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OUT OF THE CELLARS
Disability, Politics and the Struggle for Change: The Maltese Experience


Introduction: Providing a context

Although Malta has a European culture and identity, its size, history and geographical location help make it very different from other European countries in a number of ways. These three factors inevitably impinge on the way Maltese society has evolved, including the growth and development of the disability movement. This chapter looks at the significant changes that took place in the Maltese disability sector from the late 1940s to the present day. It looks at the main agents that brought change and argues that the most significant change originated from above, that it was instigated by a small nucleus of people who struggled to bring about change by obtaining the blessing of the government of the day (or individuals who were part of that government) rather than through the establishment of a grassroots movement made up of disabled people who pushed for that change. We argue in this chapter that this happened time and again over the past six decades and that it is still happening today, although perhaps the voice of disabled people is now growing louder. Finally, the chapter conjectures about what might be the future of the disability movement in Malta given its history and present trends.

Before starting, we felt it would be useful for our readers to have an idea, however sketchy, of the Maltese geographical, historical and political context referred to above. The Maltese archipelago is made up of five small islands, two of which, Malta and Gozo, are inhabited. Malta covers an area of 316km² and Gozo 162km². Malta's geographical location, approximately 97 kilometres to the south west of the island of Sicily and 360 kilometres to the northeastern coast of Libya, place it almost at the very centre of the Mediterranean Sea, making it a strategic bridge between northern Africa and southern Europe and a prime target for colonisers throughout history. At some time or another Malta has been a colony of the Phoenicians, the Romans, the Arabs, the Normans, the Knights of St. John, the French and the British. And although not itself a coloniser in the strict sense, the Roman Catholic Church has exerted a profound influence on every aspect of Maltese life.

In 1998, the total population of the Maltese Islands was 378,518, of which 349,338 lived in Malta and 29,180 in Gozo (Central Office of Statistics, 1998, pp .8-9). Of these, according to the National Disability Survey 1999 (NCPD, 1999, p. 2) 1.6% are registered as having a disability. Since the Second World War, politics have been dominated by two parties, the right-of-centre Nationalist party and the leftist Malta Labour Party. General elections, held once every
five years, are closely run affairs. There is a very high turnout (around 97%) and the party that wins usually does so with a few percentage points, which in reality represent just a few thousand voters. This means that the two parties are very careful about safeguarding voter loyalty, which sometimes leads to the deferral of necessary but unpopular decisions. It also means that politics creates a lot of polarisation and social division which in turn fosters the perception that protesting against the government of the time immediately brands you as a supporter of the party in opposition.

Many of the changes in services for disabled people and in disability awareness and activism were influenced by various factors, such as Malta's colonial ties with Britain, the influence of the family and the Catholic Church on all aspects of everyday life, post-colonial development, the gradual establishment of services by both state and church authorities and, recently, the proliferation of non-government organisations of various shapes and sizes.

One final introductory note concerns the methods used to collect the information for this chapter. We sent out a questionnaire to all non-governmental and voluntary organisations with the aim of collecting data about the way they were set up, the reasons behind their setting-up, their views about disability and the way they look at the future. We also interviewed people who played a key role in the changes that were wrought over the past fifty years. A list of their names appears at the end of the chapter. Information about dates when various services or organisations were set up was mainly taken from a list compiled by Mr. Fred Bezzina, Executive Director of the National Commission Persons with Disability (NCPD) and himself the parent of a disabled person and a disability activist.

Out of the cellars (1945 - 1969)

Unlike larger, more affluent European countries, interest in the lives of disabled persons, or their families, in Malta does not date back to more than fifty years, or so (Campbell & Oliver, 1996, p. 15). Major charitable institutions which appeared during the period between 1890-1920 were set up exclusively by the Catholic Church and tended to focus their attention on social problems of a 'moral' nature. Such initiatives were usually inspired by the wish to save the souls of those perceived in danger of moral degredation such as orphaned children and 'wayward' girls are cases in point.

On a small island where people knew, or could easily get to know intimate details about one another, it was vital that families maintained a façade of normality and that any perceived form of 'deviance' was kept well hidden away. In this way it was perfectly acceptable on the part of Maltese families (at every social level) to ensure that disabled members disappeared completely from view. Besides casting a veil of shame on their families, their presence could ruin the chances of any non-disabled siblings of marriageable age. This attitude was set in the permafrost of tradition and a slow thaw would not begin to set in until after the Second World War, when more efficient communications systems began to open up the islands to external influences.
Until the mid-1960s, disabled persons themselves were not accorded intrinsic value, but, within the prevailing religious environment, they were seen as burdens one had to bear; they were the instruments by which non-disabled persons were tested and spiritually purified. People who were visibly different in body or behaviour were considered impure on a moral level by the general population and on a cultic level by the church (Bishop, 1995, p. 8). Religious imagery and scriptural texts also ensured in a multiplicity of ways that disability in the family was seen as an indelible stigma which affected all members of the family and not just the 'afflicted' individual (Camilleri, 1999, p. 848).

