

# **XEJN DWARNA MINGĦAJRNA**

***(NOTHING ABOUT US, WITHOUT US)***

## ***70 Years of Struggle and Radical Changes in the disability sector in Malta***

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### **INTRODUCTION**

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. Disabled people in the Maltese islands only began to emerge as a vocal minority in the fairly recent past. Until World War II (1939-45) they endured oppression and social ostracism in silence and invisibility.

The period under consideration is characterised by a gradual movement away from a charity-based, to rights-based mind-set, the setting up of a national focal point on disability issues in 1987, the introduction of a number of essential services, the adoption of an educational inclusive policy and finally Malta's ratification of the United Nations' Convention on the Rights of Persons with Disability in 2012 and culminating in the more widely accepted concept of Nothing About Us, Without Us! (cf. Appendix). Both our lives span almost the whole period from the late 1940s up to 2013. It was a time when we both had the separate experiences of living in Malta: as a disabled person on the one hand and as the parent of a disabled person on the other, and then jointly as disability activists. We both retired in early 2014 so we will leave it to the younger generation of disabled activists to take the narrative on from there.

In our presentation we will look at the main instruments of change, focusing on the perhaps unique situation whereby the major changes were instigated not by the development of a grassroots movement made up of disabled people pushing for change, but by a small core of people, consisting chiefly of parents of disabled people, who struggled to make change happen in various ways, such as: introducing to Malta the Social Model of disability, and bringing about a transformation of the disability landscape by obtaining the approval and backing of the government of the day, and/or individuals who were

themselves part of that government. We will see that this pattern repeated itself time and time again over the last six decades and in many ways it is still happening today. The difference is that the number of disabled individuals who are making their voices is gradually increasing.

We will conclude by gazing into the crystal ball of the future and speculating on the future of the disability movement in Malta given its history and present trends. But first of all we'd like to begin with a brief introduction about ourselves and our reasons for becoming disability activists.

## **JOE**

My name is Joe Camilleri, I'm 66 years old and I developed juvenile rheumatoid arthritis at the age of two and half. 1950s Malta wasn't able to provide the medical treatment I needed, so between 1957 – 1962, we twice travelled as a family to the United Kingdom where I was hospitalised for long periods of time. I am also of the generation on whom steroids were first used and, albeit unintentionally, mismanaged. The medical condition as well as the medical treatment prevalent at the time left me with a life-long physical impairment.

My parents had to struggle hard against the accepted wisdom of the 1950s and 1960s: first of all to ensure that I avoided the black hole of special schooling and later on to enable me to achieve other personal milestones. So thanks to them, I attended a mainstream, catholic boys' school, and later and not without widespread opposition and prophecies of failure, I obtained a degree in English and a teacher training qualification.

Finding employment was the next obstacle. I was fortunate that my old school recognised me as an individual, rather than a disabled stereotype. Once again, many voices prophesied my imminent failure as a teacher, however, I was duly employed and spent the next ten years teaching, or trying to teach English to assorted adolescents. Later, I did a five-year stint at the University of Malta's Centre for Distance Learning. In 1994 I was finally persuaded to join chair the Kummissjoni Nazzjonali Persuni b'Dizabilità (KNPD)<sup>1</sup> (the National Commission Persons with Disability) as its first disabled chairman.

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<sup>1</sup> The Commission was originally called the National Commission for the Handicapped. The name was changed to Kummissjoni Nazzjonali Persuni b'Dizabilità (KNPD), that is, National Commission Persons with Disability in 1994. Throughout this presentation it will be referred to as KNPD.

While carrying out teacher training I met my future wife, Minda. I don't have the time to go into the prejudice, resistance, hard-words, looks, and negative behaviour we had to overcome in order to establish our relationship. Suffice it to say that we were married in 1981, are still together, and have two grown-up daughters. I don't doubt that, in the words of the Paul Simon song, many look upon us as 'still crazy after all these years'.

For me it has been very much a chance-life: a life of opportunities as well as risk-taking. As a child I was saved from imminent death through a chance visit to Malta by a foreign medical specialist. Our visits to the UK helped open my parents' eyes to the possibility of a different way of life for me other than the one pre-ordained by the authorities of the time. My mainstream education helped instill in me the same aspirations, ambitions and drive as my non-disabled peers. Finally, the self-confidence which was brought about by having a good education and financial independence through full-time work, helped Minda and I to move beyond the negativity prevalent in 1980s Malta towards a 'mixed' couple like us.

