MALTA IN THE EU: INSIGHT FROM THE DISABILITY SECTOR

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Introduction

Following on from the contribution in the 2005 Civil Society Project Report on Anti-discrimination, inclusion and equality in Malta, the following is a collection of anecdotal evidence and insight into the impact the EU has had on the disability sector post accession.

In the 2005 document, the range of issues that were raised as to the requirements of the state and policy-making on the rights of people with disability could be compared with the concerns of disabled persons themselves. Many aspects of progress could be measured in one way or the other. However the following text is based on interviews with key people in the field, backed by accessible information from the sector.

The direct impact of the EU on such progress is not necessarily clearly defined. Has our country addressed many of the concerns of disabled people because of considerate policy-making and pro-activity, or was this enforced by the EU? Without EU funding, would the government have invested tax-payers money to improve the issues related to disability? Ultimately, as far as people with disability are concerned, it seems that as long as the issues are resolved, that is all that matters to them.

Let us refer back to the issues listed by the UN special rapporteur on Disability reviewed in the 2005 publication and compare the comments on those issues to the realities of today.

“States are Expected to Raise Awareness on Disability Issues and Equal Opportunities.”

The increase in awareness on disability issues is improving due to the interest that NGOs working in the sector are gaining from the media, either due to the launch of new projects and services, or as pressure platforms on the government to implement changes in legislation. There are also a number of groups and federations that are creating networking opportunities for organisations working in the field of disability to share ideas, develop national action plans and raise awareness.

The National Commission for Persons with Disability (KNPD) remains a prime-mover in this area, with regular campaigns to raise awareness on topical issues pertaining to disability. The impact that the EU has had on the commission was positive in this respect. With an otherwise limited public fund, the KNPD has accessed EU funding to increase awareness on a range of disability issues.

“*The EU Progress Project has provided a useful funding source for carrying out awareness campaigns over a longer period of time and, because of better resources it has meant that the quality of the end product is improved.*” Mr Joseph Camilleri, KNPD Chairperson.

Awareness has also resulted as a secondary outcome of EU funded projects. The Employment Aid programme of the ETC actively promotes the opportunities available to all those who may otherwise have difficulty entering the labour market. It must be added that people with physical disabilities should not require subsidies or funding to encourage employment, but should be considered on a level playing field and given rightful opportunity. On the other hand, more could be done to promote the abilities of people with disabilities in a constructive manner.

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Awareness during fundraising activities has improved in that people with disabilities are no longer portrayed as helpless and needy; however the prize-giving aspect of these activities has taken the limelight over the beneficiaries and their issues, so important messages on disability issues are being lost.

A recent KNPD publication on the rights of persons with disability requires greater dissemination. The 2007 “Rights Not Charity” - guidelines to a more inclusive society, was funded by the ESF and collates a range of interesting and valuable pieces of information on the language, etiquette and behavior towards disabled persons, amongst other issues. It is important that every strand of society be made aware that this information is available, from educators to media producers and web designers and the public in general.

“States Should Provide Adequate Medical Care and Rehabilitation to Persons with Disabilities.”

The new hospital and the investment in healthcare services should have improved healthcare for all. There are however a number of gaps in the services, some of which are being addressed. The new hospital does not house a hydrotherapy facility, essential for the treatment of people with mobility problems. Although the hospital is primarily an acute care hospital, the St Luke’s hydrotherapy facility has not been upgraded and there is currently no provision by the state for regular and indefinite ‘maintenance’ therapies. This service is important because regular therapy reduces regression of health and the resulting immobility. The long hospital waiting lists, particularly in the case of orthopaedic surgery, are resulting in a number of people becoming disabled due to their arthritic or orthopedic conditions. The example of a lady who, with the right joint replacement would be mobile and less dependent on her partner, friends and family, has become a wheelchair user and house-bound. In constant pain, she has little motivation to live independently and her quality of life has been drastically reduced. There are other such cases that are increasing the incidence of disability unduly.

The Eden and Razzett Foundation (renamed Inspire) provides free hydrotherapy to people with disabilities, and it has become a substitute for the government service. The state does not currently provide any funding to support this service although Department of Health (DOH) doctors and therapists are constantly referring patients to the NGO. The organization is also poorly supplied with accessible public transport so it has to fund a shuttle bus with a lifter that picks up clients from the surrounding localities. The government must make a concerted effort to work closely with NGOs to use resources already available.

The DOH has plans to develop a rehabilitation centre that should address some of the above issues. One questions whether this will duplicate work being carried out by the private sector.