During the late '40s-'50s a gradual shift began to take place, away from traditional attitudes which equated disability with sin and punishment, towards a more empirical, positivist approach based upon what is now called the medical model of disability. It was during this time that the first non-government organisations for disabled persons began to be established and the education sector began to lay the foundations of what was to become the special education sector. Since Malta was a British colony between 1800 and 1964, it is hardly surprising that these and subsequent innovations were very closely based on equivalent British models.

For instance, 1947 saw the establishment of the Polio Fund (which later changed its name to the Physically Handicapped Rehabilitation Fund (PHRF)). This was set up by a small group of Maltese people and British expatriates and was originally aimed at alleviating the effects of the serious polio epidemic which hit the islands after the 1939-45 war. Over the years, the PHRF developed into a traditional charity, focusing on fundraising, projecting physical impairment as a personal tragedy and with the stated aim of normalising its members in order to re-integrate them into society. None of the original committee members were themselves disabled persons, nor were the latter ever part of the organisation’s decision-making process. For a brief period of time, one of the present writers did serve on this committee, but soon resigned in disgust when it became clear that the opinions and voices of disabled persons carried no weight whatsoever. Significantly, and in spite of repeated calls for change, the PHRF still continues to identify itself with the terms 'handicapped' and 'rehabilitation'.

1947 also saw the setting up of a Commission for the Sick and the Handicapped (CSH) which was one of the first initiatives of Monsignor Michael Azzopardi, who pioneered a number of services for Maltese disabled people. The CSH was to bring disabled people into public focus in two ways: firstly, through its weekly radio programme and secondly through the establishment of the first residential complex for severely disabled persons in 1965. The CSH eventually changed its name to The National Commission for the Sick and the Handicapped and finally The National Commission for Sick and Persons with Disability. However, despite the use of more modern terminology, the correlation between sickness and disability has persisted. In their questionnaire, the CSH stated their aim to be “to provide spiritual and material solace for sick and disabled persons and their families”. Its weekly radio programme, originally entitled “A Call to the Sick and the Handicapped”, offers an unvarying mix of light entertainment and spiritual comfort in the face of personal tragedy. After five decades, and following pressure from the National Commission Persons with Disability (NCPD), the name of the programme
was changed to "A Call to the Sick and to Persons with Disability" and introduced a news slot which features items related to the social model of disability and which is compiled by NCPD's Executive Director.

Until 1965, with the establishment of *Id-Dar tal-Providenza (Providence House)* by Mgr. Azzopardi, there was no residential service of any description for Maltese disabled persons. They lived with their families, sometime hidden away in appalling conditions. There were instances of people having lived twenty years and more chained up in windowless cellars, or hidden in byres and stables in the countryside, by families fearful of the shame and stigma associated with disability (Cuschieri, 1995, p. ix). According to its answers to the questionnaire, *Id-Dar tal-Providenza* was founded with three services in mind: long-term housing for disabled people whose families could no longer take care of them; a temporary respite service; and occasional activities for disabled people and their families. Today, it is mainly a long-term residential institution for people with intellectual disabilities. Ironically, the set-up occurred at a time when similar services were coming under attack in Scandinavian countries through the work of N. Bank-Mikkelsen and Bengt Nirje, by Wolf Wolfensberger in the United States and by other advocates of the normalisation principle. What is even more ironic is that, at the time, Mgr. Azzopardi’s work was innovative in Malta and created a revolution in people’s attitudes towards those who had a disability, especially those who had intellectual disabilities. According to John Micallef, the present administrator of *Dar tal-Providenza*, "Mgr. Azzopardi’s aim was integration from the very beginning". He first sought to acquire a building in two different desirable residential areas, but without success. In 1965, he was given a building which is completely cut off from the surrounding villages. Although the 1968 statute of *Dar tal-Providenza* states that integration is one of the main aims of the service, the physical isolation of the residential complex, and its present size, militate against this aim. A recent change has seen some residents grouped into ‘flatlets’, rather than large dormitories and the setting-up of a house for five residents in the heart of a neighbouring village. However, with the exception of these five, residents still live in what is effectively an institution in a remote location. Moreover, *Dar tal-Providenza* depends for its day to day running on the charity of benefactors and handouts from the general public. This need to raise funds constantly leads to the portrayal of residents as pathetic objects of charity. The main fundraising event is a high-profile annual volleyball marathon which is successful in raising scores of thousands of Maltese liri and in breaking world volleyball marathon records, but does little to raise the profile of people with disabilities who do not play any active role in the activities organised, nor are they part of the decision-making process of the organising committee.

