

THE GENESIS OF DISABILITY STUDIES IN MALTA: *from a colonial past to an independent future?*

Introduction

In this presentation I will attempt to place disability studies in the socio-political context of Maltese society. I will give a brief overview of our approach to disability issues and their development into disability equality training programmes and our first attempts at establishing disability studies as an integral part of our overall work. Finally, I will take a look at some of the major concerns and preoccupations regarding disability studies which have developed over the last ten years or so. I will conclude by posing a number of questions which are relevant to our situation in Malta and which may, or may not, have a wider relevance. The perspective throughout will be entirely that of a disabled activist.

The Maltese Context

The Maltese archipelago comprises the islands of Malta (316km²), Gozo (162km²) and Comino, and the uninhabited islets of Comino, Filfla and St Paul's Island, with a total population of approximately 400,000. The island group is centrally located in the Mediterranean Sea and, throughout history, primarily due to its tiny size and strategic location, the archipelago has been fought over and colonised by almost every major European and Middle Eastern power imaginable from the Phoenicians, Romans, Arabs and Normans, to the Knights of St. John, the French and finally, the British.

Until the mid-1950s the Maltese economy was based on subsistence farming with the average Maltese worker just barely scraping a living. Illness, poor diet and other factors related to poverty meant that impairments were widespread. Traditionally the Maltese themselves have always been a relatively peaceful race with a strong Judeo-Christian tradition which included opposition to infanticide and a desire to 'care' for the 'sick' and the 'less fortunate' either through alms giving or the provision of 'direct care' (Davis, in Barnes 1997).

On the whole, the paternalistic aspect of strong family structures have had a negative effect on the aspirations of disabled people; however, these family ties, where they have worked, have ensured a better quality of life for individual disabled people.

“Nonetheless, being presented as objects of charity effectively robbed disabled people of the claim to individuality and full human status. Consequently, they became the perfect vehicle for the overt sentimentality and benevolence of others - usually the priesthood, the great and the good.” (Barnes, 1997)

Into the Light

The journey of Maltese people with impairments towards inclusion into the mainstream of economic and social life is a very recent occurrence. In fact, we only began to come out of the cellars, literally in some cases, as recently as forty years ago.

In the 1890s, the first well-established charitable institutions opened their doors. They had a strong religious bias and focused almost exclusively on people with social problems with an accent on moral regeneration. Between 1945 through to the mid-1980s disabled people were regarded through the spectacles of a medical model and an empirical, positivist approach.

The post-1945 polio epidemic which affected large numbers of Maltese children and led to the setting up of the first charitable organisation based on the concept of rehabilitation, rather than just 'care'.

Thus the period between 1945 to 1973 saw:

- the establishment of the first non-government organisations (NGOs) *for* disabled people;
- the introduction of the first residential home for severely disabled people run by the Catholic Church;
- the setting up of the first special (segregated) schools for disabled people;
- the enactment of the one and only piece of legislation directly related to disabled people, that is the 1969 Employment (Handicapped Persons) Act which was based, almost completely on similar British legislation enacted in the 1940s ;
- the establishment of the first, very limited, social benefits for disabled people.

The 1970s & 80s: some landmark episodes

The study of disability-related topics remained focused on medicalised concepts of functional deficit, personal tragedy, cure and care. In 1977, an isolated attempt was made to re-direct the debate on the 'complexity of the relationship between the disabled individual and their social environment' (Barnes, 2003).

The initiative was part of a wider strategy by the University of Malta to establish the teaching of sociology, initially within the Department of Economics, which was renamed 'Department of Economics and Social Studies' in the early 1970s. The Department of Social Studies was set up in the mid-70s with the help of the Open University. Mr. David Boswell was seconded to the University of Malta by the Open University as Visiting Professor in Social Policy for three years. During this period, courses in sociology were introduced in the Faculties of Theology and of Law. (UOM website).