“States Should Ensure the Provision of Support Services, Including Assistive Devices, to Enable Independence and Support Daily Living.”

EU ERDF funds are enabling KNPD to create a Centre for Independent Living which will focus on assistive apparata for persons with mobility impairment. It will offer advice, carry out assessments, provide a ‘try before you buy’ facility, and incorporate a driving school.

ESF Funds are being used by the KNPD to train professional staff who will be servicing the needs of the Independent Living Centre and its clients. Inspire has benefitted from EU funds to provide assistive technology training for disabled persons, and also has a number of readymade services for independent living that the KNPD could utilize to quicken the pace towards provision.

There is a dedicated service both in the education system and available to the general public that provides training on assistive and communication technology devices. Whilst the service in the education division is supporting students well, there is little by way of financial support for people who require personal assistive technology to achieve greater independence. There are VAT-exempt schemes on particular assistive technologies but many are required to seek financial support from NGOS and the Community Chest Fund. This is worse in the case of lightweight wheelchair provision, which is critical for enabling independence and mobility for those with physical disabilities. Many newly disabled wheelchair users are given inadequate wheelchairs which result in further immobility, damage to shoulder joints and undue strain on carers.
There is a need for a more transparent ‘Independent Living Fund’ of sorts that allows individuals with disabilities to access funds for devices that will enable greater independence. The fund within the KNPD has a waiting list and the fund is limited and capped. With the above-mentioned plans for an Independent Living Centre, it is now a necessity. It is pointless training someone on assistive devices when they cannot afford to purchase the equipment they need. There is also a drastic shortage of environment controls to enable more independent living, and even less support for people with mobility problems or wheelchair users to adapt their homes to their needs.

“States Should Recognize the Overall Importance of Accessibility…”

The main barriers to accessibility can be broadly summarised as ‘architecture’ and ‘attitude’. There has been considerable investment and effort to ensure that architectural barriers are removed, and people with mobility problems can access public buildings and spaces. Building planning is now being scrutinised by experts on accessibility and the KNPD has been given considerable power to ensure that physical barriers are avoided at planning stage. Unfortunately there is not enough being done to ensure that present standing commercial property is made fully accessible.

Architectural barriers are further compounded by attitudes that do little to empower individuals needing to access such properties. An ill-equipped back entrance to commercial premises, although ‘physically’ accessible, is not conducive to equality.

The above-mentioned need for an improved dissemination of assistive technologies will further enhance accessibility, particularly in the workplace. The Employment and Training Corporation (ETC) currently has no funding for companies wishing to install assistive technologies to enable people with limited mobility to work and perform on a level playing field. Persons in gainful employment may be working well below their full potential because devices required to enable greater function (such as access to a PC) are not readily available.

On a positive note, EU legislation is ‘forcing’ us to improve accessibility, for example the EU Regulation 1107/2006 regarding Persons with Reduced Mobility (PRMs) has ensured a more level playing field and better service for disabled people in Malta. A case in point is the carriage of guide dogs on aircraft at no extra charge to the owner. The 2001 EU Directive on Buses and Coaches (2001/85/EC) helped to persuade decision-makers in Malta to opt for low-floor buses with a ‘lifting device’. The actual incidence of these buses along public transport routes is poor, and few, if any, of the buses have ramps that would allow wheelchair access. Wheelchair users have to resort to cost-prohibitive private rentals, drastically reducing their travel ability.

“States Should Ensure that the Education of Persons with Disabilities is an Integral Part of the Educational System.”

There has been considerable uptake of EU funds to improve and invest in the education systems in Malta. There seems to be a great deal of investment and opportunity for further training, yet there still is poor uptake of vocational and tertiary training by people with disabilities who leave secondary school.

The implementation of the recommendations in the Spiteri Report² is slow; however the education department has commissioned a series of assessments on the provision of Inclusive and Special Education. We expect to see the outcomes shortly.

ESF funds have enabled some NGOs to develop training programmes for their client base, including the creation of training programmes for students with learning disabilities that link into Institute of Tourism Studies (ITS) and the Malta College for Arts, Science and Technology (MCAST). These are primarily focussed on employment. Other NGOs have used EU funds to employ trainers to teach independent living skills to youths with learning disabilities, whilst other funding has been used to create opportunities for youth exchanges, attending conferences and overseas training and work experiences.

Where it not for these initiatives, MCAST is not accepting students with disabilities because the necessary support for these students is not available.