Conscious of the deep-rooted and widespread demonisation of disabled people in the Maltese culture, Mgr. Azzopardi had also sought to bring about a positive change in this respect by inverting the language normally used when referring to anyone with an impairment. In his vocabulary they became 'angels'. However, by referring to disabled people as 'angels' he gave rise to new stereotypes of untouchability, which, over the years, have themselves become powerful instruments of oppression.
From today's viewpoint, this could hardly be considered progress, but in the context of the time, the developments mentioned above were regarded as revolutionary and indeed they represented a terrific improvement on an immediate past overshadowed by rampant superstition, blind prejudice and violent suppression. Therefore, the medical model was enthusiastically espoused as a more humane, 'modern' and pragmatic approach to the problem of disability and 'reforms' based upon these new assumptions were espoused with sincere intentions and generally looked upon favourably where funding was concerned.

**Education and employment: rights denied**

By the mid-1950s government was beginning to concern itself with the issue of educating disabled children. The need for specialised provision was felt after the introduction of compulsory primary schooling in 1954. Students with a hearing impairment were the first to be identified as needing special provision. According to Mr. George Samuel, former Education Officer for Special Educational Needs, they were a challenge to schools, since teachers found it difficult to communicate with them. In fact, provision for students with disabilities started in 1956, when two special classes for hearing impaired children were set up within the local primary school in Paola, a town in the southern part of Malta. In 1957 the two special classes increased to five and were transferred to another school in Gzira, which is more centrally situated. This meant that these students could be integrated for most of the school-day and then be withdrawn from their classes for daily sessions with a peripatetic teacher (Bezzina & Camilleri, 1996, pp. 35-36). Unfortunately, this model became a victim of its own success and by the next year enough students with a hearing impairment had been identified to warrant the setting up of a special, that is segregated, school, the *Deaf Unit*. The perceived success of this model led to the opening of more segregated schools, especially since children with mild learning difficulties began to be considered as being able to benefit from schooling. The first school, the *ESN Unit* which is today called *Santa Maria Day School*, for children with mild to moderate intellectual disabilities opened in 1963 and the next year another one, the *Guardian Angel School* was set up for children with severe intellectual disabilities. This was followed two years later with a special school for boys with emotional difficulties, *Mater Dei*. It is not surprising that, in a Catholic country, schools that were perceived to have a social role to play were given religious names.

Soon after its establishment in the Fifties, the special education sector rapidly became the Cinderella of the education division, attracting less and less resources: human, financial and technological. In many instances, teaching curricula existed only on a notional plane, with the same simple lessons being repeated *ad nauseum* for years on end, with no "real preparation to enable students ... to develop the ability to live and work as part of the community." (Galea-Curmi et al, 1996, p. 232). Children with impairment (particularly an intellectual impairment) were not expected to function properly in the adult world and it was thus considered legitimate to provide them with the lowest common denominators of functionality and leave it at that (Galea-Curmi et al, 1997 p. 232).
In 1970, secondary level education was made compulsory for all. This development was complemented by an expansion in special education provision with a school being set up in Gozo, as an annex to a local primary school, to cater for students with a severe disability, and an increase in the population of the special schools in Malta. A second school catering for students with mild intellectual disabilities in Malta, Dun Manwel Attard, was inaugurated in 1982.

Throughout the fifties and sixties it was considered inconceivable to educate disabled children in the mainstream, and equally inconceivable was the prospect of disabled children continuing with their studies at secondary, or tertiary, level. In 1973, one of the present authors has vivid memories of being the only disabled person out of a total student body of 1,500 at the University of Malta. Naturally, single individuals did occasionally slip through this system of oppression, but they were usually schooled to deny their impairments and strongly pressured into functioning in the same way as their non-disabled peers. This subtle form of brainwashing made these 'supercrips' avoid contact with their disabled peers, avoid any mention of the existence of disability as an individual or national reality. (Camilleri, 1999, p. 846).

Something of a sea change occurred in the education sector in the early nineties with a move away from segregated 'special' education provision and the government of the day espousing a policy of mainstream schooling for all students. Ironically, this change occurred in tandem with the opening of three new special schools. In 1989, a school (San Miguel Febres Cordero) for students with severe physical and intellectual disabilities was opened. This was followed in 1992 with a new school that integrated services for students with visual and auditory impairments. It was named Helen Keller School, making it the only special school whose name does not have any religious connection.

