Friends and colleagues, good afternoon.

“He star’d at the Pacific …
... Silent, upon a peak in Darien.”

We are here today to celebrate the life of our friend Gordon Cardona, whose untimely departure robbed us of a proud and independent spirit, a poet of promise and a passionate activist for disability rights. His brief life-span, love of poetical language and his deep concern about suffering and injustice of others bear similarities to a favourite poet of mine, John Keats. Both men were torn between a life of action and a life of contemplation and during their lifetime they managed, in their different ways,, to inspire the people who knew and loved them.

Gordon felt strongly about a number of different issues, but none more so than the yearning towards independence of mind and the free expression of ideas, concerns which are very relevant to the disability sector in Malta and which I want to take up on in this presentation. My own journey as a disabled person has been a metaphorical climb to the peak on Darien, from which prospect I propose to look backwards in celebration of our collective past and forwards towards a future in which disabled people want to stake their claim. This will be a non-academic, personal perspective, the viewpoint of someone who has lived with a long-standing impairment and who has been a disability activist for some decades now. I make no apologies if this paper is seen as being selective in content and subjective in tone.

As I stand on this metaphorical peak and cast my mind back I ask myself: “What did I and my colleagues do right? Where did we fail? What could we have done better?” If I turn around and look forward I wonder: “What does the future hold in store for us? Where should we be putting our main energies?” No one can deny that we have made many gains, but equally I contend that the gains we have made in so many different areas are still mere, fragile shoots: easily trampled underfoot and easily withered, unless we take good care to protect them. If we are not clear on our vision for the future and
resolute in our pursuit of it, we will quickly lose everything we have gained and the hurt will be all the greater, because if one cannot lose something one has never had, the loss of a treasure gained through much effort and sacrifice by so many people doesn’t bear thinking about.

GROWING UP DISABLED

*Malta in the 1950s-60s*

Let me begin by casting my mind back as far back as I can. My own experience of growing up with an impairment in Malta has, I think, been quite unusual. I had my first birth in 1952, but I must confess I have no memory of anything before the age of five, thus I must count my second birth in a hospital in the United Kingdom as the beginning of today’s journey. In the UK my family and I were introduced to new ideas, new ways of doing things, but above all we were introduced to new possibilities for a different and better future. My mother learnt that even in a traditional Maltese marriage a woman need not be utterly dependent and helpless and with that idea in mind she pushed herself and us, her children, to our absolute limits. My father eventually stopped being a ‘salary slave’, discovered his own potential for entrepreneurship, and eventually led the family out of the financial straits brought about by crippling expenses brought on when one, or more, family members has a severe impairment. One important lesson I was taught was to see on my own impairments not simply as constraints but as opportunities, to find ways and means of adapting to them and to develop real abilities and potential and always to do so without depending unnecessarily on the help of others. In our household we were always fiercely, obstinately, independent. I was later to discover a sense of independence was a state of mind that had been almost entirely crushed out of most disabled people in Malta.

Malta in the late 1950s and the 1960s lacked almost all the services, benefits and support networks which my family had experienced in the UK and which everybody now takes for granted. One person who was working resolutely to bring about a positive change in the lives of the most severely disabled people in Malta and Gozo was Mgr. Mikiel Azzopardi. During the 1950s, 60s, Mgr. Azzopardi set up the first residential facility for disabled people. The original idea was to convert community-based houses residences, but in the end, due to various constraints, he accepted the gift of a disused, ex-British military rest camp deep in the Maltese countryside and thus Dar tal-Providenza was born. Mgr. Azzopardi also dedicated much time and effort to changing negative public attitudes. He did this chiefly through a very popular weekly radio programme. It was there that he began refering to disabled people, especially children
and people with intellectual impairment as ‘angels’. Although nowadays the expression sounds quaint and even insulting this language was a deliberate and bold departure from 1960s Maltese society’s widespread fear and loathing of disabled people as symbols of sinfulness and social burdens.

Growing up with a severe impairment in Malta in the 1950s and ‘60s was an extreme challenge for us all. Maltese society hadn’t yet discovered the medical model, but was still completely mired in the individual model of disability. Besides being exposed to the ubiquitous ‘gaze’, which all disabled people are so familiar with and which still makes an occasional appearance today, there was widespread mockery and even isolated instances of assault (although I never experienced the latter myself). It was difficult for young disabled persons to forge positive images of ourselves, immersed as we were in society which focused totally on our perceived impairments. People only registered an image of our total helplessness and ineptitude so, for our own good, incarceration at home, or in a some other segregated environment like a special school, a day-care centre, or a residential institution was seen as the best and kindest solution.

My family’s return to Malta when I was six years old was a cultural shock for me in many different ways. Our permanent return to Malta in 1962 instilled in me an abiding sense of ‘otherness’: I lived and breathed in Malta, but I wasn’t of Malta. I didn’t think and behave as a Maltese disabled person was expected, much to the surprise of people around me. On the other hand, my obvious differences cast me in the role of ‘abnormal’ outsider. I was oblivious to my differences to people’s reactions when they say me for the first time surprised me and hurt me deeply. For many years I was under the illusion that this situation was rooted in cultural, geographical and linguistic differences. As I grew up I realised that my experiences were, in fact, almost universally common among disabled people who lived in, but were never quite part of, mainstream society.