In 1977 David Boswell recruited Minda Millar (later my wife) and I to assist him with the setting up of an informal course which was loosely based on the Open University 1954 course 'The Handicapped Person in the Community', a course-book of the same name having been co-edited by himself and Janet Wingrove in 1974. Meetings were open to local NGOs and professionals working in the field of disability. The aims of the sessions were:

‘to help ... to improve ... professional and social skills in order to assist handicapped people to achieve maximum autonomy.’

and

‘... to examine your professional role and ideology and ... encourage ... an interprofessional approach to problems.’ (Finkelstein, 1998)

There was also an emphasis on the notion, considered radical at the time, of disabled people living in the community.

I believe I was invited to participate in the course for three main reasons. First of all, at that time I was arguably the only visibly disabled person on campus. Secondly, I was required to translate into English presentations which were in the main given in Maltese. Thirdly, I was asked to give an ‘insider perspective’ of the material under discussion and to report on its relevance to the daily life of disabled Maltese. To the best of my knowledge this was the first time that anyone, including the University of Malta, had conceived the notion of giving a Maltese, disabled individual a direct and decisive say in disability issues.

Unfortunately, the late 1970s and entire 1980s were politically fraught times in Malta. In late 1977 the Faculty of Arts was closed down and the embryonic Department of Social Studies was suppressed. David Boswell’s contract, like that of many others, was not renewed.

Another decade would pass before the advent of the first NGOs, owned and run by parents of disabled people, came into being and a national discourse on disability issues would begin to assert itself. Initially, parents’ concerns were specifically impairment- and services-driven. However, over time the debate within this tiny nucleus would eventually fasten on the recommendations made in the ‘World Programme of Action Concerning Disabled People’ (1982) and eventually, in 1987, with high-level political backing the *National Commission for the Handicapped*, (its name was changed to *National Commission Persons with Disability* in 1994), was set up and chaired by Dr. Lawrence Gonzi, then Speaker of Malta’s House of Representatives and, although non-disabled himself, he was closely related, by marriage, to a disabled person.

Among its aims, KNPD (as it is known in Malta) sought to create:

- a national focal point on disability;

- a think-tank advising government on disability issues, with access to decision-makers at the highest level;
- a direct link with local, disability NGOs and especially,
- an important forum which, for the first time, placed the voices of disabled people at the forefront of the debate on disability.

In 1989 KNPD organised a landmark national seminar entitled ‘Towards the Future: principles and policies for handicapped persons and their families’. The conference marked a first conscious effort at placing a relatively large number of disabled people in the forefront, both in terms of organisation as well as in the setting of its agenda. On a personal level, it also marked my official return to disability activism.

Basing its work primarily on disabled people’s needs, as identified by themselves, KNPD began to chart a slow, gradual course away from the predominant Medical Model approach, to the Social Model viewpoint, that is, it set itself out

“... to provide a clear and understandable focus on that which can and should be changed: specifically, a value system which is rooted in a particular type of society, which is clustered around a particular view of the human condition, and which, in one way or another, oppresses all of us who are unwilling or unable to conform to its requirements.” (Barnes, 1997)

In 1994, as a tangible commitment to its ‘nothing about us without us’ principle, I was invited to become KNPD’s first, full-time, disabled Chair. In 2000 the Equal Opportunities (Persons with Disability) Act was enacted, finally and firmly establishing disability as a rights-, not a charity-, based issue. It may be pertinent to remark that this legislation also made it obligatory for KNPD to ensure that at least half of its membership consists of persons with disability, or family members of disabled people unable to represent themselves. This is also reflected in the organisational structure of KNPD’s secretariat where a strict 51% balance in favour of disabled employees is maintained and an understanding that disabled employees come to the fore in all public matters.

An interest in Disability Studies began to emerge almost as soon as KNPD was set up. Originally, the thrust was two-fold. First, to put forward the social model of **disability** as a viable alternative to the predominant medical model. Secondly, to give an opportunity for disabled people’s voices to be heard directly.