In 1993, NCPD published a report about special education in Malta that recommended the adoption of an inclusive education policy. Up till then, only some students with physical or with sensory impairments had been accepted in mainstream schools. The new policy advocated that even students with intellectual disabilities be included in mainstream education and that they are supported by facilitators. According to Paul Bartolo (2000), the term ‘facilitator’ was imported from Canada “because there more emphasis is put on teacher-facilitator collaboration” (p.81). “Inclusion and Special Education”, a report presented at the National Minimum Curriculum conference this year, states that today there are over 600 students who attend school under this system (Inclusion and Special Education, 2000, p. 2).

Although the term ‘inclusive education’ is now used widely in Malta, it should be pointed out that a revision of the curriculum for mainstream schools is still being carried out and that it is only expected to be implemented within a few years’ time. This means that, while efforts are made to help students with disabilities become part of their local mainstream schools, the latter operate within a highly selective system. In state schools, students are streamed for the last two years of primary schooling, in preparation for an eleven-plus examination that selects students for grammar or area secondary schools. Needless to say, inclusion and selection are contradictory. This paradox is now being addressed in the new national minimum curriculum (NMC, 2000).
Along with NCPD, a major factor in the introduction of an inclusive education policy was The Eden Foundation. Set up in 1993, Eden has since introduced a wide spectrum of innovative services to Malta and has also helped to raise the profile of persons with intellectual disabilities. Part of its operation is the provision of services for children that focus on early intervention and on psychological assessment and therapeutic services (according to its responses to the questionnaire). The other work is carried out with adults with mild to moderate intellectual disabilities for whom it provides job-related training. However, although this is a relatively recent organisation it has developed all the characteristics of a traditional charity: a medical model approach. Amongst other things, this is clearly reflected in very limited involvement by disabled persons and parents in the decision-making process and a perpetuation of negative stereotypes in its fundraising campaigns.

Since educational provision for severely disabled individuals has been driven by very low expectations, it is hardly surprising that schooling has focused at best on 'giving them the basic three Rs' (reading, writing, and a little arithmetic) and at worst providing a respite-cum-custodial service. Until quite recently, disabled people were not specifically prepared either for employment, or for adult life.

Vocational and careers counselling were, of course, non-existent (Galea-Curmi et al, 1997, p.230). Disabled people's subsequent inability to achieve a high quality of life in the 'big' world was put down to the nature of their impairments, not to the complete failure of the system to provide them with a basic civil right: an adequate education. Inadequate educational provision has been one of the major factors contributing to the continued oppression of Maltese disabled people, robbing them not only of their potential leaders, but repeatedly preventing them from even comprehending, let alone articulating and struggling against, patterns of oppression when and where these continue to manifest themselves (Camilleri, 1999, p. 846).

In the same way that changes in educational practices were not comprehensive and were sometimes downright contradictory, the move towards training people with intellectual disability for work was not accompanied by an across the board change in day services for adults. In fact, during 1993, two of the existing Day Care Centres for people with intellectual disability (where care and respite, not vocational training, were the priorities) moved to larger premises, while a new centre, run on the same lines as the others, opened in 1998. From their inception, these centres have been chronically under-resourced, and their development has been seriously hampered by the absence of clear policy guidelines. It is hardly surprising then that they have been largely ineffective and unable to offer quality services. Nor have the intellectually disabled persons who make up the majority of the clientele been able to maximise their individual potential in any way. There are no formal job-related training programmes in place and the only productive work offered by the Centres involves wickerwork and pottery, which are then sold.

The employment sector was, and is, another aspect where disabled Maltese citizens continued to lose out. Productive, gainful employment on the open job market was still considered way beyond the aptitudes or aspirations of all disabled persons, irrespective of their proven abilities. Thus, this market was largely closed, or offered only the most menial, low pay,
low status jobs, such as lift attendant, telephone operator, public toilets attendant, messenger, cleaner and so forth. Towards the end of the 1960s, a first effort was made to allow disabled persons access to the job market. This was made possible through the passage into law of Act No. II of 1969 Employment of Disabled Persons Act, a piece of legislation closely modelled on the British Disabled Persons (Employment) Act of 1944. The 1969 Act established:

- vocational guidance and training courses;
- a Register of Disabled Persons;
- a quota system that established that all enterprises employing 20 or more people had to recruit 2% of their workforce from the ranks of people with disability;
- the designation of classes of employment for disabled persons;
- a Disablement Resettlement Advisory Committee;
- the post of Disablement Resettlement Officer.

From the outset, this Act was doomed to fail. Firstly, the 2% requirement is notoriously difficult to enforce and secondly, no provision was made for the creation of a legal mechanism which would ensure that 2% of employees were in fact disabled persons. In the words of Fred Bezzina, "... the 1969 Employment Act succeeded on an individual level, as a number of people did find a worthwhile job on the strength of the Act; however, it has to be admitted that the Act has failed on a national level." This seems to tally with the experience of other countries where such a quota was introduced. The Centre for Educational Research and Innovation (1986), focusing on the experiences of young adults, reports that “[t]here appears to be little evidence in many countries that a quota system helps the young disabled school leaver” (p. 23). For example, in the UK the quota system was put into place in 1946 but in 1990, Morell reported that only a quarter of employers met the 3% target (cited in Riddell, Ward and Thomson, 1993, p. 69).