For two decades I put all thoughts of ‘handicap’ (as we referred to it in those days) behind me and made every effort to live my life as a ‘normal’ person. I studied, worked, married and became a parent. In order to live what seemed a ‘normal’ life I had to employ many artful stratagems. While the sense of ‘otherness’ persisted, at the same time, however, I did feel that I had somehow been fortunate and that most of the opportunities I had had were unknown to other Maltese disabled people. My parents had defied the received wisdom of Maltese society and countless professionals and decision-makers, and in so doing they took what were, with hindsight, many correct decisions. They had had me educated in a mainstream school, they had encouraged me to participate in mainstream activities with people of my own age, they had allowed me
to experience success and failure and, above all, allowed me to develop high aspirations for the future.

On the other hand, I also understood that many of the good things in my life had come about largely by pure chance and not by design. No one can build a future on pure chance alone. Therefore, I felt that my ‘good fortune’ was something that could, and should, be replicated for other disabled people, but with the element of chance replaced by a more deliberate approach to the creation of more equal opportunities, that is, planned changes in social attitudes, the development of efficient formal and informal support networks, the provision of adequate funding, of person-centred planning, of the gradual removal of disabling barriers and of a strong, underlying foundation of consolidation and continuity.

THE SOCIAL MODEL

The baby and the bath-water

By the 1970s-80s the medical model of functional deficit and the individual model held complete sway over Maltese perceptions of disabled people. My own very brief experience in the voluntary sector taught me that disabled people’s opinions were never sought and never listened to when offered. Luckily, in 1989, quite by chance, I might add, I came into contact with the still fledgling Kummissjoni Nazzjonali Handikappati and its then Director, Fred Bezzina. Fred, the parent of a disabled child, was a passionate disability activist in his own right and it was he who introduced me to many of the major international texts on disability, among them those written by Mike Oliver, Vic Finkelstein and Len Barton, who would later become a lifelong friend. That was how I came to discover the social model of disability.

There was no instant moment of enlightenment, no Damascene epiphany. It was more like a precious long-forgotten memory, vividly recalled. It was as though the ‘big idea’ of disability, the social model, had been with me always. I was always aware of the fact that my impairment was, and always would be, a serious drawback, and I would have to constantly adjust to the various limitations impairment imposed on me. But at the same time I always felt that there was some intangible something that was actually the chief impediment to my progress through life and the social model identified this as socially created barriers, and that realisation:

“... turned the understanding of disability completely on its head by arguing that it was not impairment that was the main cause of the social exclusion
of disabled people but the way society responded to people with impairments.” (Oliver, 2004: p.19)

In 1997 I attended a conference organised by the University of Leeds and entitled ‘Doing Disability Research’ I could sometimes feel the hostility of a few individuals if someone argued that impairment as a contributory factor to loss of quality of life. This seemed to me to be an extreme reaction, but it also reminded me of Newton’s third law of motion in action, that is, “for every action, there is an equal and opposite reaction.” To me it seemed natural that after centuries of having our self-esteem eroded with accusations of functional deficit and individual failure, some disabled people should swing the pendulum completely in the opposite direction and deny that impairment was in any way a contributory factor to loss of quality of life and instead to insist vehemently that social oppression is the sole cause of disablement. I said some disabled people because I remember that many leading disabilities of the time emphasising that:

“In the broadest sense, the social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment ...” (Oliver, 2004: p. 23)

Understanding the social model is fairly straightforward, but implementing it is very difficult indeed, as I came to realise once I had been appointed Chairman of the Kummissjoni Nazzjonali Persuni b’Dizabilità in 1994.

From its inception, in 1987, KNPD understood that if major improvements in the quality of life of disabled people were to take place then key social areas, such as: education, employment, community participation and social interaction would have to be targeted. Unlike previous initiatives which were based on the individual models of disability which sought individual solutions to impairment-related problems, KNPD set itself the formidable task of enacting large-scale, social changes based on the principles of the social model. Hence, it was imperative to bring about radical changes in public transport, the built and natural environments, improved access to means of communication and information. Above all, this meant having to bring about a complete change in social attitudes towards disabled people.

At the outset many individuals and organisations resisted the changes which social model-thinking was trying to bring about. For instance, even today, some traditional, local charities still use social model language while actually perpetuating the individual model in the interests of fundraising. Maltese media has also been particularly resistant to the social model way of thinking and to social model language. Some English-
language newspapers still insist on using what Gordon used to call ‘non-terms’, ‘wheelchair bound’ is a case in point. Even today, after almost 30 years of disability equality training, of meetings with disabled people, discussions and publications on more accurate and acceptable language, practically all media: print, visual, auditory and electronic, base the vast majority of their stories on the triumph-over-tragedy stereotype, or reports about ‘non-existent cures for this or that’ (Oliver, 2014). In other words stories “that have no relevance to the lives of the vast majority of us” (Oliver, 2014).