My own involvement in disability activism came in two stages: one, was when I realised that whatever 'success' I enjoyed in life had come about *in spite* of our social system and *not because* of it and, secondly, my having been introduced to the social model of disability with its insistence on changing society more than changing the disabled individual. I wanted to see a change in social policies, service provision, language and attitudes that would, as much as possible, ensure that disabled people could enjoy a high standard of living and an excellent quality of life.

My own life has spanned most of the time-scale we plan to discuss today: from the late 1940s to 2013. Whether or not we have managed to achieve some of our aims, you can judge for yourselves at the end of our presentation.

## **FRED**

My involvement in the disability sector started in 1978 when our eldest daughter was diagnosed as profoundly deaf. I soon became involved in the Maltese voluntary sector and within months found myself elected President of the Deaf People Association. Immediately we set up to open the Deaf Club aimed mainly for deaf adults. The Club's aims were twofold: first, to ensure that Deaf

adults had a place where they could socialise in an environment where communication is not a continuous struggle, and secondly to serve as an incubator where the Deaf community could grow around Maltese Sign Language. This activity reached a peak in 2010 when, during my voluntary work with the same Association, this time as its co-ordinator, the Association succeeded in introducing the government funded Sign Language Interpreting Service. I am proud to say that to-day this organisation is one of the few DPOs we have on our island run by disabled people themselves, in this case Deaf adults.

In 1987, together with Dr Lawrence Gonzi, I was asked by the then Minister of Social Policy, Dr Louis Galea, to set up and run the Kummissjoni Nazzjonali Handikappati, later the Kummissjoni Nazzjonali Persuni b'Diżabilità (KNPD). Thus I left my teaching career and for more than 22 years I headed the secretariat of this organisation, under the chairmanships, first of Dr Gonzi and later of Mr Joseph Camilleri.

For the last three years prior to my retirement I occupied the post of Administrator at Dar tal-Providenza (which we will be discussing in more detail later on in this presentation). My mission there was to, slowly but steadily, run this large institution on a model which was closer to the social model of disability by providing its services in smaller groups and by reducing the organisation's dependency on charity and fund-raising, by ensuring financial support through state funding.

My latest endeavour has been to write the history of KNPD's first 25 years of work. The book entitled: Xejn Dwarna Mingħajrna was published last year.

## **MALTA**

There are several characteristics which make Malta an interesting case study for disability issues: its geographical position, its size, its history, and the socio-politico-religious tensions which have prevailed throughout its history.

The Maltese archipelago is made up of five small islands, two of which, Malta and Gozo, are inhabited. Malta covers an area of 316km<sup>2</sup> and Gozo 162km<sup>2</sup>. 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.

Since the Second World War, politics have been dominated by two parties, categorised very loosely as the centre right Nationalist party and the centre left Labour Party. General elections, held once every five years, are closely run affairs with a very high voter turnout (around 97%). The two parties are very jealous about safeguarding voter loyalty, this can often lead to the deferral of important but unpopular decisions and the distribution of 'largesse' in return for voter loyalty. It also means that politics create a great deal of polarisation and social division, so 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, post-1980s, the proliferation of non-government organisations of various shapes and sizes.

## **OUT OF THE CELLARS (1945 – 1970)**

After the unspeakable horrors of the 1939-45 world war, a sense of idealism swept many countries, Malta included. A willingness to recognise basic human and civil rights, together with a new-found tolerance of minorities saw the gradual emergence and strengthening of civil society and the formation of various groups focused on safeguarding the rights, and improving the quality of life of hitherto neglected social groups, such as disabled people.

In Malta, public interest in the lives of disabled people and their families does not date back to more than sixty years, or so. Major charitable institutions which appeared during the period between 1890-1920 were set up almost exclusively by the Catholic Church and tended to focus their attention on social/

moral problems. The main aim of these initiatives was the wish to save the souls of those perceived in danger of moral degradation, such as: orphaned children and 'fallen' women.