The employment sector was given a boost in 1995 when NCPD published a document setting out policy for the employment of persons with disability. As a result of this document, the 1969 Employment Act was amended and the Employment and Training Corporation (ETC) was given responsibility for this work. Nowadays, ETC has a specialist Support Unit that acts as an employment agency for disabled people and also offers life skills courses for persons with a mild to moderate intellectual disability. In 1999, according to the National Disability Survey, 10.6% of people registered as disabled were employed. Of these 1.9% were working in a sheltered workshop (Bezzina, 1999, p. 26).

Notwithstanding all these endeavours, since the 1960s disabled persons employed in high status high pay jobs can, almost literally, be counted on the fingers of one hand. Since education and gainful employment are generally the cornerstones of an independent adult life, it is clear from the preceding discussion that even today, after forty-five years of 'special' educational provision and at least thirty years of statutory employment rights, the majority of Maltese
disabled persons remain virtually totally dependent financially and unable to adequately express their own wishes and needs.

**A rise in service provision and parent power (1971 - 1987)**

Historically, blind persons in Malta have always been more vocal in their demands, and, until the advent of *Id-Dar tal-Providenza*, they were at the forefront of fundraising activities. They also advocated the introduction of a non-contributory pension. However, following the pattern of many single-impairment organisations, their lobbying was specific to their own needs and did not benefit the generality of disabled persons. In fact, by 1964 the *Department of Social Services* had already agreed to provide unemployed, blind adults with a non-contributory pension. Physically and intellectually impaired persons would have to wait until 1974 before the *Pension for the Blind* was re-christened the *Handicapped Pension* and was extended to include them (Bezzina, 1996). In 1987 an allowance for families who had a disabled child was also introduced. During the seventies and eighties other measures were introduced which were aimed at the improvement of disabled persons' quality of life, including tax exemptions on specially adapted cars and subsidies for disabled people to upgrade their homes.

In spite of all these measures, however, the notion that disabled adults wanted to and indeed could lead independent lives was never seriously entertained by the authorities. Family ties in Malta are very strong and the general attitude is that, if all else fails, there is always the family to fall back on. Moreover, the practice of leaving the family home before getting married, even by non-disabled persons, was very rare up to a few years ago, and even today is still relatively uncommon. For adults with a disability who remain single it is considered normal and respectable to go on living with their parents throughout their lives. Not to do so would cast a slur on the family honour, implying that it does not look after its own. Family support is therefore a double-edged sword: at its best it can ensure a high degree of support and encouragement for a disabled person, at its worst it is a life sentence of oppression. Camilleri, one of the present authors, maintains that even when families are very supportive they can manifest a strong reluctance to “let go,” once the disabled individual has decided to live independently. While the family is an integral and often positive part of Maltese culture, in the case of disabled persons, strong family ties have perpetuated the myth of disabled people as eternal children, unable and unwilling to function as adults. This pervasive stereotype has had a disastrous effect on the manner in which financial support is perceived and the degree of financial assistance required to enable disabled persons to enjoy an acceptable quality of life. To date, the state has not felt compelled to facilitate independent living, but only to provide disabled persons and their families with some financial support. The level of the existing Disability Pension can never facilitate independent living (Kinsella, 1998) and remains one of the most powerful tools of oppression, condemning Maltese disabled people to a life of dependence and denying them the opportunity for personal development and empowerment. It is very much a part of what Campbell and Oliver (1996) describe as “a massive infrastructure of complex,
confusing and dependency-creating services” which is reinforced by “the existence of passive and disempowered disabled people” (p. 44).

As has already been pointed out, measures introduced during this period were for the main part instigated by the government of the day or by the church authorities. Inevitably, the changes and services were very much introduced with a top-down approach. Before the introduction of these measures there was practically no service provision of any description for people with disabilities and consequently these changes signalled the beginning of a willingness on the part of the authorities to shoulder some of the responsibility of service provision in this sector. On the other hand, the strength of the family ties and the responsibility of family members, especially parents, means that these same parents have been an important agent for change. Thus, in Malta most of the services now available to disabled persons came about as a result of strong lobbying by different groups of parents, often focusing on single impairment needs, rather than at the insistence of disabled persons themselves. In 1976, for instance, a group of parents of children with various disabilities joined together to form the Parents' Society for Handicapped Children (a name which was changed in 1994 to the Parents' Society of Persons with Disability). Initially, the Parents' Society lobbied for severely disabled children to be admitted into special schools even if they were incontinent (at the time only children who were toilet-trained were allowed to attend school). Their first success in resolving this issue spurred them on to more open criticism of the special education system, which had until then been considered a good thing. Since it was evident that their severely disabled children could never be “cured”, or “normalised” to any significant degree, it became clear to these and other parents that quality of life issues were not the exclusive domain of medicine, where, as one parent succinctly put it: "there exists a very rich sea for 'sharks' ... prepared to do everything for the sake of financial profit." (Bezzina, 1989). It was thus that a small nucleus of parents began to shift their focus away from the medical model of disability and to look for more enduring solutions through social change.