The ripple effect of this Xarabankification, or sensationalisation, of our lives, is far-reaching in its negative implications. The freakish aspects of impairment are still a useful tool to many people in different contexts. Among these opportunists are commercial and media people for whom disabled people are a convenient source of free advertising, or of increasing viewer numbers; politicians who lust after the photo-opportunity portray them in the role of godfather-patron-fixer and the medical industry fundraising to ensure ever bigger research budgets. Ultimately, it is we disabled people who are the only losers. Thanks to these and other self-interest groups, Maltese society still sees us as the loveable, but feeble dependents, unable to care for ourselves, unable to manage our lives and therefore unworthy of adult status that the sterotypical media portrayal of us leads everyone to believe as an incontrovertial fact.

Tragically, this prurient and widespread preoccupation with the perceived differences engendered by impairment-based issues and stories has also been taken up by disabled people. Some years ago, when disability was the only civil rights issue on the Maltese national agenda and when disabled people were the minority flavour-of-the-month, there was a general attempt at understanding disablement as caused by social injustice and socially-constructed barriers. However, over time, other sectors have taken over the social model vocabulary, without the concomitant dedication to change which real social change demands. Any quick trawl through the social media will show how very many disabled Maltese are now more interested in discussing their impairments and depicting themselves as tragic victims, or fearless superheroes, rather than emphasising the need for the removal of disabling barriers.

I must stress here that there is much value in disability pride and demonstrations of self-confidence that are often the result of overcoming obstacles that would crush most people. Similarly, there is much to merit in the practice of sport, drama, or just having a good time and socialising. But these alone are not enough to bring about a deep, lasting change in attitudes, nor will self-absorption remove disabling barriers. At some point these preoccupations become repetitive and when that happens people just lose
interest and reach for the remote control. As disabled people, we need to become capable social reformers, as well as successful individuals. We need to lobby strongly for the creation of an inclusive society, for the removal of disabling barriers, for design for all, for a society in which everyone, regardless of their difference, is included. If non-disabled society is too wrapped up in itself to see this, then we must become the agents of change ourselves. Let’s not play the discontented victim, trying to grumble and whine our way to change. If we must complain then let us complain assertively, as citizens who have an equal right to demand better things of our politicians, public administrators and service-providers. Let us also have confidence in the rightness of our cause and equal confidence in the social model as a useful tool for change.

Irresponsible undermining of the social model undermines the very cornerstone upon which the successes of our recent past have been built. Unfortunately, those who would control us and our lives have found willing champions in a few strident individuals, academics among them, who assert that the social model is outdated, as is everything even remotely associated with it. I find it all the more frustrating that a small number of Maltese, disabled people also began to intone the same social-model bashing mantra. It seems that in the interests of furthering their own personal agendas some people felt it necessary to throw out the social model baby with the bathwater. What were the motives behind this demonising of what is a life-changing and life-enhancing idea? Is it a coincidence that the wave of mockery and debunking of the social model peaked just before the national elections of March 2013 and then subsided immediately afterwards? We would do well to listen to Mike Oliver’s warning that those “who have talked down the social model while failing to replace it with something more meaningful or useful must bear a heavy burden of responsibility” (Oliver, 2014). I maintain that Malta is already beginning to see a slow resurgence of traditional, negative attitudes towards disabled people, attitudes based on patronage and charity, but cunningly wrapped in politically correct, social model language and expressions. Reactionary attitudes are having a negative effect in key areas, such as: education, employment, the provision of goods and services and a slow-down in the removal of disabling barriers.

EDUCATION

*Still integrative, rather than inclusive*

During the last 28 years, by choosing the social model approach KNPD and its allies set themselves on a direct collision course with powerful social groups and their deeply entrenched vested interests. We soon realised that many people for whom the existing social system worked very well would maintain continuous pressure to reduce, or even
neutralise, all efforts to bring about meaningful change. This became immediately apparent when, in the early 1990s, KNPD, together with a few non-governmental organisations began to challenge the system of de facto segregated education for disabled youngsters.

The 1988 Education Act (Part XI para. 126.(1)) already gave parents the right to choose which school their children would attend, but few parents availed themselves of this right. In the early 1990s there was a strong lobby (vociferously opposed in other quarters) for the introduction of an inclusive education policy in all schools. In 1994 the Ministry of Education introduced the policy incrementally so that within ten years all state-funded schools had become inclusive, in word, if not entirely in deed. 1994 was also the year when Malta became a signatory of the Salamanca Statement (UNESCO, 1994) which, besides advocating inclusive education as the way forward, also declared segregated provision ‘the exception’ (Art.8) rather than the rule that it had been in the past. Finally the statement recommended that, in future, special schools were to ‘serve as training and resource centres for staff in regular schools’ (Art. 9).