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 semblance of normality. Therefore any perceived deviation from what were considered social norms had to be kept well hidden away from prying eyes and ears. Thus, it was perfectly acceptable for Maltese families from every social background to ensure that any disabled family member 'disappeared' completely. Such behaviour was deemed necessary because, besides casting a veil of shame on their families, the presence of a disabled family member could ruin the prospects of non-disabled siblings of marriageable age. These attitudes were fossilised in the strata of tradition and society would not begin chipping away at them until after the end of the 1939-45 world war, when more efficient communications systems helped to open up the islands to external influences.

Until the mid-1960s, Maltese society saw no intrinsic value in the lives of disabled people. Within the prevailing socio-religious environment, they were mostly seen as 'burdens' one had to bear, as instruments by which the non-disabled were tested and spiritually purified. The general population considered anyone who was visibly different in body, or behaviour, as physically and morally impure and therefore stigmatized. The Catholic church held similar views on a cultic level (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 1940s-'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 with the aim of alleviating the effects of the late 1940s polio pandemic which also effected the Maltese islands. 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 disabled persons ever part of the organisation's decision-making process. For a brief period of time, Joe did serve on this committee, but he eventually resigned when it became clear that as a disabled person, his opinions carried no weight whatsoever. 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 brought disabled people into public focus in two ways: firstly, through its weekly radio programme and secondly, in 1965, through the establishment of the first residential complex for severely disabled persons. CSH eventually changed its name to *The National Commission for Sick and Persons with Disability*. However, despite the use of more modern terminology, the correlation between sickness and disability persisted. The CSH's stated aim was: "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", offered a mix of light entertainment and spiritual comfort in the face of personal tragedy. After five decades, and following pressure from KNPD, the name of the programme was changed to "A Call to the Sick and to Persons with Disability" and it introduced a news slot which features items related to the social model of disability and which was compiled by Fred Bezzina, then KNPD's Executive Director.

Until the establishment of *Id-Dar tal-Providenza* (*Providence House*) by Mgr. Azzopardi in 1965, there was no residential service for Maltese disabled persons. Disabled people lived with their families, quite often hidden away in appalling conditions. Mgr. Azzopardi himself sometimes rescued disabled people who will have been kept for many years 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, in Camilleri & Callus 2001)).

*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.

People who helped Mgr. Azzopardi set up *Dar tal-Providenza*, maintain that his aim was integration from the very beginning. In fact, he originally sought to acquire a building in two different desirable residential areas, but without success. In 1965, the British military which was in the process of withdrawing its presence on the islands donated a military camp which is completely cut off from the surrounding villages. Unfortunately the physical isolation of the residential complex, and its present size did not encourage very much inclusion into community life.

Nowadays, *Dar tal-Providenza* focuses its efforts more on providing small residential units within the community, while still caring for its ageing population of original residents. *Dar tal-Providenza* depends for its day to day running on the charity of benefactors and handouts from the general public, activities which, however unintentionally, by their very nature reinforce the stereotype of disabled people as pathetic objects of charity.

Mgr. Azzopardi was also sought to counteract the deep-rooted and widespread demonisation of disabled people in the Maltese culture. He did this by inverting the language normally used when referring to anyone with an impairment. Thus, common terms of reference, such as 'demon', 'Mongol', and 'invalid', in Mgr. Azzopardi's vocabulary became 'angels', 'special' and 'God's beloved'. But once again, good intentions can back-fire. Decades-long reference to disabled people as 'angels' gave rise to new stereotypes of untouchability, and 'otherness', 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 were regarded as revolutionary and indeed they represented a terrific improvement on an immediate past, overshadowed as it was by rampant superstition, blind prejudice and violent suppression. Therefore, throughout the 1960s-70s 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.

## **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. By 1964 the *Department of Social Services* had already agreed to provide unemployed, blind adults with a non-contributory pension. However, 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 other forms of impairment (Bezzina, 1996). In 1987 an allowance for families who had a disabled child was also introduced. During the 1970s-80s other measures were introduced which were aimed to improve disabled persons' quality of life, these included 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 and could lead independent lives was never seriously entertained by the authorities. Historically, family ties in Malta are very strong and the prevailing attitude has been that, if all else fails, the family can always be relied upon to provide succour. Nowadays, it is much more common for non-disabled individuals, at least, to leave the family home before marriage. However, for adults with a disability who remain single it is considered normal and desirable to go on living with their parents, or other close family members, throughout their lives. Not to do so would cast a slur on the family honour, implying that the family 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. Indeed, the level of the existing Disability Pension 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.