The advent of the social model and the establishment of the National Commission Persons with Disability

Perhaps the most momentous outcome of parent power and the growing disillusionment with the medical model of disability was the establishment of the National Commission for the Handicapped (NCH) in 1987. From a political point of view the establishment of the NCH was a direct response to the United Nations' document World Programme of Action Concerning Disabled Persons (WPA), which urged governments to:

... establish a focal point (for example, a national commission, committee or similar body) to look into and follow the activities related to the World Programme of Action of various ministries, of other government agencies and of non-governmental organizations. Any mechanism set up should involve all parties concerned, including organizations of disabled
persons. The body should have access to decision-makers at the highest level. (WPA, 1988: para. 89)

However, the establishment of NCH was not in itself an indicator that there was a groundswell for change as a result of lobbying from an increasingly self-aware disability movement. On the contrary, the Commission's genesis was brought about by a small core of people putting their heads together and pushing for change themselves while the majority of disabled people remained voiceless and virtually invisible. The fact that NCPD was set up by government meant that change could proceed without political opposition. But there was also the realisation by politicians that disabled people and their families formed a significant constituency. One respondent to the questionnaires wrote that “holier than thou attitudes by MPs” was a major factor in bringing about change. This change, however, occurred mostly in the decision-making processes of Ministerial and Departmental offices. The continued absence of a strong grassroots movement has made it all that more difficult to change mentalities and attitudes at a more popular level.

Running contrary to current practice, the NCH immediately set itself the task of including a meaningful percentage of disabled people and listening to the voices of disabled persons and parents of disabled youngsters and acting upon their advice. This meant that often the Commission was seriously at odds with established charity-based organisations and the advice of well-known ‘experts’ in the field. Furthermore, by investing in recent disability literature the NCH became aware of the struggles of disabled persons in other countries and examples of civil rights activism in the United States, Canada and the United Kingdom influenced it to adopt a social model (Oliver, 1990), civil rights approach to disability issues quite early on. One of the earliest initiatives was the setting up of the Child Development Advisory Unit (CDAU) whose task it was to identify impairment, offer immediate support, give parents timely information in plain language and recommend future strategies for development (Bezzina, 1989). CDAU was emphatically not meant to focus exclusively on the medical aspect. Perhaps it was to be expected that professionals entrenched in the medical model approach would not give up their power base so easily, and indeed today the CDAU offers not only a purely medicalised service, but against advice, its name has been changed to Child Development Assessment Unit, thus completely undermining its original raison d'être and ensuring that Maltese parents still remain without effective guidance when they most need it. However, other than this foray into the medical sector, NCH’s other major campaigns focused on the struggle for equal opportunities in the social field: accessible public transport, inclusive education, ending discriminatory employment practices and the development of community-based services focusing on the specific needs of the individual. Between 1993 and 1995, following consultation with a wide spectrum of individuals and groups, it published its National Policy documents on education and employment.

In keeping with social model definitions, in 1993 NCH changed its name to National Commission Persons with Disability (NCPD). The American usage 'persons with disability' was
preferred over the British 'disabled persons' for the following reason: the British phrase simply does not render itself into Maltese, whereas the American phrase translates perfectly into the Maltese 'persuni b'dizabilità'. It is in using the social model as a standard that NCPD has brought about the greatest changes. By doing so it has brought about a change in definitions, in language usage and more slowly in perceptions. We cannot delude ourselves into thinking that the changes wrought in the last thirteen years have brought about a complete and lasting transformation, but without doubt, the influence of NCPD has forced government, the two main political parties, the civil service, some traditional charities and an increasing proportion of key individuals to redefine their approach to disability and to disabled people as a group.