KNPD partnered in Access to Professional Training (APT), an EU funded project which aimed at giving disabled adults a chance and providing skills for them to find their place at university. One disabled student in Malta is now following a university course as a direct result of this project. The 2007 national policy on The University of Malta and students with disabilities (ACCESS - Disability Support Unit) discusses a range of issues that impact the uptake of tertiary education at university. The policy explains the University’s outlook on disabled students vis à vis tertiary education, the need for accessibility of infrastructure and curricula, and guidelines for examinations, however it is too generic and not specific enough to reflect particular disabilities and impairments. More detail may be required.

“States Should Recognize the Principle that Persons with Disabilities must be Empowered to Exercise their Rights, Particularly in the Field of Employment.”

The fact that the statement is clearly proactive is of critical importance. States MUST empower people with disabilities, not merely provide them with prescriptive models of equal opportunities. As mentioned previously, architectural barriers may be broken but attitudes remain. There is little being done to actively encourage people with disabilities to work and stay employed. The reasons include:

A person with disability is on a meagre pension, and this is further reduced if an individual works over 20 hours a week. This is clearly a deterrent to full time employment in many cases. The ETC has provided considerable funding to companies employing people with disabilities through an EU funded Employment Aid programme but has stopped supported employment funding.

In the Employment Aid Programme an individual’s wages are considerably subsidised, reducing the barriers of employability from a financial perspective at least. Although not always the case, a person with disability, including a physical impairment or a learning disability, may not perform equally at work due to underlying physical conditions, increased incidence of illness and complications, and poor on-the-job support. In such an economic climate, companies that are downsizing may seek to retain their highest performers. The employment aid counters some of the disadvantages a person with disability may have to face because of their impairment, but it instils the wrong message. Furthermore, although equality is of primary importance, it may be the case that the minimum wage rule for people with complex difficulties may not reflect on their performance, leading to unfair comparisons between workers from the employer’s perspective. Whist we must be extremely careful that there is no abuse, performance-related pay might make more sense in some cases.

An individual with physical disability who, with the right training, job flexibility and technology, should be able to perform on a level playing field with his/her peers, may not benefit if employed under the employment aid scheme. In fact, the employment aid fund may result in people with disabilities being employed for the wrong reasons; not their capacity to perform, but their apparent cost-effectiveness. This may result in layoffs after the funding stops in 3 years’ time.

EU funding is restricted to supporting employability. There is no provision for supported employment. It is of concern that people in supported employment, who require job coaches and regular support, are not able to access state funds and have to use their own income or depend on charity. This may result in a large number of persons with disability currently being employed with the Employment Aid schemes losing their jobs when the fund dries up in 3 years or so. A long-term solution for supported employment needs to be found.

Some NGOs are starting to consider social enterprise as a solution to the above problem. One of the fastest growing sectors in the UK, social enterprise may be a plausible solution for groups of people with disability to start up their own micro-businesses. The ‘20-million for industry’ scheme introduced by Malta Enterprise could have been more empowering by actively seeking dialogue with NGOs and disability groups to develop such activities. Again, another case where funding and opportunity is being made available, but people with disabilities aren’t being empowered enough.
The 2% legal minimum quota for companies to employ disabled persons may or may not be currently enforced, but ultimately the law does not favour those with more profound disabilities. Since the law applies for ‘any’ disability, the more highly functional individuals with disabilities are usually given an opportunity over others, who remain unemployed indefinitely.

“States are Responsible for the Provision of Social Security and Income Maintenance for Persons with Disability.”

The government is currently reviewing pensions in order to improve the quality of life of persons with disabilities; however it would make more sense to invest in increasing the productivity and contribution of persons with disability in society. The ways to achieve this are to invest heavily in supported employment and social enterprise, to invest and enable independent living and supported community living, and to improve the general health of persons with disability.

This investment will take time to bear fruit, but will reap considerable benefits for society in general.

“States Should Promote Full Participation of Persons with Disabilities in Family Life.”

Where sexual education may still be a taboo in Malta, it is particularly so in the field of disability. There is no support that encourages people with learning disabilities to marry, and very little to support them to live independently. As a result, people with learning disabilities remain at home and are often treated as ‘children’ throughout their life.

There is a great deal of concern from parents and NGOs on the provision of care and supported living after the parents or guardians pass away. Unless thorough services that support community living whereby people with disabilities can live within the community (and not in institutions) are developed, their participation in society will not increase.

