings 'one' in line with the complex application of such a discourse (Clark *et al* 1995; Ballard 1999).



### **8.3 THE MAKING OF THE RESEARCH QUESTIONS**

The contradictions, inconsistencies and challenges in this debate led me to the research questions about "inclusion" which I attempted to answer in the various stages of this *Thesis*. I hope my choice of questions, method and methodology, as quoted from Campbell and Oliver (1996), "does justice to the silent many as well as the vocal few" (p.27).

I have looked into the following quandaries:

- The stories of children at the margins that position the issues and debates on "inclusion" and exclusion.
- The different perspectives of parent and disabled activists, teachers, university students, labelled students and social workers in relation to presenting a transformative agenda for "inclusion".
- Identifying the practices that enable "inclusion".
- Analysing to what extent the use of narrative research provides an adequate exposition on "inclusion".

### **8.4 THE MAIN ISSUES OF CONTENTION**

It was not an easy task to bring to an end four years of *Doctoral* work following two years of a very hectic *Masters* programme, all immersed in an eventful personal and professional experience (Sacks 1985; Goodley *et al* 2004). In a way I read nostalgia because this research has not only helped me reflect on my research questions but it has also brought into perspective what I believe in (Plummer 2001), what I would like to see in the "inclusion" debate happening, what seems to be lacking in the general experience and what makes up my concerns in this discourse.

#### **8.4.1 DEEP-SEATED OBSERVATIONS**

The following are some key annotations that emanate from this enquiry. First and foremost, "inclusion", means and constitutes, separate realities to

different countries, contexts and perceptions. The argumentation that I have developed in Chapters 1 and 2 has to be understood rigorously (Barnes and Mercer 2003). We need to analyse the context to be able to get engaged with the diverse complex issues that make up the dynamics of the day-to-day presence (Corbett 1998). We also need to call for strategic forms of action that suit this milieu. We cannot keep looking at foreign models and merely transport these frameworks into our educational system without first looking closely at what will be appropriate to help 'us meet our ends'. For example, no one attempting to engage with "inclusion" in Malta will do this without recognising, admitting, maybe acknowledging (without feeling too good about doing so) that the *Catholic Church* is closer to our society in its political, social and economic influences than it is for other countries. The *Catholic Church* is extremely powerful in; influencing this complex agenda, what can or cannot happen, the value scales, the thinking processes, the policy prioritisation and the curriculum (Sultana and Baldacchino 1994). We are also a very insecure, timid and unconfident society. This condition may have come about partially as the result of our long years of colonialism, of having 'a big brother to protect us'. It may also be the fact that we are so small and insular in size because of our geographical configuration. It may be just a combination of all these elements (Sultana and Baldacchino 1994; Corbett 1998). This work has enlightened my understanding that there is still a great deal to be done in the meaning, operationalisation and consequences of following an inclusive policy, especially the thinking that is now beginning to surmount the notion of human rights (Barton and Armstrong 1999). In addition we need to think about the different ways on how discrimination and exclusion need to be understood. The emphasis on disenfranchisement, marginalisation and exclusion all lead to a very wide debate that has to be read within an agenda of "inclusion" in Malta which is in its early developing stages.

'We' are still at the beginning. Within this whole philosophical concept of "inclusion" there is an accompanying discourse usually carried forward by other professions, especially psychologists, who are speaking about "inclusion" as needing a practical dimension. This whole discourse starts to encapsulate the various arguments about having comprehensive schools, 'reinventing' assessment, differentiated teaching, teaching around themes, auditing inclusive practices and the design of *Individualised Education Programmes* (Ware in Ballard 1999; Salend 2001). The role of facilitators, 'our' values, the economic effects of education and its reaction to industry, the teacher's role in the "inclusion" process, classroom management and the function of SENCO's amongst others are all debatable issues. Unfortunately, countries like Malta, where "inclusion" is a relatively new appendage to the education process, is focused on the basic improvements and short sighted strategies rather than looking at the more ideological and abstract issues associated with disability politics (Corbett 1998; Azzopardi 2000). I have observed in my work with informants, that there are a number of initiatives that are starting to ensue. Parents are more vociferous and so are disabled people. There may be a lot of boardroom talk going on but there is also a lot of networking that is starting to happen amongst the disabled community as well. I believe that "inclusion" is now part of the national agenda, even though I feel that it is a schema that is being exceedingly dictated by policy-makers and politicians. Apropos, this mentality brings in what Corbett (1998) refers to as, "...attitudes towards disability are influenced by crisis-led value systems" (p.41). This work has also touched upon what the grassroots think about "inclusion". This discussion was evident in the data analysis chapters. It is palpable that there are a lot of tensions and challenges. You still get arguments in favour of 'Deaf Schools' and other special/segregated provisions (Oliver and Campbell 1996). It is increasingly worrying that a number of parent activists I know are taking