In 1993, Fred Bezzina (KNPD’s Executive Director and the parent of a disabled person) successfully negotiated to have a 14-hour credit course offered as a core-credit to students at the University of Malta’s Institute of Health Care: nurses and midwives, podologists, occupational-, physio- and speech-therapists. Fred also drew up a first-draft outline of the topics to be covered. Almost at the outset, I was offered the opportunity to develop the course more fully and to coordinate the lectures, a

move aimed at sending out the clear message that disabled persons should themselves be in control of all aspects of disability issues.

In the 1990s, major influences in the structure of the course included the work of UPIAS (1976), Irving Zola (1979), Gerben de Jong (1979), Finkelstein and Oliver (1990), and Morris (1991). In 1999 we sought to increase interest in Disability Studies by inviting Mike and Joy Oliver, together with Len Barton, to organise what was to be a seminal workshop on disability politics entitled: 'Back To Our Roots'. More recent influences on our work have included the writings and guest lectures by some of you gathered here today. It will be obvious then that to a certain extent our main influences have tended to be drawn from the British model, rather than the European continent, or the United States. Perhaps this too is a form of colonisation?

Today, Disability Issues lectures have been given a modular structure to address the needs of different faculties within the University of Malta. They were designed with a threefold aim in mind:

- **the theoretical aspect:** to give participants a theoretical introduction to key issues related to disablement, together with a selected reading list of relevant literature;
- **the experiential aspect:** to provide participants with opportunities to meet disabled individuals with different impairments on an equal basis and to listen to their experiences;
- **the attitudinal aspect:** to enable participants, as a result of their reading and discussions, to critically engage with some of the root causes of disablement and to develop a personal understanding and a positive image of disabled persons as equal and valuable members of society.

In line with the principles of disability equality training and in order to ensure that the authentic voices of disabled persons are heard, the majority of speakers in these lectures are either disabled persons themselves, or close relatives of disabled persons. Preference is given to speakers who have a proven track-record of activism in the Maltese disability sector. Non-disabled speakers are usually 'partnered' with disabled speakers, in order to ensure that issues were discussed from an 'insider' perspective 'grounded on the direct experience of individual disabled persons (Oliver, 1994).

From the outset, disabled speakers' narratives emphasised the importance of personal lived experience which took into account both the social aspects of disablement, as well as the biological limitations of impairment. They made clear in their presentations that impairment was not seen 'as irrelevant or neutral' (Shakespeare & Watson, 1996). However, over time, as coordinators of these lectures, we began to realise that some speakers were becoming too focused on:

“... either sentimental autobiography, or else preoccupied with the medical and practical details of a particular affliction.” (Hunt, 1966)

We have since attempted to address these concerns in two ways. In 1998 we began a series of encounters entitled ‘Speak Out!’ which through a combination of set talks and informal discussion, aimed at encouraging disabled speakers to engage critically with their personal experiences in the light of Social Model thinking. Secondly, we have ‘partnered’ some of our speakers with someone else who is not necessarily disabled, but, who, in our opinion, had a clearer understanding of the inter-relationship of social oppression with the main causes of disablement. The task of this person is to look at the wider context of disabling barriers, without detracting from emotional impact and value of the main speaker’s individual experiences.

The ‘Speak Out’ sessions, referred to above, developed directly from a programme set up by the Commission in 1996. Known by its Maltese acronym PEKTUR, the Continuous Education, Training and Research Programme was established to provide limited financial assistance aimed specifically at addressing the pressing need to:

- develop a cadre of activists from among the ranks of disabled people and parents of disabled people unable to represent themselves;
- encourage applied, scientific research in areas considered a priority by KNPDP;
- have an adequate number of professionals working in different fields related to disability;
- provide opportunities for enrichment and further education to potential disability activists who had been let down by existing educational structures.
- undertake research in the disability field.

‘Speak Out’ sessions were also attended by relatives of people with mental health difficulties. Repeated attempts at getting the latter to deliver talks themselves have, unfortunately foundered. This situation has tended to play into the hands of those professionals who want to remain the primary spokespersons in this field.