NCPD organises regular seminars on areas of national priority, mainly during Disability Week which centres around the International Day of Persons with Disability (3rd December). In 1993, it began offering a credit course on Disability Issues to students at the Institute of Health Care. Over the years the credit has become compulsory in courses in Health, Education, Social Work and Social Administration. Modified versions of the course are also given to students at the Faculty of Engineering, the Faculty of Management Studies, and latterly disability awareness lectures have been extended to private and parastatal companies. These lectures treat disability as essentially a civil rights issue and are thus firmly based on the social model. They are coordinated by a disabled person and include a high proportion of speakers who are either disabled or closely related to disabled persons (NCPD, 2000a). In 1996 NCPD established the PEKTUR Programme, a continuing education, research and training initiative which aims at funding research in areas considered a priority by NCPD. The principle aim of PEKTUR is to actively encourage research based on the social model of disability and in areas considered a priority by disabled persons themselves. (NCPD, 2000b).

By 1990 there was a growing realisation that awareness campaigns and social pressure alone would not bring about the radical and lasting changes required to ensure both an acceptable quality of life and the safeguarding of disabled persons' civil rights. A small number of disabled activists began to lobby for the introduction of anti-discriminatory legislation, along the lines of the 1990 Americans with Disabilities Act (ADA) and the original, pre-1995, draft of the British Disability Discrimination Act (DDA). A national seminar organised by the NCPD in 1992 set the agenda and in 1996, after a long process of consultation with disabled persons' organisations and other interested parties, the final draft was completed and presented to the Maltese parliament. Unfortunately, a general election was called on the very day the bill was to have its first reading. A subsequent change in administration resulted in the publication of a White Paper with the aim of completely reviewing the draft bill. For the second time, when the bill came up for its first reading in 1998, Parliament was dissolved and an early election called! In January 2000, the Equal Opportunities (Persons with Disability) Act finally passed into law as Act I of 2000. NCPD has been given the responsibility of ensuring that the provisions of the Act are adhered to and, to this end, it has set up an Equal Opportunities Compliance Unit, which by October 1 of this year will begin functioning as an Ombudsman for disability matters, with the power to investigate and sue, if and when necessary.
The first glimmers of identity: The road ahead

There has been considerable progress in areas of service provision, educational policy and legislation. Providing services for disabled people is “in.” This is exemplified in a report in *The Times* (Malta) (2000) reports that the local council of the town of Cospicua objected to plans by the Church to build a home for battered men and women. The mayor was quoted as saying:

We believe that there are more urgent things required in Cottonera [the town of Cospicua forms part of a largely socially depressed district known as Cottonera], such as a respite centre for the handicapped.

Moreover, *battered men and women would continue to add to the stigma that already exists in the area.*

(p. 4, our emphasis)

This mayor does not see ‘the handicapped’, as he calls them, as carrying a stigma. However, like so many other people in Malta he does not take into consideration the ability of Maltese disabled persons to fend for themselves. In fact, the latter still remain largely passive and silent in the face of oppressive disabling barriers.

One may at this stage ask: what was the role of disabled people themselves in all these changes? The short answer is ‘not extensive’. Both Eden and NCPD were founded and are still run by small core groups which have continued to use the top-down approach when it came to changing attitudes. One thing in their favour is the fact that they were endorsed by the relevant authorities and, to a large extent, had backing from above in order to bring about the changes they did in a relatively short time span. They have also presented people with a different mindset and started to foster a culture of self-determination. The questionnaires returned indicate that many NGOs working in the area of disability were set up during the past four years. The majority of them involve disabled people in the main committee. However, the main aim of these organisations is to offer support to its members and to lobby for small changes in areas that affect its members directly. Consequently, despite their existence, there was, and there still is, no widespread movement lobbying for change at a lower level; no public outcries and mass demonstrations that helped bring about a societal change of attitude in other developed countries. The emergence of the disability movement as a social movement, as described by British authors such as Campbell and Oliver (1996) and Oliver and Zarb (1997) has not yet taken place in Malta.

The reasons for this are many and complex. Part of it may be the fact that, as was pointed out in the Introduction, the bipartite political system in Malta makes for a rather polarised environment in which protest does not simply place you as being anti-government but also as being firmly in the opposition’s camp. Despite the fact that there is no curtailment of the right to freedom of speech, many others may feel constrained from exercising this right because of their political allegiances. Thus, if you are a keen supporter of the party in power you might think twice before protesting publicly and loudly because you may be seen as an agitator. If, on the other hand, you support the opposition party, your involvement in protests may brand you as
a puppet of that party. Such attitudes add to the existing fragmentation within the disability sector, and of course, this works in favour of better established groups with their own agendas.

A palpable sense of vulnerability also militates against Maltese disabled persons speaking their minds and demanding their rights assertively. Unless the disabled individual finds support from their family, or other (usually voluntary) means of assistance (MEU, 1999, p. ii), there are no alternatives to institutionalisation in its crudest form. In Malta, at the time of writing, this, means a 'choice' between a residence for the elderly, or a mental hospital. Thus, disabled persons are extremely reluctant to voice real frustration when they experience overt, or covert, injustice. The pre-eminence of paternalism, through the family networks serves to reinforce passivity and to ingrain a sense of over-riding gratitude and a "can't complain" attitude.