their children out of mainstream schools and re-positioning them in special schools. Parents are expressing serious concern on the effectiveness of the current "inclusion" provisions and the program design (Ballard 1999). There are also parents who are being left with a bitter taste when their children finish secondary school. These young people are not finding post-secondary alternatives or else adequate 'skill training schemes' that compliment their social, psychological and economic development. There appears to be a new trend in using research methods around the issues that are being investigated. Research seems to indicate that even though there are a lot of struggles, debates and a general sense of indecisiveness in this whole debate on "inclusion", the fact that we allow the informant to 'say his/her own' is becoming a more imminent and urgent issue. Participatory and emancipatory frameworks guarantee that the informants are not used as passive recipients to the hauling of information but are actively engaged in their own stories intimately and thoroughly (Corbett 1996; Plummer 2001) a debate I have engaged with in Chapters 4 and 5. Another notion that emerges out of this work is the development of 'a culture of encouragement'. We have to create the right milieu that will enhance this debate and push forward opportunities. The disabled community needs to have a stronger disability voice in all levels of government, a forceful presence of parents and students participation in the organisation of school communities. Schools need to contribute to creating policy. The contribution that this work has made is for its representation of the voice of disabled people and the constancy that rests in the message (Corbett 1996; 1998; Fulcher 1999; Tregaskis 2000). The purposes and the values of inclusive education are re-examined and re-thought, one in which old ideas give way to new strategies. We need to develop new creative relationships in a very different world with dissimilar pressures and diverse realities. Another engagement we need to make is to have 'a culture of questioning'. We

need to learn how to ask questions positively and assertively. We necessitate opportunities to learn to ask without feeling threatened or threatening. The impact of marketisation, performativity, competition, selection and the hierarchical organisation of power has become much more controlling and more distant from the grassroots. However, this divide is less evident because professionals are more skilful in the use of language. Professionals are mistrusted, and their interest is dealt with caution. This experience of hostility that was manifested in my work with the informants can only be transformed in time (Corbett 1996). We have an insularity that is worrying. Heightened forms of self-awareness can further constrain people and not just empower them. It is a social process and a social outcome. There is no room for arrogance or complacency but for sharing, supporting, encouraging and mutual effort to engage with the complex debates if we want to witness progress.

#### **8.4.2 "INCLUSION" IS NOT A RESOLVED ISSUE**

There still is a lot to worry about. There is no room for complacency and arrogance. "Inclusion" is by no stretch of the imagination, a resolved issue – it can never be. It hasn't even, in my opinion, permeated our cultural DNA and is still an alien notion to many (Clough and Corbett 2000; Barnes and Mercer 2003). The disabled community has progressed following a strenuous struggle against oppression. It is not at all easy to give space within a scenario that disallows the struggle (Oliver 1996).

"Inclusion" has massive issues to sort out, deal with, think about and find solutions to. It is important that people talk and listen to each other and to have a respectful ear. There is also a danger of seeking the easy and quick slick solutions rather than thinking things through of these highly complex and difficult issues.

## 8.5 SOME KEY STRATEGIES FOR "INCLUSION"

The struggle for inclusive education is part of a wider struggle to bring about an inclusive society in which all individuals and groups enjoy full and equal membership. As such, it involves asking questions and making demands that are disturbing, because they challenge the familiar and the way in which our societies are organised (Barton and Armstrong 1998, p.262).