On the other hand, attempts at including people with learning difficulties have been much more successful, with disabled people themselves speaking out and parents focusing on their parenting role, rather than attempting to voice the aspirations of people with learning difficulties. This followed the organisation of disability equality training sessions for people with learning difficulties. The sessions have similarity with the Learning Difficulty Awareness Training offered by People First (2006).

In 2003, mindful of the continued absence of a strong grassroots movement in Malta (Camilleri & Callus, 2001), KNPDP organised a residential weekend exclusively for disability activists and a limited number of parents of disabled people unable to represent themselves. A direct outcome of this activity was the setting up of the Maltese Council Of Disabled People (MCOOP) in May 2003. MCOOP determined

from the beginning to be an organisation owned and run exclusively by disabled people.

One of its first initiatives was the setting up, in 2004, of a Maltese Disability Studies Group (MDSG). In order to ensure maximum ownership and control by disabled people the Group was conceived as a special interest sub-committee set up within the Maltese Council of Disabled People. MDSG's principal aim was to explore and develop the field of disability studies in Malta by encouraging teaching, research and scholarship in the field (MCOOP, 2005). However, a number of constraints have militated against the continuation of MDSG, which at present is non-functioning.

Due to its tiny size and population, Malta tends to suffer, perhaps more than other countries, from a serious brain-drain. A dearth of committed activists with the necessary skills to take our discourse and struggle forward also bedevils our attempts at achieving our ultimate goal of establishing a secure research and lecturing base for Disability Studies firmly within the structure of the University of Malta.

Present & Future Concerns

Many of our present and future concerns in Malta reflect the preoccupations put forward by the excellent 'Activists and Academics: part of the same, or a world apart' by Penny Germon (1998) and Oliver & Barton in their paper 'The Emerging Field Of Disability Studies: A View From Britain' (2000). Therefore, rather than risk treading (very inadequately) on a trail already blazed by them and others, I will focus my forthcoming observations purely on the Maltese scene.

- ***Towers: of ivory and of Babel***

The sadly predictable tale of inadequate benefits, ineffectual educational systems, low rates of employment, limited choices in mobility and housing and low self-esteem, mean that like their peers in other countries, disabled people in Malta face a daily struggle to survive, leaving them with little time to organise, reflect and study. In this scenario we ask ourselves: 'How relevant are Disability Studies to the lives of most disabled people?' Similarly, we talk incessantly about the need for 'access for all', but how 'completely incomprehensible' (Light, 2000) or otherwise are we being ourselves in terms of language usage, teaching methods and use of media? Are we increasingly speaking to each other, while being viewed as an irrelevance by the majority of disabled people? Thus, in seeking to establish a presence at the University of Malta, as we are doing, are we simply creating yet another ivory tower?

- ***Researcher Fatigue Syndrome***

Many disabled people in Malta are experiencing researchee-fatigue syndrome, a disaffection and disillusionment brought about by excessive requests for interviews, coupled with the knowledge that they are gaining nothing from these repeated processes, while successive interviewers acquire academic and career kudos in the shape of marketable qualifications, publications, and professional experience.

We would very much like to be in a position to introduce, develop and critically engage with the issue of 'emancipatory' research (Barnes & Mercer, 1997). We are also concerned that the research agenda (notwithstanding, initiatives such as PEKTUR and MDSG) is still firmly controlled by non-disabled academics, the majority of whom are firmly cast within a medical model mould.

Building working relationships with academics has sometimes led us into questions of equality and control and the sometimes exclusive value placed on paper credentials, over experience and activism. With our relatively minor footprint in terms of undergraduate credit courses and our equally relative off-campus presence we have, so far, been able to draw directly upon the experiences (and less frequently the writings) of disabled people in both curriculum development and teaching. But how can this presence be secured within an expanded academic context?