We began this paper by referring to Malta's geographical size, a fact which, at the outset may seem to bear no direct relevance to the present argument. However, we believe that limitations of size and population is a significant element in hampering the development of a Maltese disability movement, by making it that much more difficult to achieve a critical mass of disability activists working together for a common goal. In Malta, the loss of a single individual who carries their disability with pride and who projects disability as essentially a civil rights struggle can have a devastating effect on the development of the whole sector. Furthermore, as stated earlier, the long-term neglect of educational and employment provision has robbed disabled persons of potential thinkers and leaders, making the disability sector overly dependent on traditional charities and individuals, who repeatedly put personal agendas before the interests of the disabled people they purport to represent.

Another serious constraint which stifles activism is the sheer amount of energy many disabled Maltese expend just struggling to get through the day. Despite the growth and improvement of services in general, the absence of basic services geared specifically towards independent living: schemes for residential support, personal assistance schemes, realistic disability income, and an efficient and accessible transport system, Maltese disabled people complain that they spend all their time struggling to survive from day to day, so that they cannot afford the time to organise themselves into an effective movement. Anger, where it exists, is kept firmly under control and is seen as a negative force. On the other hand, one realises that the majority of these constraints had to be confronted and, if not overcome, at least come to terms with in every country where disabled people have sought to grasp and control their own destinies. The struggles are no different here. The truth of this came out clearly during a five-day workshop entitled 'Back to Our Roots' and held in October 1999 during which a significant number of disabled people in the audience voiced their frustration and anger at the status quo, first steps, we hope, towards more assertive action.

**Conclusion**

The disability movement in Malta may still be in its infancy. But, when one looks back to the 1940s and the dearth of disability awareness then, one realises that disabled people in Malta
have in fact come a long way in the past fifty years or so. From a struggle against blind prejudice and superstition, we have moved on to challenge the charity-based services that had evolved as a result of that initial struggle. The task for the immediate future must be to raise the stakes of that challenge by creating a critical mass of activists, a strong, independent movement of disabled persons.

Because of the hold political parties have over the Maltese electorate, lobbying politicians will continue to play an important part in the activities of this emergent movement. There cannot, however, continue to be a dependence on anti-discriminatory legislation on its own or on the blessing of politicians to safeguard the rights of disabled people and to dismantle the disabling barriers created by society.

There needs to be a movement that is made up of disabled people who are conscious of the fact that it is not enough for them to fight their corner to make their lives marginally better in material terms. They have to realise the need to raise the consciousness of the public in general, and of decision-makers, employers, educators, and service-providers in particular. Similarly, the increasingly vocal parents’ lobby also needs to realise the importance of getting together and fighting for the rights of their disabled offspring to access the same resources and services as their non-disabled peers. No lasting change can come about if it is not founded upon, and safeguarded by, a strong, independent movement of disabled persons.
References

Interviews with:
- Mr Fred Bezzina, Executive Director, National Commission Persons with Disability
- Mr George Samuel, former Education Officer, Special Educational Needs
- Mr John Micallef, Administrator, Dar il-Proviedenza


“Inclusion and Special Education” 2000. Report presented to “NMC on its way” a conference on the implementation of the National Minimum Curriculum held at the University of Malta in June 2000.


The Times (Malta) February 19, 2000 “Cospicua council objects to Church plans for battered men and women”.


**Note** - many of the Maltese references in this paper can be downloaded from the National Commission Persons with Disability's website: [http://www.knpd.org/](http://www.knpd.org/).

Questions:

1) In your opinion, what concerns should an emergent disability movement address and act upon?

2) In this chapter, the mayor of the town of Cospicua is quoted as saying that a home for disabled people is preferable to one for battered men and women since the latter “would continue to add to the stigma that already exists in the area”. Do you think that this type of attitude indicates that disabled people’s status in Maltese is secure or that they are still considered as objects of charity, albeit worthy ones?
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Joe Camilleri, attended a mainstream school and the University of Malta. He trained as a teacher at the then Malta College of Arts, Science and Technology. Between 1977 - 89 he taught English at secondary level in a Church school. Between 1989 - 1994 he was in involved in the development of distance education packages with the University of Malta’s Centre for Distance Learning. In April 1994, Mr. Camilleri assumed the position of Chairman of the National Commission Persons with Disability. He is heavily committed to raising public awareness regarding disability issues, in this respect he has made many appearances on radio and television, and written articles in newspapers and journals. He is a member of various committees and boards and he organises a variety of disability-related lectures at Tertiary and other levels. Joe has a mobility impairment.