Within this instability and uncertainty there are some firm notions that can integrate these complex debates. There are always issues around "inclusion" that we need to work around and struggle for. We, as professional allies and 'disabled and parent activists' need to keep questioning ourselves around the processes that make up these discourses, a debate I raised in Chapter 4. The quickest way to wipe out "inclusion" is by not providing adequate resources. Recently the *Minister Of Education* in Malta was quoted in the media as saying that one million Maltese Lira was given to this sector, an estimated 1% of the global expenditure on education, just for facilitator support. Whether this practice enabled "inclusion" is another debate that was raised in Chapter 6. We need to develop 'a culture of reduced fear' of human differences. The most effective means of combating discrimination is creating welcoming communities, designing an inclusive society and achieving education for all (Booth and Ainscow 1998; Bartolo et al 2003). "Inclusion" is about participation, friendship and interaction. Schools are idiosyncratic communities, each with their own biographies, circumstances and profiles. Each school has to develop on its own steam drawing from the most important of resources – the students themselves. There is a need for flexible patterns in schools. We have to develop a critical discourse that does not put us down but encourages the roles and relations within them. Disabled students in our schools are atypical. Their



disability is represented as being an impairment and disability is pathologised in the form of essentialist abjection. Research, as analysed in Chapter 7, in the form of narrative, can become one way of creating an effective channel of communication.

The social model helped us to bring into contention a number of debates that will enable 'us' to read the "inclusion" debate. The social model is an important social response suitable to this reality and poses an important struggle whereby people choose to analyse whose side they are on (Clough and Corbett 2000)? Literature has often accused researchers as being dogmatic and officious, professionals have regularly been considered as defending their status and protecting their 'own' rather than helping people find solutions to the social constructions that they come across (Oliver 1996; Barnes and Mercer 1997). Policy makers and politicians are often seen as more concerned with the economic value of services and their search for standards (Corbett 1998). Parent activists seem to govern the debate and as a consequence disabled activists are excluded (Brown 1999; Ware 1999).

Nonetheless, there are some interesting changes that are starting to take place. Parents, students, teachers and other professionals are searching for examples of positive inclusive practices and are demanding a more active involvement in research which they want to participate in as long as they are in control. We can and need to find ways how other countries and other societies are making "inclusion" work. We need to apply the right communication channels. We must be creative and find ways how to make it happen.

The social model has been used in the past in a rather formalistic way. Many people have come to think about disability within a theoretical

representation as if it were an explanation and a definition and nothing else (Finkelstein 2001). The local scene lacks dialogue, debate and fora. The people who manage the two coalitions in Malta are either immersed in personal issues or else are too tired and too uninvolved to make the necessary moves and changes. Our agenda for "inclusion" must be planned around this key notion of debate. It is necessary that we discuss how to make "inclusion" and not just define it. We need to exchange data, information and reflections (Barton and Armstrong 1999). This model helps us to find ways how to minimise the individual function into creating a collective agenda, without riding the crest of the other dangerous wave of homogeneity (Corbett 1998).

Unless there is a recognition of personal, cultural and locational differences which influence the ways in which disability is experienced, the medical and social models will offer limited scope for effective use in analysis beyond the most elementary level (Corbett 1998, p. 30).

## **8.6 BACK TO SCHOOL—ECHOES OF NARRATIVES**

Going back to the school based "inclusion" debate, has been interpreted as a process of extending boundaries. "Inclusion" has or can become the springboard to interpret the existing tensions. My informants recognise the need to create a network within the wider community thus dealing with the disadvantage of students' identities without trying to eradicate them from their roots.

They are working-class... shown in their relationship with siblings, parents, friends and colleagues. They are an integral part of the community and not separate from it. For this very reason, the issues they raise... are powerfully presented (Corbett 1998, p. 63).

This reality threatens the social firmness and fosters intransigent attitudes. Given the opportunity, through the adaptation of the curriculum, all

students can find themselves a place and an active dynamic and distinct role in the neighbourhood (Giordmaina 2001). It is up to the school to create the best possible conditions for these changes.

"Inclusion" in itself can provide a response to political inventiveness. Students convey their ambitions for the improvement of their own education and development, and of the challenges they face in realising these targets within a society that declines their legitimacy. "Inclusion" depends on an experience of interaction, participation and partnership in their neighbourhood. "Inclusion" does not exist in isolation. The community schools' leadership should be one that nurtures enthusiasm for the participation in a journey that enables community members to grow and develop personally and collectively (Giordmaina 2001, p.358).