As positive as the investment in an Independent Living Centre by the KNPD is, there is a dire need to address the issue of supported community living in Malta. The Housing Authority, Ministry of Social Policy, NGOs and other stakeholders including financial institutions need to create a ‘task force’ to address this issue. The relatively new provision of Trusts by the local banks will further enable the funding of such projects.

“States will Ensure that there is Adequate Provision for Persons with Disabilities to Access Recreation and Sports.”

There has been a positive movement through the Good Causes Fund and the Malta Sports Council (KMS) to provide accessible sports equipment such as hand-cycles, and investment for architectural adaptations of sports venues respectively. Furthermore, sports associations are offered funding to create both integrated and specialist adapted sporting activities.

The Special Olympics team is being supported by the KMS through the provision of training facilities, amongst others. The creation of a National Paralympics Committee (of sorts) has allowed Malta to participate in the Beijing Paralympics. Unfortunately this is only helping the few. A much greater effort is needed to create accessible facilities and actively encourage participation, particularly for those with a physical disability and wheelchair users.

Wheelchair sports are relatively unheard of in Malta except for a small effort from some NGOs. Although encouraging the sport-specific organisations to promote adapted sports themselves, if this fails to work, a sport academy might provide the expertise and drive required to encourage participation in sports and competition.
“States Assume the Ultimate Responsibility for the Collection and Dissemination of Information on the Living Conditions of Persons with Disabilities.”

The KNPD and the National Statistics Office (NSO) have collected data from people with disabilities that have helped the country gain deeper insight into the issues impacting their lives. The ‘census’ may not have been comprehensive enough to gain as much information on these needs as necessary. More information is required, particularly on the nature of disabilities and the more varied needs and concerns within society.

The Academic Network of Experts on Disability (ANED), set up just over a year and a half ago, included Malta as a founder-member. We now actively contribute in terms of research and data gathering which in turn impacts decision-making at EU level.

“States have the Financial Responsibility for National Programmes and Measures to Create Equal Opportunities for Persons with Disabilities.”

It is probably in this area that the EU has had the greatest impact on the disability sector since accession in 2004. The funding that has been made available for employment, education and accessibility has been positive, as well as the awareness campaigns that are influencing the attitudes of society. The virtuous cycle of empowered individuals with disability creating a stronger voice for themselves in society, is the holy grail. It is up to the state, civil society and individuals to empower active participation and equal opportunities by investing soundly in long term solutions.

The creation of the Voluntary Organisations Act and the resulting Commission and Council will strengthen civil society if they are given a wide berth to support NGOs in Malta. However, months after the commission has been set up, there is little evidence of its practical value. The state budgets for NGO support are the same as they have been for years, and there is no resource for capacity-building for NGOs in Malta. The economic policies that the government should be seeking to develop should revolve around empowering NGOs and supporting them through service level agreements and capacity-building. As in the UK, government should outsource more and more to NGOs working in the various sectors to support civil society themselves, rather than invest in growing government services.

Support services, community care-giving, special education and other similar services should be the domain of NGOs who have built expertise and knowledge over the years and gained strong support from their community. The state may find outsourcing a much more cost effective solution, with secondment of staff to NGOs if necessary.

“States Should Recognise and Encourage the Right of Self-Representation by Persons with Disabilities.”

Although the KNPD is the main advisory body on accessibility as well as a range of other matters, there does not seem to be enough representation of people with disabilities in policy decision-making. The effect of the many NGOS working ‘too’ independently in the disability sector is leading to fragmentation. There are a number of federations or umbrella organisations that represent people with disability yet they could be more effective as one voice.

The 2006 National Policy on self-advocacy of people with an intellectual impairment was a step in the right direction. A series of consultations and workshops with people with disabilities and their families on the range of services, education, residential care and other social issues were held to encourage self advocacy. The findings were not as surprising, however. There is felt to be a lack of access to information, inaccessible transport, a lack of supported living facilities, and a need for training and representation for self-advocacy.

It is up to the NGOs to unite as one common platform from which to impact policy and decision-making. It is clear that it is not the role of government to actively pursue this but the role of the leaders of these NGOs to network and pool ideas. There is a need for a unifying non-government umbrella organisation to dialogue directly with the government, as reliance on the KNPD is not ideal due to its strong link to government.
However ultimately, self-advocacy should be encouraged at all levels.

“States are Responsible for Ensuring the Adequate Training of Personnel to Support Persons with Disabilities.”