This new system was a huge step in the right direction, but I repeat, it was strongly resisted in various quarters. Over the years a variety of factors have conspired to undermine what has to be the most important element in any disabled person’s journey towards self-fulfilment. A recent report entitled ‘Special Needs and Inclusive Education in Malta’ by the European Agency on Special Needs and Inclusive Education for All (EASNIE) has identified a number of “system factors [that] reinforce an integrative approach for some learners, rather than an inclusive approach for all learners.” (EASNIE, 2015: 13).

If, as stated in the EASNIE report: “Malta spends over 5.9% of GDP on education – slightly above average” (EASNIE, 2015: 24) and we have “a segregated placement rate of just over 0.1%, which is one of the lowest across EU countries” (EASNIE, 2015: 29), then why is inclusive education such a negative experience for so many disabled schoolchildren and their parents? After over 20 years of inclusion in schools why is there a “‘backlash’ against mixed-ability teaching [that] has led to the (temporary) introduction of ‘banding’ in 2014” (EASNIE, 2015: 25)?

From the information I was able to gather from a number of major stakeholders, it became clear that LSAs and their representatives, parents associations, and the Malta Union of Teachers were not consulted prior to the introduction of banding. LSAs were not involved in any preparatory seminars, conferences and training sessions. In fact, the
introduction of banding through Letter Circular DCM 75/2014, attracted widespread objection and in sometimes, condemnation, from many well-respected educators:

- The University of Malta’s Disability Studies Unit within the Faculty for Social Wellbeing and the Inclusion and Access to Learning Unity within the Faculty of Education jointly expressed their ‘grave concern’ at the introduction of ‘banding’ in primary schools. (DSU, in TOM: 2014a)
- Professor Mary Darmanin has stated clearly that “‘banding’ is a form of streaming”. She described the introduction of banding as ‘perplexing’ and “perturbing” (quoted in TOM: 2014b).
- In an open letter to the Ministry of Education and Employment twenty-six academics from the University of Malta’s Faculty of Education stated that “banding is a ‘less differentiated form of streaming’ and emphasised that “repeated and reliable studies both locally and internationally [establish] the negative effects of streaming on individuals and on national achievement” (Faculty of Education: 2014).
- Dr Colin Calleja, head of the Unit for Inclusion and Access to Learning at the University of Malta: “the practice of grouping children by ability leads to more inequality, with those in the lower bands being the most affected” (quoted in Debono, J: 2014).

One of the few organisations that welcomed the introduction of banding was the Malta Union of Teachers (MUT) which emphasised in its press release that the Union “has been highlighting the difficulties of mixed ability grouping since its introduction and that it is “schools and educators, who are ultimately facing the difficulties of mixed ability and differentiated teaching” (MUT, 2014). No mention was made of the right of disabled children to receive an education in the mainstream.

Clearly, there is no single reason why inclusive education in Malta isn’t functioning as it should. I interviewed some parents and educational professionals specifically for this paper. While respecting the request that they remain anonymous, here are a few of the observations they made about their experience of inclusive education:

“Both educators and parents are rushing to get a child assessed in order to get him in-class support and support during benchmark examinations.” (an LSA)

“Unfortunately, notwithstanding the introduction of inclusion in our education system, some children are still not included in mainstream classrooms. For example, some children with autism are being sent to Resource Centres. A number of pupils with special needs and disability
are included in programmes given at San Miguel. The population at these Resource Centres is on the increase and such Centres could do with an extension in the building.” (a parent)

“The truth is, you know, for inclusion to really work and for teachers to cope they need to have been some other strategies put in place, which weren’t.” (an LSA)

“If the teachers/LSAs are actively involved with the preparation of the IEP, they would feel more inclined to use it as a tool.” (an LSA)

“LSAs, together with teachers, are at the core of the support given to special need pupils and therefore, [we think] that when there is a change in systems, processes and policies they should both be consulted.” (an LSA)

We need to keep our focus firmly on essentials in order to try to tackle the problem at source. For instance EASNIE interview information “suggests that many school-level stakeholders view inclusion as ‘just another initiative’ or some sort of ‘charitable’ imperative, rather than seeing it as a learners’ rights issue” (EASNIE, 2015: 44). Professor Carmel Borg elaborates on this, stating that: “the [Maltese] education system is stubborn in its refusal to embrace a human-rights perspective on inclusion and persistent in shortchanging students by providing services that are inconsistent in quality and fragmented in delivery” (Borg, 2015). In other words the “hegemony of special education has barely been challenged in schools” (Oliver, 2013). The charity-based model is still the one that informs our inclusive education provision and calls for improvement in most of the ‘standards’ or ‘statements of aspiration’ adopted for review purposes. Unfortunately, a similar situation exists in Europe and most of the rest of the world.

Notwithstanding all the negatives, we must also note that over the last 7-8 years there has been a small, but steady increase in the numbers of disabled people from different impairment groupings attending the University of Malta and the Malta College of Science and Technology (MCAST).