Students at the margins have a right to equal participation in all aspects of society and in all decisions that concern them. School institutions endeavour to be accessible to all and to strive towards a comprehensible society. This applies not only to "inclusion" in education, employment and social life, but also to participation in the political processes they are engaged with.

The population of disabled students in the region I have been teaching at, are a minority within another minority with such particularities and distinction that prevalence brings with it. I refer to it as the "sqaq"<sup>13</sup> culture. It is a culture that interprets the dimension of daily life from the common citizen's own critical perception of the world. This culture of diversity is in fact a stream of contradictions. It is not a culture based on poverty but founded on a string of paradoxes. There is grinding poverty in

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<sup>13</sup> 'Sqaq', is a narrow lane with just one point of entry and exit.



isolated rural areas and in the slums of the cities within this region because of a lack of opportunities and because of idiosyncratic education (Sultana & Baldacchino 1994; Riddell and Watson 2003).

The socially dominant culture shapes the way in which disability and impairment are viewed, and has contributed to the oppression of disabled people. At the same time disabled people have forged their own cultures as acts of resistance. Culture, therefore, is both a source of oppression and of liberation for disabled people, and is therefore central to the politics of disability. (Riddell and Watson 2003, p.1).

Affluence exists side by side with deprivation. Diversity, by the 'bureaucrats' and academics is interpreted as being un-constructive and off-putting rather than a chance for the community to move on. The 'civil servant's' crusade persistently to modify the mentality, notions and identity of the inhabitants in the region heightened my research and created the "appropriate balance". The "administration" encourages particular behaviour as long as it conforms rigorously to regulations. This affection to the rules may eventually lead to the displacement of the community's goals and dysfunctional consequences (Haralambos & Holborn 1991). The lack of entrustment to schools in decision-making processes contributes to the schools failure to meet the need of their communities.

The narratives that have been shared via the autobiographies, auto-ethnography, the semi-fictional stories and the debates in the focus groups bring in many features, which contribute to the creation of inclusive schools. Firstly, one needs to qualify the responsibility of each member in the school community. Parents, students, teachers and administrators need to believe that relationships and their equivalent actions are at the heart of creating a compassionate environment for all children that would

in turn affect learning. Taking responsibilities for the different roles we best play add to the possibility of an inclusive school (Ainscow 1995; Booth and Ainscow 1998).

"Inclusion" in this particular region of Malta (the inner harbour region) I teach at, tends to suggest a process of extending boundaries. It renders invisible the social divisions and differences. This "spatial" dimension that Armstrong (1999) refers to as the capacity for schools to locate socially the needs of the particular communities they represent, thus playing a crucial role in reproducing an experience. The ordinary becomes odd and the tension escalates. Most people in this region are poor because they are excluded. These children are generally prosperous in potential and talents that have been switched off. The manifestation of such a situation becomes implosive. They develop bitterness towards a society (represented by school) that has not given them space (Armstrong 1999). It is an experience succumbed by a "long history of humiliation and dishonour" (Montebello 1999, p.4).

There are three major advantages that follow from a serious and sustained effort to end this dual segregation of disability and social isolation, located in urbanisation (Bagilhole 1997). Firstly, the policy of segregation impoverishes the life experience of children in mainstream schools. The rest of the students would be enriched by understanding and experiencing the diversity of human society and by improving their communicative competence (Riddell and Watson 2003).

We regard "inclusion" and exclusion as processes rather than events, and define them respectively as the processes of increasing and reducing the participation of students in the curricula, cultures and communities of neighbourhood, mainstream schools. Any real school, at any one time, reflects a complex interplay of including and

excluding forces, acting on individuals and groups of students (Booth, Ainsow and Dyson 1998, p.194).