The plans to train and up-skill Learning Support Assistants is underway. However, the needs of the students with disabilities are often not met due to the way that LSAs are assigned to students. In a recent case, over 250 students with disabilities were denied recreational and therapeutic services as part of their national curriculum for close to a whole scholastic year due to a technicality in the job descriptions of the LSAs.

There is still not enough training available for carers of people with disability. There is little capacity-building in NGOs in the sector as the limited funding available is aimed at service provision. Job coaches in supported employment are no longer funded by the ETC and there is a considerable shortage of therapists. On the other hand, numerous EU funded training programmes are available to therapists, tutors and carers, so adequate training is expected shortly.

“States are Responsible for the Continuous Monitoring and Evaluation of the Implantation of National Programmes and Services Concerning Equalisation of Opportunities for Persons with Disabilities.”

KNPD is Malta’s official representative on the European Commission’s High Level Group on Disability. The KNPD has also represented Malta at various EU conferences. Most notably during 2004-2007 Malta, through KNPD, made its voice heard as part of the EU Region in the drawing up of the United Nations Convention on the Rights of Persons with Disability (UNCRPD) and its Optional Protocol.

It is the role of the KNPD therefore, to monitor the national programmes and services concerning equal opportunities. Through dialogue with central government, the ETC and the MSP, the commission is actively involved in supporting and promoting equal opportunities. One wonders whether such a small commission has enough resources to drive the necessary changes to address a number of the issues raised in the 2005 report still unresolved today. Is it time for a ‘minister for disability’?

The National Reports on disability need updating. The laws and policies are being reviewed and updated but there needs to be more focus on particular concerns voiced by people with disabilities in Malta.

The National Federation of Maltese NGOs (NFNM) is actively involved in the EU Social Platform discussions and channels any information, including that from the European Disability Forum to the respective members. Conversely, issues that its members wish to raise on issues including disability are brought up through the EU NGO umbrella organization CEDAG, to be proposed to the Social Platform for discussion.

Failings of the state to address issues on disability may therefore be raised at EU level in this way, or via MEPs.

“States have the Responsibility to Co-Operate in and Take Measures for the Improvement of Living Conditions of Persons with Disabilities in Developing Countries.”

SOS Malta has been extremely successful, through astute strategies, in channeling EU funds to developing countries, greatly impacting the quality of life of the communities they support. A number of programmes that enhance healthcare, illness prevention and disease control will inevitably impact the incidence of disability.

Central government has supported, through funding and resources, countries struck by disaster and turmoil. Through this intervention communities have gained improved living conditions and quality of life.

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3 See European Commission Communication COM (96) 406 final.
Conclusions

The 2005 report suggested that the greatest improvement in the disability sector in Malta was the removal or reduction in architectural barriers. The current report is a collection of insights and anecdotal evidence derived from interviews and discussions with individuals involved in the sector. It is clear from these discussions that things are changing for the better in many areas, yet there has been little if any change in some areas.

The aim of the report was to shed light on the impact EU accession has had on the sector, and there is evidence that this has overall been positive. The over-riding positive factor is access to finance. EU funding seems to have had a greater impact on the sector than anything else, certainly if referring to tangible benefits such as new services and resources.

Although the EU has brought with it legislation and best practice, (as in the case of public transportation, for example) we are still way behind in making the necessary political decisions to make the changes needed. Supported employment schemes that were funded by a 5 year EU project collapsed when the funding stopped. Little has been done to gear the country’s citizens with learning disabilities to live as independently as possible, within their communities. Little adequate care is available for people with profound disabilities who wish to live at home, so they must resort to institutionalisation, limited as it is.

It is critical that individuals with disabilities are supported from the very first days of their life. Identification, awareness of services and support for parents needs to improve. Communication with the various stakeholders, in particular the range of NGOs that provide services in the sector, is critical. The government must take a leading role in developing consistent public-private partnerships with the NGOs, whilst encouraging capacity building and self-regulation. Early intervention will go a long way to improving quality of life, and a national screening/service framework needs to be developed, collating the full range of services and opportunities available in Malta.

Awareness campaigns are improving but still lack the media ‘pressure’ to encourage positive change. Examples of both good and bad practice must be publicised, applauding and encouraging business and commercial entities that take a lead in providing equal opportunities.

The country needs to look at long term strategies to resolve these issues. There seems to be a lot of goodwill, but the state must team up with civil society to find solutions to these problems. Problems that if left unresolved, will severely impact the way we live. We need to find the balance between individuality and a sense of inclusive community.

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A number of parents with daughters and sons (children and adults) with disabilities.