As has already been pointed out, measures introduced during this period were mostly instigated by the government of the day or by the church authorities, that is 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 what is today 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, in Camilleri & Callus, 2001). 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.

## **FROM 'FOR' TO 'OF' (1987-2013)**

In the 1980s, a new generation of Maltese parents of disabled people had a dream. Desperate with the fragmentation and chronic lack of services in the disability sector, angry with the resulting exclusion of many of their children from the mainstream Maltese society and inspired by new thinking from abroad, specifically the United Nations' seminal document: World Programme of Action Concerning Disabled People (WPA, 1988: para. 89) they, together with some non-disabled allies, sought and found political backing to create a national focal point on disability issues in the Maltese islands.

It was in 1987 when the then Minister of Social Policy, Dr. Louis Galea, took the politically daring decision to set up a national focal point on disability, later to be known as KNPD. Its first Chairman, Dr. Lawrence Gonzi and its Executive Secretary (later Executive Director) Fred Bezzina, were given the twin task of safeguarding the rights of disabled people and taking the necessary steps to improve disabled people's quality of life.

However, the establishment of KNPD did not indicate a groundswell for change issuing from a strong, self-aware disability movement. On the contrary, as we have already seen, KNPD's genesis was brought about by a small core of people, largely parents, putting their heads together and pushing for change. In the meantime the majority of disabled people remained voiceless and virtually invisible. However, the setting up of KNPD proved clearly that, nationally, disabled people and their families now formed a potentially significant constituency. Changes in decision-making continued to be made at Ministerial and Departmental levels, but nationally, it was more difficult to change negative attitudes and stereotypes. The absence of a strong grassroots movement further hindered any real breakthrough in self-representation for disabled people.

Running contrary to current practice, the KNPD 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 KNPD 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, in Camilleri & Callus, 2001), civil rights approach to disability issues quite early on.

One of the earliest initiatives was the setting up of the *Child Development Assessment Unit (CDAU)*. KNPD lobbied hard for the unit to be essentially 'advisory' in nature, but the medical professionals changed both its name and its direction (Bezzina, 1989, in Camilleri & Callus, 2001). CDAU was emphatically not meant to focus exclusively on the medical aspect. However, perhaps it was to be expected that professionals entrenched in the medical model approach would not give up their power base very easily, so that, over time, *CDAU* came to offer a purely medicalised service, thus undermining its original *raison d'être* which was, to focus more on providing early intervention guidance and support.

KNPD'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, both of which were, at the time regarded as radical policy proposals in the field of disability. For example, KNPD's educational inclusive policy had a direct and lasting influence in: (a) helping disabled people to achieve a higher level of education, (b) to increase expectation for a better educational provision than was being offered at the time, (c) to demand full inclusion and participation in society, ; and (d) to help the younger generation of non-disabled persons to be more inclusive of disabled persons, thereby reducing the fear of the unknown since disabled students were being educated right next to them.

In 1993, in line with social model definitions, the Commission changed its name to *Kummissjoni Nazzjonali Persuni b'Dizabilità* (KNPD), that is, the *National Commission Persons with Disability*. The distinction between the American usage 'persons with disability' and the British 'disabled persons' was debated and understood. However, a decision was taken to adopt the American phrase which translates perfectly into Maltese as 'persuni b'dizabilità'. It is in using the social

model as a standard that KNPD has brought about the most significant changes: in definitions, in language usage and more slowly in perceptions. We cannot delude ourselves into thinking that the changes wrought in the last decades have brought about a complete and lasting transformation, but without doubt the influence of KNPD 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 minority group.

These changes in thinking led to 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, this time the group also included a number of disabled people, 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 KNPD 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, two general elections were called, each on the very day the bill was to have its first reading! It wasn't until January 2000 that the *Equal Opportunities (Persons with Disability) Act* finally passed into law as Act I of 2000. KNPD was 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 soon began functioning as an Ombudsman for disability matters, with the power to investigate and sue, if and when necessary.