Secondly, the relevant resources, expertise and proficiency, which are currently confined in the special schools sector should be released and made accessible to a far wider group of children. There are many children within our education system that may not be identified as having a disability or learning difficulty. Nonetheless, they might benefit from known forms of pedagogy, support service interventions and information technology. Mainstream schools are at present inadequately resourced, thus unable to provide the best possible service. Schools would benefit from support provisions and expertise for children that could easily fall under the category of needing special schooling facilities. The local situation is based on a system of provision that exercises a detrimental effect on this specific regional culture of mainstream schools (Riddell and Watson 2003). There is the illusion that the rest of the school population (those who are not labelled as 'special needs students') can be treated as a homogeneous group who begin their educational program on a level footing. Consequently, they are encouraging stereotyped institutional responses to children's unique patterns of learning and development.

Education policy required schools to provide the opportunity for all children in the local community to participate and experience success in joint learning activities. Efforts are made towards the development of more flexible and creative forms of pedagogy and school organisation. This process has to prevail to ensure "inclusion" within already restrictive and stressed conditions. An effective inclusive program would entail facilitating relationships outside school. This institution now becomes a



community (Booth and Ainsow 1998). It is necessary for parents, students and educators to work together in a joint effort to help the relationships flourish beyond the limited parameters of the school (Tabone 1994).

The communities in this region have reacted to the tensions that this mélange of "inclusion" has brought about. Corbett and Slee (2000) identify three stages in the course of understanding "inclusion". They place at the first level "inclusion" that is dominated by developing strategies and school efficacy. Then there is the second echelon where a commitment is made to adapt the infrastructure and the core programmes. Finally, there is a third level. At this stage, "inclusion" is in the unseen curriculum of cultural experiences, deep-seated values systems, customs and routines. This level is the most significant and most difficult to achieve (Ballard 1999). At this level "inclusion" becomes a proper educational process.

The school is an important space for the playing out of struggles and conflicts... The increased marketisation of education has entailed a sharpening of curricular, social and organisational boundaries and selection practices within and between schools making the social and political purpose of testing, selection and inspection more apparent (Armstrong 1999, p. 75).

One of my respondents said that an important and contributing factor in a successful school community is when the teaching/professional community come from the same or a similar neighbourhood. Unless the people who will be working within these school communities are 'converted' to that specific sub-culture and received by the inhabitants, it will become impossible for them to function effectively. Professionals are not expected to become citizens of *Cottonera* nor to resemble them but

to be open and adaptable to the cultural requisites of those inhabitants. Teaching has grown dependent on other resources within the community and is no longer isolated and detached from the people (Freire 1970). Schools have developed into a social hub.

Although research on "inclusion" has been on the increase in these last few years, more research is needed to examine additional factors that have influenced and effected the development of attitudes towards "inclusion". My respondents came up with a number of interesting considerations to enrich the school experience and to provide the right climate to reduce the strain that exists between urbanisation and "inclusion";

- As educators, we are to help children reach out to each other. We need to encourage friendships at a personal level, by initiating ways for the children to connect outside school.
- It is vital that children with 'labels' participate in community groups and activities that involve other neighbourhood children. This would give the opportunity that students in the school can perceive a more comprehensive dimension of the respective classmate.
- The aspiration of most disabled activists is 'visibility'. The day-to-day struggles are fought out in the lives of those children, parents and disabled persons who contest the forces of social exclusion in their fight for the right to education. Teachers play an important role in this struggle.
- Schools need a mixture of leadership, committed teachers and an active cluster of disabled students and parents. Staff must know the 'region' they are assigned to well. Ongoing professional development, mechanisms for dealing with burnout, and allocation of adequate resources are other essential components. "Inclusion", both at the regional and disablist frameworks will not just happen on

its own; it needs to be nurtured. Being excluded is an alienating experience. Making sure pupils feel at ease within their school reduces the likelihood of developing an environment that is restrictive, limiting and that leads to other social problems.

A school community is alive when it is actively engaging with the changes and development of the wider social realm. The basic goal in a school project is the experience to reach out to all students and empower them with the skills they need for the future they want to be part of (Clark, Dyson & Millward 1995). Students benefit if they are to make part of a school community, which prepares students to integrate and engage in experiences that respect diversity (Corbett 1998). Real world experience is the most natural way for students to be taught. Disabled students learn how to function independently through the support of their friends, families, peers, and teachers.