I have dwelled at some length on the issue of education, because, as I said earlier it is the keystone for a better future for disabled people. Its successes, or failures, reach out into every aspect of our life and follow us to the grave and also because, to my mind,
the education sector has learned to talk the social model talk, but it is still very far from walking the social model walk.

**EMPLOYMENT**

*non-productive, social cases*

Inclusive education as a rights-based principle has a serious knock-on effect on disabled people’s lives so if there is general agreement that if a lack of commitment to the social model in education is widespread, then in the employment sector that lack of commitment is almost total. Most employers show little, or no, enthusiasm for attracting young disabled job-seekers, with the result that schools are lukewarm in their careers and vocational preparations of disabled youngsters.

At age sixteen, the majority of disabled school-leavers begin the process of job-hunting already burdened by the failures of an educational system which still measures their success by examination results and certification. They are further disabled by hugely damaging media stereotypes of disability rooted in the attitudes and language of the individual model of disability. Oliver’s analysis of the failures of the employment system in the United Kingdom could well apply just as accurately to the situation in Malta:

“The social model has barely made a dent in the employment system because although it has identified many of the disabling barriers in the international labour market and with employers' behaviour, the solutions offered have usually been individual model-based.” (Oliver, 2013)

From the very beginning the KNPD team had understood that the endemic problem of unemployment among disabled people had to be tackled holistically and that in doing so, the main target had to be changing attitudes. To that end, in 1995, KNPD set out its framework for change in the employment sector by publishing a national policy document which was revised in 2010 under the title ‘National Policy on Disabled Persons and Employment’ (KNPD, 2010). True to social model principles, disabled people were directly involved in the drafting of both documents and widespread consensus of social partners was sought and won before they were published.

Other important publications aimed at creating better understanding and improving employment practices included:

- ‘Rights Not Charity: Guidelines towards an inclusive society and a positive difference in the lives of Maltese and Gozitan disabled people’ (Bezzina, 2007)
which highlighted different methods for including disabled people in mainstream activities and

- the *Access for All Design Guidelines* (Spiteri, 2010) a document which set standards for accessible design in the built environment, of course, including one’s place of work and which was, by 2010, in its third edition. In order to further strengthen the authority of the guidelines, the Malta Competition and Consumer Affairs Authority, together with KNPD, are in the final stages of changing them from guidelines into national standards.

In spite of all, however, these seminal documents seem to have had little or no impact on the wider employment prospects of disabled people.

An area which Gordon was directly involved in was face-to-face meetings with individual private companies and employers. Notwithstanding his, and all our, best efforts these meetings also failed to make a serious difference to the employment levels of disabled people. Symptomatic of this failure was the seminar organised for major employers during Disability Week of 2008. As many as 50 prominent employers confirmed their attendance, but only three of them showed up on the day. Again, in May 2008 during a meeting held, this time with the General Retailers and Traders Union, KNPD arguments were presented in a cordial, sympathetic atmosphere. However, during a follow-up meeting held at my office, it became abundantly clear that the main concern of employers was to use KNPD as leverage to secure more government concessions, subsidies and incentives. Employers already benefitted from, among other things, the Employment Aid Programme (EAP) managed by the Employment, Training Corporation (ETC), which offered financial assistance to employers by subsidising 75% of the wage of the disabled employee for the first year and 60% of the wage for 2 other years and a subsidy of 50% of employers’ national insurance contributions for disabled employees (KNPD, 2009).

After decades of effort the social model has barely made any inroads in the employment sector: employment is still seen as an act of charity and ever-increasing incentives seem to be a compulsory *quid pro quo* for employing what are seen as basically non-productive, social cases.

Over the years KNPD worked very closely with the ETC advising the corporation, for example, on different kinds of training schemes for disabled job-seekers and how to ensure physical accessibility and inclusive practices in their different training programmes. Advice was also given on the structure and functions of the then Supported Employment Unit within ETC. While there was agreement on most issues, there also were points of disagreement. A notable few in ETC’s senior management
believed in a social model approach to employment issues, but they were never enough to counter the deeply-entrenched culture of charity and individual, impairment-based solutions that politicians, employers and society in general seem to prefer.

For instance, over the years KNPD repeatedly insisted that the 1969 Employment (Handicapped Persons) Act with its 2% quota provision should be used to more positive effect. However, there was never any political will to put the quota system to work, resulting in an ETC encouraged to focus almost exclusively on strategies of persuasion. These did not work, with the result that while more and more disabled people were successfully completing ETC training courses, their success was to accumulate more and more training certificates, but certainly not in significant numbers of job placements and retention. Last year we were informed that the present administration is to take the 1969 Employment Act out of ‘mothballs’ and begin actively implementing the 2% employment quota (Bartolo, 2014). No tangible results have, so far, been noted. The media has also reported that the boards of public entities are to include persons with disability (Maltatoday, 2015; TMID, 2015) as if this were an innovative idea, while in fact, over the years many disabled people have been members on the boards of public entities, myself included. However, if these reports mean that the initiative is to be further expanded then that is good news. Of course, only time will tell whether this is a real step in the right direction, or whether it is just another example of tokenism.