Besides emphasising the importance of legislation, KNPD also focused on public education. Throughout 1987-2013 it organised regular seminars on areas of national priority, mainly during Disability Week which centred around the International Day of Persons with Disability (3<sup>rd</sup> December).

In 1996 KNPD established the PEKTUR Programme, a continuing education, research and training initiative which aims at funding research in areas considered a priority by KNPD. 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.

Largely thanks to its unswerving dedication to a social model approach to service provision, Agenzija Sapport is today a foundation stone for community-based services for disabled people. Along with KNPD, Agenzija Sapport, was one of the very first organisations to place disabled people at the very centre of its decision-making processes. Of course, this does not mean that it has been entirely successful in the fullest sense. It is worth observing that after the initial investment Agenzija Sapport was never given the resources it really needed to develop further. Although the agency's services are, admittedly, the most person-centred, there are still many restrictions. To take one example, with very limited provision of residential services, disabled people cannot simply choose to move out of their family home when they choose where to live and with whom.

Another area where Malta has scored well over the years has been information and communication technology (ICT). In 2000, the Foundation of Information Technology Accessibility (FITA) was set up as a joint venture between KNPD and the Malta Information Technology Agency (MITA). It was given the specific task of ensuring that Maltese disabled people did not fall victim to the disabling barriers in the ICT of the so called Digital Divide. FITA's small team is made up almost exclusively of disabled individuals who network with private industry and public entities to create different initiatives and services. On an individual level, disabled clients are provided with a highly personalised service including detailed needs assessments, matching of technology to functional ability, training where appropriate and follow-up consultation. On a national level and thanks to EU funding, FITA, was instrumental in developing a Maltese Speech Engine. FITA is another example that the social model in practice works and is sustainable over the long-term and how disabled people can also contribute directly to mainstream society.

A credit course on *Disability Issues* to students at the *Institute of Health Care* was first offered in 1993. Over the years the credit became compulsory in courses in Health, Education, Social Work and Social Administration. Modified versions of the course were also given to students at the *Faculty of Engineering*, the *Faculty of Management Studies*, and later, disability awareness lectures have been extended to private and parastatal companies. The lectures treated disability as essentially a civil rights issue and were thus firmly based on the social model. They were co-ordinated by a disabled person and included a high proportion of speakers who were either disabled or closely related to disabled persons. A high point in the study of disability issues was reached in July 2012 with the setting up of the Disability Studies Unit, by the University of Malta. In

2014 the unit became a fully-fledged department within the University of Malta, headed by a disabled academic. Both speakers reiterate their initial concern that disabled people must always focus on maintaining control of disability studies, that is, disabled academics must ensure that disabled people always have direct control of (a) the leadership of the department, (b) over what is taught and (c) how it is taught.

## **FROM A COLONIAL PAST TO AN INDEPENDENT FUTURE? (2013ff)**

We have already seen how Malta's size, isolation from the global mainstream and the near-total control exerted over people especially by family traditions and divisive political parties, militates against the existence and maintenance of such a grassroots movement. Anne-Marie Callus, in her 2013 paper: *From 'for' to 'of': a typology of Maltese disability organisations*, identifies six categories of disability NGOs in Malta:

1. Government organisations
2. Church-run organisations
3. Partnership organisations
4. Parent-led organisations
5. Disabled people's organisations
6. Umbrella organisations (Callus, 2013: 6)

But how representative of disabled people themselves. State-funded services for disabled people in Malta and Church organisations tend to have negligible involvement of disabled people in decision-making processes. Partnership organisations are predominantly *"run by various people who work in partnership. In some cases, some board or committee members are disabled persons or parents of disabled persons. However, these are in the minority and the respective organisations cannot therefore be considered to be disabled people's or parent-led organisations."* (Callus, 2013: 8) Parent-led organisations, as their name indicates consist of parents and parents' concern, which may not always coincide with the needs and aspirations of disabled people themselves. In Malta, disabled people's organisations (DPOs), in the true sense, that is where the majority of board members themselves disabled and where the agenda is set exclusively by disabled people, number no more than a handful: approximately 8 of the 40+ NGOs which comprise the Maltese disability sector. Until recently,