## **8.7 A FINAL WORD**

Finally, who will not recall the renowned opening sentence of *A Tale of Two Cities* (Dickens, 1968);

It was the best of times, it was the worst of times,  
it was the age of wisdom, it was the age of  
foolishness, it was the epoch of belief, it was the  
epoch of incredulity, it was the season of Light, it  
was the season of Darkness, it was the spring of  
hope, it was the winter of despair, we had  
everything before us, we had nothing before us...  
(p. 7).

Such contradictions and inconsistencies mentioned in *A Tale Of Two Cities* are veracity explored in this *Thesis*. Inventiveness, national standards, types of examinations, voice and participation, active engagement in the struggles, and community-focused teaching, stories that expose, transformative agendas, good/bad practices, narrative expositions are



divergences that are very difficult to bring together. At the heart of this is the "inclusion" discourse within a system that has been denied its distinctiveness. Contests trigger exclusion (Stirling 1992; Armstrong, 1999). The optimum contradiction in this is in trying to implement a discourse on "inclusion". The reality of schools to-day is still one of segregation, especially if schools do not manage to meet the terms put down in the *National Minimum Curriculum* (Armstrong 1999). Inclusive education in this region does not deny difference but makes a strong political statement against a system hijacked by standards (Corbett 1998);

.... schools vary in their general ability to promote the positive development of their students .... The consistency of school effectiveness in promoting different student outcomes, however, is an area of considerable complexity.... Studies which focus on the major domains of activity (academic, affective, and behavioural) .... are likely to prove helpful both to practitioners seeking to improve different aspects of the performance of their schools and to researchers exploring the nature of school influences (Mortimore 1997b, p. 479).

If we have a belief that "inclusion" is more than merely education and is more than categorisation of students, then it is important that we give time to really think about this. "Inclusion" goes beyond the restricted thinking of a classroom, it is a force to reckon with.

For me the critical issue is how can disabled people have a meaningful, if not revolutionary, impact on the disabling society? Clearly, as long as we remain 'socially dead' we are unable to engrave our signature in the fabric of society – in particular those material aspects of social relations which render our 'disabilities permanent' (Finkelstein 2001, p. 7).

By reading stories of "inclusion" and engaging with different perspectives I have come to list out an agenda for "inclusion". I reiterate what the well-

known academic Professor Len Barton is often contending in his typical archetypal and emblematic problem, 'what is "inclusion"?' This project has taught me to understand that disabled children are unable to meet the society that non-disabled adults are constructing through strong institutions like education.

"Inclusion" in Malta is essentially a contemporary debate in education. It is interesting that most of my informants consider that an effective "inclusion" program is based on a school community that supports different forms and styles of teaching (Giordmaina 2001). Disability is constantly being placed on the fringes of society where tolerance is a rare ingredient. Schools are there to affect change, design an agenda and engage with the stories - will this happen?

# Afterthought

**And they lived...**

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As I sit outside in the lovely belvedere of the new school I will be working at next year I convene my thoughts. Somehow, I feel happy but cheerless. No more trips to Sheffield. No more lectures on a Saturday night. No more walks around the good-looking *Student City* in the middle of the night. No more dreams of what I will do when it's all over and done with. No endless chats with friends. Just nostalgia. Feeling poignant that I have no dream, no more. People will start asking and I worry, "What now, you're a *Doctor*?" I'm staggered and annoyed, afraid of this question because bareness takes over. I will miss 'All Bar One', Tony and Laurel, the staff at Sheffield Uni. I will miss Ranmoore and its pretty bar I've known for years (that sheltered us from some annoying lectures I couldn't connect with) and (Oh yes), I will miss the lovely pillows of the little bedrooms. It's been a long long walk – "...got there, been there', I tell them all".

Back here. Some love me dearly and some hate me passionately - many admirers but few friends. I suppose it's the way I am. I keep thinking...is this about me or what I am? Is this about the way I speak or the way I think? Can't arrive to any conclusion. Not really interested anymore. I'm a *Doctor* now – but I wait in vociferous silence to employ a new dream hoping that the ardour and knowledge will serve to make "inclusion" an engrossment come through... It's not all sorted out I'm afraid. Let's hope and work that this 'game' that has so many facets to it will be the epitome of songs of praise.

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