Once again, amid the general gloom shone occasional rays of hope. For instance, KNPD’s dealings with the unions were perhaps more cordial and productive. For example, there were cases of disabled members of both the GWU and UHM where KNPD was involved in an advisory role and the negotiation on behalf of the person was done by their union. Another modest success was the ESF-funded ME2! Project which was launched in June 2009 by the Agenzija Sapport, in collaboration with KNPD and the ETC. Participants in the project aimed besides receiving increased training and working opportunities were also supported by a job coach who assisted them during working hours (KNPD, 2009). Maltese local councils were also strongly encouraged to participate in the role of model employers.

To conclude this brief chapter on employment we must accept the fact that the employment of disabled people was, and still is, seen more as an act of charity rather than a good business proposition, as well as part of a company’s corporate social responsibility. Unfortunately, our many attempts over the years to dispel long-ingrained negative attitudes failed to bring about a substantial increase in the numbers of disabled people employed in the private sector.
PERSON-CENTRED SERVICES

Everything About Us, Without Us

When KNPD was set up in 1987 the outlook in terms of provision of services in the Maltese islands was bleak. A few fragmented services existed, but there was no critical mass upon which disabled persons could build even a semi-independent life for themselves. Since then we have seen a proliferation of agencies (public and private) of non-governmental organisations run by disabled people, parents and volunteers and these have brought about a sea-change in service provision. Respite care, transport, home care, the purchase of assistive apparatus, the purchase of, and training in, information technology, improved medical services, residential services within the community, all of these, even within their own obvious limitations have brought about a drastic improvement in the quality of life of many disabled people.

I want to mention just two great achievements in service provision:

- the setting up, in August 2001, of the Supported Living Division within the Foundation for Social Welfare Services, which in turn became an Agency in February 2003, under the name of Aġenzija Sappo and
- the Foundation for Information Technology Accommodation (FITA).

If Aġenzija Sappo is today the foundation stone for community-based services for disabled people, then it is largely thanks to its unswerving dedication to a social model approach to service provision. Aġenzija Sappo, along with KNPD and FITA, 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 Aġenzija Sappo 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 to, to, and 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 mainly 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, and its partners, like Crimsonwing (Malta) Plc, were instrumental in developing a Maltese Speech Engine (ERDF 114). 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.

The variety of services now available may be important in themselves, but they have one common aim and that is to help banish poverty and social exclusion from the lives of disabled people. Our lives are as varied as our impairment and our other individual circumstances and that is why we insist that all services must be based on individual aspirations and need, and that assessments of individual need must be made on the basis of individual functionality. A uniform approach is both inappropriate and wasteful of limited resources. In law, we talk about being judged by a jury of our peers. But how often are disabled people judged by others who know nothing about disablement, nothing about impairment, nothing about our daily experiences? How many public and private organisations have followed KNPD and Agenzija Sapport’s examples and enabled disabled people to participate in different levels of decision-making?

In the past, when innovations and reviews took place, sidelining the opinions of disabled people was normal practice. But why do we continue to perpetuate the mistakes of the past? In 2014 the parent of a Deaf adult was quoted as saying that in order for Maltese Sign Language to become effectively embedded in Maltese culture there would have to be “an adequate infrastructure that will include an official body to oversee the development of Maltese sign language and the engagement of interpreters” (TOM, 2015). Therefore, everyone welcome the announcement that government had prepared a Bill aimed at setting up a Maltese Sign Language Council. In itself that was a most welcome piece of news. However, one’s enthusiasm failed when it became clear that the main stake-holders: Deaf people and their association and university sign language specialists had not been consulted in the drafting of the same bill. Furthermore, the structure of the Council was to be made up of five members, who were to be entirely government-appointed and only one of whom was to be a Deaf person. Unless the bill is radically changed it may come to have legal authority, but it will have no moral authority whatsoever.

The above illustrate two different approaches to how services are designed and implemented. Once again, powerful social groups seem to have appropriated social
model language, without understanding its implications and without any desire to implement its principles. First it was the introduction of ‘banding’, then a Bill on Maltese Sign Language, both of which excluded disabled people from the decision-making equation. It seems that the slogan: ‘Nothing About Us, Without Us’ is in danger of fast becoming ‘Everything About Us, Without Us’.

**INCOME: issues of choice & control**

*Skating away on the thin ice of a new day*

I want to touch very briefly on the issue of income choices and poverty. Research shows that globally, “in developing countries, 80% to 90% of persons with disabilities of working age are unemployed, whereas in industrialized countries the figure is between 50% and 70%” (UN-enable). Disabled persons are two to three times more likely to be unemployed than others, of course, “lower employment and education levels mean the poverty rate for those with disabilities is 70% higher than the average” (EU Commission, 2010). A local study by KNPD found that almost 15% of respondents receive no income at all while half of them claim to earn less than Lm200 (€465.87) a month, Lm40 (€93.17) less than the national minimum wage (Deguara, 2008: p.77).