- ***A parasitic, or symbiotic relationship?***

Can the relationship between disabled people and academics be symbiotic, or is it always fated to be parasitic? (Hunt, 1981; Oliver & Barton, 2000). Notwithstanding my continued fear that most disabled people can easily be cast into the shadows by non-disabled colleagues, I know from experience that, given the right circumstances, the two can work well together.

Fred Bezzina and I who have worked together for the past seventeen years in a partnership of equals, a partnership securely based on our track record in the field and a clear understanding that the voice of disabled people is paramount. This often means a reversal of traditional roles with the non-disabled partner becoming virtually invisible. Throughout we have consistently tried to emphasise teamwork and not allow disability issues to become attached to individual personalities. Above all, our litmus test has always been the measure of one another's sincerity and one's overriding commitment to the cause, over and above career and personal concerns.

I most certainly do not advocate a total ban of non-disabled academics from the field of Disability Studies. On the other hand, I do have to express my deep concern at what I see in Malta as a growing number of people with academic qualifications in the field who very convincingly 'talk the talk, but don't (pardon the disablist language) walk the walk'. Some of these people are non-disabled, but --- and this to me is truly distressing --- others have impairments, but their identification with the plight of the majority of disabled people is notional at best.

- ***A homeland for Disability Studies?***

Underlying many of the 'issues of power, hegemony, and the interconnectedness of research, policy and practice' is 'the need for a sense of place within the discipline, as well as within society.' (Peters & Chimedza, 1995)

A recurring question for us in Malta has been where to position Disability Studies within the University of Malta, should the opportunity arise for us to establish it there. For the past thirteen years KNPD has kept a close guard over and control of Disability Studies in Malta. As indicated earlier, this stand has stemmed from our fear that disabled people can lose control over what is taught and how it is taught. However, we are also very much aware that it would be preferable for Disability Studies in Malta to become embedded into the mainstream, in our case to be absorbed within the structures of our only university.

At the moment we are debating two possibilities. The first is to find a home for Disability Studies within an established department or faculty. The second is to consider setting up a small, independent centre, or institute. Our concerns with the latter option is whether we could find the necessary financial resources to start-up and maintain such an initiative and equally to the point, whether we can identify, foster and sustain the necessary human resources --- specifically, disabled academics --- to make such an initiative effective in the long-term.

Conclusion

Ordinary disabled people in my country have been badly let down by the educational system. Too few disabled Maltese end school with creditable certification, still less make it to post-secondary and tertiary education. The chances of identifying disabled youngsters willing, and more to the point, with the potential to develop disability studies as a discipline, are, for the present, bleak.

On the other hand, the increasing proliferation of Disability Studies in overseas universities and, in particular, the increasing number of degrees offered at a distance has made it easier for qualified non-disabled Maltese to make disability studies a field of specialisation, with what I see as the inevitable danger that eventually they will come to dominate the field and leave little room for disabled academics.

In 1964 Malta achieved independence from Britain and in 1974 it declared itself a republic. Thus, I've been fortunate to have lived to see the end of centuries of colonisation of my native land. However, if there's one lesson we Maltese have learnt along the way it's that internalised colonisation (or oppression, if you prefer), is the far more difficult to be rid of. Disabled people in Malta are at a disadvantage both in terms of academic qualifications, as well as in terms of self-confidence. I don't want

to live to see the colonisation of Disability Studies by non-disabled academics. I don't want to see disabled people relegated once more to the role of mere research objects.

Note

Thank you to all the members of staff at KNPD (disabled and non-disabled), to my disabled friends for the inspiration they provide and especially to Fred Bezzina and Anne-Marie Callus --- our on-going debates have helped immensely to develop my own thoughts on disability issues in general. Finally, I can never redeem the debt of gratitude I owe to Minda, my wife of 25 years, without whose unceasing support and encouragement my disability activism, besides other, most treasured aspects of my life, would simply not exist.

Any shortcomings, omissions, or inaccuracies are entirely of my own making.

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