DPOs were so few that it proved impossible to create an umbrella organisation comprising solely of DPOs. However, following an aborted attempt to set up an umbrella organisation of 2-3 DPOs in the early 2000s another, more successful attempt was made 2015, by which time 8 DPOs came together to form the first umbrella organisation owned and controlled totally by disabled people. However, this organisation still has to make its presence felt and until that happens the only functioning umbrella organisation representing disabled Maltese people internationally remains the Federation of Organisations Persons with Disability (FMOPD) which is made up of service providers and parent groups with disabled people making up a very small minority.

It will hardly come as a surprise to most of us here that the vast majority of the groups mentioned above have not, and many still, do not embrace the social model, and some 'continue to accept and internalise medicalised understandings.' More ominously however many organisations which are not really representative of disabled people's rights have learned 'to talk the talk' without walking the walk. In Malta too, many traditional disability organizations now consider themselves to be part of mainstream disability issues. (Oliver and Barnes: 2008, 397). Between 1945-2013, despite the existence of scores of disability organisations in Malta, there was never and there still is no grassroots movement. Malta has never witnessed a single public outcry, or large-scale demonstration, that resulted in genuine social change, as has happened in many other developed countries. Sadly, Malta has not yet seen the emergence of a disability movement as a social force.

There are many reasons to account for this vacuum. We will mention just five:

- The polarising, duopoly of the Maltese political system, leading to a serious 'us' versus 'them' fragmentation within the disability sector;
- A sense of constant vulnerability which prevents Maltese disabled persons speaking their minds and demanding their rights assertively, especially when challenging the hegemony of paternalism, which is emphasised through family, religious and political pressures.
- Limitations of size and population making it virtually impossible to achieve the critical mass of disability activists necessary to create real and lasting change. In Malta, the loss of a single individual can have a devastating effect on the development of the whole sector.
- Decades-long failure of educational and employment provision has robbed the sector of its thinkers and leaders, enabling the disability to be colonised by

traditional charities and ambitious, non-disabled individuals, who repeatedly put personal agendas before the interests of the disabled people they profess to represent.

- Another serious constraint is the sheer amount of energy many disabled Maltese expend just struggling to get through the day. Although there has been widespread improvement in basic services specifically aimed at improving independent living, most Maltese disabled people speak of struggling to survive from day to day. This means that they cannot afford the energy, or the time to organise themselves into an effective movement.

Disabled persons working exclusively within the government/ state system, as was the case for some time in the past, is no longer enough to foster change and bring about the development and strengthening of disabled people's organisations. Disabled people must also choose whether to attempt to transform organisations for disabled people into ones of disabled people by working from within the same organisations, which is a proposal that is strongly criticised by disabled writers such as Mike Oliver and Colin Barnes (Oliver and Barnes 2008). (in Callus, 2013: 11), or to go on trying to create a movement that is made up of disabled people fighting to improve their quality of life. A group that is funded through public funds, along the lines spelled out in the 1993, United Nations' Paris Principles, where: *"the purpose of this funding should be to enable it to have its own staff and premises, in order to be independent of the Government and not be subject to financial control which might affect its independence."* (U.N., 1993: para.2).

No lasting change can ever come about if it is not founded upon, and safeguarded by, a strong, independent movement of disabled persons. Maltese disabled cannot continue to be dependent on anti-discriminatory legislation, or on the blessing of politicians, or being constantly 'positive' about life. These approaches alone will not safeguard the rights of disabled people, nor will they dismantle socially constructed disabling barriers. What has happened in the past is still happening now, that is, the stealthy co-option, indeed absorption, of disabled people's organisation into the state agenda, thus rendering disabled people useless as free-agents of change. How many times have we seen disabled people's organisations begin with the courageous assertion of having 'teeth' and 'ruffling feathers', only to watch them morph in toothless Uncle Toms. Therefore, our challenge for the immediate future remains to overcome the issues which divide us to create a critical mass of activists who will, in turn, lay the foundations for the first strong, independent movement of disabled persons.

Thank you.

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