Once again this brings us to a point where social model thinking as so far failed to make a positive impression on policy and its implementation. The thinking behind the introduction of a disability pension in the early 1970s was based on the assumption that disabled persons were lifelong dependents on the family and that therefore a pension would not need to cater for any basic needs, such as: accommodation, food, utilities, transport, clothing, but it had only to provide a little extra income to alleviate the burden of care and perhaps to provide the occasional treat. While these and similar patronising stereotypes may have been understandable 40+ years ago, they are unacceptable given the realities of today.

Disabled Maltese adults, genuinely unable to hold a full-time job and therefore in dire need of a disability pension, have long-argued that the present system needs to be radically revised to reflect current realities. If expectations have increased across the population as a whole, why should disabled people be expected to content themselves with life on the poverty line, with significantly lower income leading to an severely impoverished quality of life? Why are families of very severely disabled people still expected to assume all the responsibilities of care on their own? Why must disabled people still face the sceptre of institutionalisation, or be thrown on the mercy of family, friends, or charities if their support network fails?
Another important point concerns the present disability pension. At the moment it seems that this pension is being given to disabled people not only to disabled people who are genuinely unable to hold down a job due to the severity of their condition, but also those whose impairment is mild, or even negligible, people who are also in gainful employment. This approach is not sustainable, nor is it a priority, especially if one takes into account the fact that the disability pension remains very low and therefore does not cover the basic needs of those very severely disabled people who need it most. Furthermore, there are various categories of severely disabled people, among them people with mental health issues, (excluding people with severe schizophrenia (Laws of Malta, 1987: p. 130)), who are still not receiving a disability pension in spite of the fact that they need it badly. The law regarding the disability pension hasn’t changed (Laws of Malta, 1987) so even if these people are receiving a pension, they must be receiving it as a concession and not as a right.

We need “a national disability income to banish poverty from the lives of disabled people for ever.” (Oliver, M: 2013) and it must be realistically pegged to reflect the lives of Maltese disabled people living in 2015. Many disabled people in Malta and Gozo today experience different forms of poverty as a result of the continued exclusion of disabled people from mainstream lives, a national disability income, which includes consultation with disabled people themselves and their active involvement in the decision-making process, is central to lifting many disabled people out of very real poverty. We are the people who must somehow finance the extra-costs of disability. We are the ones who wake up every morning to skate away “on the thin ice of a new day”.

I don’t want to have to sit opposite another politician and have to justify disabled people’s quite ordinary demands for an independent adult life in the community and be patronised and dismissed with disingenuous expressions, like: “Yes, but that’s the ideal” or, “We have to focus on what’s practical, what’s achievable, what’s practical, what’s doable”, when what they actually mean is: “Get real, stop dreaming. That’s all we’re politically willing to concede to this sector.” The way I live my life has been ‘doable’ because of the hard choices and compromises I have had to make and which have impacted directly and sometimes negatively on the quality of life of those closest and dearest to me. But it’s also because I ‘got real’, took my dreams seriously and saw dreaming as a first step towards the road to personal freedom.

Blaming the lack of progress in the disability sector on financial constraints is an argument that wore thin long ago. Malta may be the smallest member state in the European Union but we have repeatedly shown that, even as a micro-nation, we still have the skills and initiative to generate fairly considerable wealth. We have the
economic resources, but what we most certainly do not have is the conviction and political will to ensure a just distribution of our common wealth. Why, for example, should KNPD’s Servizz Ghajnuniet Specjali, which provides financial assistance for disabled people to purchase much-needed assistive apparata, remain starved of funds, when, throughout the years, Maltese political parties have shown themselves very willing and able to create made-to-measure jobs for friends, and friends of friends, to tolerate widespread tax evasion, to issue exemptions, amnesties and bailouts for favoured individuals and organisations, to make countless ‘special arrangements’ for a select few, and all of this at considerable financial cost to all of us, the tax-paying majority. If such largesse is possible, then surely disabled people can demand of our politicians that they direct funds to where they are most needed and to where they will make the most difference to the lives of people most in need. The disability sector can never register real progress unless policies are underwritten with realistic and regularly updated funding packages.

SELF-ADVOCACY
Support, not control

I don’t think that there is any individual or particular social group to blame for our failures, if the fault lies anywhere it is with the collective. Over the years we’ve heard how there is no real disability grassroots movement and that disabled Maltese people are not assertive enough in their demands for equal rights and equal opportunities. But I believe we should see that failure in the context of the time. Thirty years ago my generation was the dominant force in the disability sector, but we were too few and too ill-prepared to step onto the national stage with confidence and with the necessary skills to take on the status quo in a head-to-head struggle.

My generation has used a social model approach to set the stage for a new generation of disabled people who are bettered prepared than we were. The introduction of inclusive education, the organisation of regular Speak Out! Training programmes aimed at creating a generation of disabled activists, the information technology support services, all these have been contributory factors to the creation of a new cohort of disabled activists. Admittedly, in the past, change came from the top down: it had to. Today, there is nothing to stop disabled people taking control of their own lives and their own sector.

By this I do not mean to ignore, or to detract from the very valuable contribution of non-disabled people: parents, advocates, helpers and professionals. Their work is very much
appreciated and I hope that we shall continue to benefit from their support. However, it is important to emphasise that theirs must always be a secondary role and that disabled individuals must always be the leaders and decision-makers of this sector. Those who do not understand this should be made to do so, if they cannot understand this then they must understand that there is no place for them in the disability sector. When I say that disabled people should be the protagonists in their own sector I mean all disabled people, including people with intellectual impairment. People with an intellectual impairment have shown us that they have many individuals in their midst who are quite capable of speaking for themselves and who can represent their peers who may be unable to speak for themselves (Callus, 2013). We say ‘Yes’ to support, and an emphatic ‘No!’ to control.

I strongly believe that the time has come for disabled people to take control of their own lives and their sector. Between 1987 and 2005, out of a total of approximately 40 non-government disability organisations, Malta and Gozo between them counted no more than two or three disabled people’s organisations (DPOs), that is organisations where the majority decision-makers were disabled people themselves. Today, at the last count there were about 8 DPOs and we hope to see the number growing. Our further hope is that these DPOs will group together into a strong coalition which will give moral authority to the voice of disabled Maltese people at home and abroad, something which is sadly lacking at present.

DISABILITY STUDIES

*Debate and praxis*

A final word before we begin our descent from the heights of Darien back to the present. One of the proudest events of my life has been to see the setting up, by the University of Malta, of the Disability Studies Unit (DSU). Robust and lasting changes in the disability sector can only happen if social policy is rooted in evidence-based research, providing such research is one role that the DSU has to fulfil. The other, of course, is to carry out theoretical research. My praise of, and commitment to, the social model of disability does not mean that we should not embark on other research questions, or that the social model itself should be beyond research and criticism.

In respect of the DSU I would offer two words of caution. The first takes its point of departure from Swedish Academy member Horace Engdahl who has said that the ‘professionalisation’ of the job of the writer, via grants and financial support, was having a negative effect on literature. “Even though I understand the temptation, I think it cuts
writers off from society, and creates an unhealthy link with institutions,” (Flood, 2014). I think that it is absolutely crucial that the DSU does not drive itself away from ordinary life experiences into the ivory tower of academe. It is absolutely vital that the intellectual debate on disability does not stifle praxis. Some argue in favour of art for art’s sake, or research for research’s sake, but can a tiny nation-state like Malta afford to maintain that degree of navel-gazing?

The second point is that the DSU team must be made up of a majority of disabled academics. If, in order to ensure the right balance, it means introducing some form of positive discrimination to help in the process of identifying, supporting and enlisting the services of suitably qualified disabled researchers then so be it. I wouldn’t normally be in favour of positive discrimination and by this I certainly don’t mean a lowering of academic standards. But unless there is some form of positive discrimination in place, disabled people simply will not be able to compete. We are too few and in many instances our impairments, as well as existing social barriers, all conspire against a large enough number of disabled students making it to doctoral level, without some sort of support network being put in place. I appeal to the university to seriously consider this recommendation and to act upon it to the maximum extent possible.

THANKS

I would like to thank you all for joining me on this personal journey. Thank you to all those who have given selflessly of their time and labour to bring the local disability sector to where it is today. Thanks also to the many young, disabled people who are taking over from us and who will be the leaders of future generations of disabled people and finally, a sincere “Thank you and farewell” to all disabled activists who have gone before us, to Gordon, and to all our dear friends and colleagues.
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APPENDIX A

Questions posed regarding the introduction of ‘banding’

1. Was there wide consultation with LSAs and LSA representatives before the 'banding' process was introduced in Years 5 and 6 of state schools in October 2014?

2. Exactly when was it introduced and which primary classes are involved?

3. What preparations were made a school level to address this change in teaching/learning? That is, were there preparatory seminars, conferences, training sessions for managers, teachers and LSAs?

4. How is 'banding' being implemented in different schools?

5. Have you noticed any changes (positive and negative) in the way this change has effected all the children involved and especially disabled children? For instance, in the case of statemented children have traditional low expectations influenced where and how they are positioned in the 'banding' process?

6. In your opinion has 'reasonable accommodation' been made to cater for the needs of statemented children?

7. How have the parents of statemented children reacted to this change in their children's educational entitlement?

8. How have teachers and LSAs reacted to this change in the educational entitlement of statemented children?

9. What are your views on the European Agency on Special Needs and Inclusive Education for All's recently published report on Special Needs and Inclusive Education in Malta?

10. Are there any other points, critiques and/or recommendations that you would wish to add with regard to the introduction of 'banding' in Maltese schools?