

ISSUES RELATED TO DISABILITY AND EQUALITY - STATE OBLIGATIONS AND AN AGENDA FOR ACTION: A FIELDWORKER'S VIEW

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The following are issues that need to be addressed in full, or improved upon, or given more weight, in order to reduce discrimination and equalise opportunities for persons with disabilities.

The office of the *UN special rapporteur on Disability* issued a survey to all countries to assess the need for government action on quality of equality in all aspects of disability. The following titles encompass this report and others, and are guidelines for evaluation that this paper and future research will consider, with the highlighted words being the title description of each clause:

- a. "States should take action to raise *awareness* in society about persons with disabilities, their rights, their needs and their potential and their contribution".
- b. "States should ensure the provision of effective *medical care* to persons with disabilities".
- c. "States should ensure the provision of *rehabilitation services* to persons with disabilities, in order for them to reach and sustain their optimum level of independence and functioning".
- d. "States should ensure the development and supply of *support services*, including assistive devices for persons with disabilities, to assist them to their level of independence in their daily living and to exercise their rights".
- e. "States should recognise the overall importance of *accessibility* in the process of equalisation of opportunities in all spheres of society... through the introduction of programmes of action to make the physical environment accessible; and undertake measures to provide access to information and communication".
- f. "States should recognise the principle of equal primary, secondary and tertiary *educational* opportunities for children, youth and adults with disabilities, in integrated studies. They should ensure that the education of persons with disabilities is an integral part of the education system".

- g. “States should recognise the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of *employment*. In both rural and urban areas, they must have equal opportunities for productive and gainful employment in the labour market”.
- h. “States are responsible for the provision of *social security and income* maintenance for persons with a disability”.
- i. “States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to *sexual relationships, marriage and parenthood*”.
- j. “States will ensure that persons with disabilities are integrated into and can participate in *cultural activities* on an equal basis”.
- k. “States will take measures to ensure that persons with disabilities have equal opportunities for *recreation and sports*”.
- l. “States will encourage measures for equal participation by persons with disabilities in the religious life of their communities”.
- m. “States assume the ultimate responsibility for the collection and dissemination of *information* on the living conditions of persons with disabilities and promote comprehensive *research* on all aspects, including obstacles that affect the lives of persons with disabilities”.
- n. “States have the financial responsibility for national programmes, (*Economic policies*) and measures to create equal opportunities for persons with disabilities”.
- o. “States are responsible for the establishment and strengthening of *national coordinating activities*, or similar bodies, to serve as a national focal point on disability matters”.
- p. “States should recognize the right of the *organisations of persons with disabilities* to represent persons with disabilities at national, regional and local levels. States should also recognise the advisory role of organisations of persons with disabilities in decision-making on disability matters”.
- q. “States are responsible for ensuring the adequate *training of personnel* at all levels, involved in the planning and provision of programmes and services concerning persons with disabilities”.
- r. “States are responsible for the *continuous monitoring and evaluation of the implementation of national programmes and services* concerning the equalisation of opportunities (as above) for persons with disabilities”.
- s. “States, both industrial and developing, have the responsibility to co-operate in and take measures for the improvement of the living conditions of persons with a disability in developing countries”.

The above is an exhaustive list of “expectations” that covers all aspects of equal opportunities. Many of these are currently being addressed, but just as many are not taken to the level that can make a difference. Primarily, we see less effort put into “non-basic” activities such as leisure and rehabilitation than we do in housing and social funding.

The purpose of my paper is to assess these issues independently and also relate them to one another.

1. “States should take action to raise awareness in society about persons with disabilities, their rights, their needs and their potential and their contribution”.

The KNPD (Kumitat Nazzjonali Għall-Persuni b’Dizabilità) organises regular campaigns and publications with regard to disability issues in society. It is their core competency and mission to promote awareness on Disability issues and Social Equality, and to advise and consult on reports of inequality through the Equal Opportunities Compliance Unit.

The Equal Opportunities (Persons with Disability) Act provided a pathway for action for the Commission, namely to increase awareness among persons with disability and their parents about their rights.

With the theme “Flimkien Naslu” (Together We Can Make It) the Commission is working to realise the ideals for which it was originally founded. One of its main objectives is to ensure that every citizen is aware of the meaning of disability. This campaign was supported by Billboard advertising, publications on various disability issues and a play entitled ‘Lives worth living’, written by Lawrence Evans and Jane Nash and translated into Maltese by Marcelle Theuma and Paul Portelli - who also took part in the play now renamed "Lajf". This play was shown in all schools throughout the European year of persons with a disability, in 2003.

After the YOTD 2003, little has been done to maintain the momentum gathered in the promotion and awareness of disability issues by the KNPD.

The rise in televised fundraising activities has brought forward disability issues to mainstream TV, however it is difficult to determine whether these have any positive effect (if not indeed negative) on equality and disability issues. These programmes have become more mundane and ‘lottery’ oriented, with less and less features on the achievements of persons with disabilities within these organisations. On a positive note, KNPD carefully monitor clips of the promotional material to ensure that the portrayals of persons with a disability are humane and respectful.

2. “States should ensure the provision of effective medical care and rehabilitation services to persons with disabilities”.

The Health Service of the Department of Health provides healthcare services to persons with a disability. This service is free of charge, and disabled persons get preferential treatment such as ‘queue jumping’ and transportation. Their medication is also mostly supplied free of charge (Means-tested).

Health department services include inoculation, disability diagnosis, medical assessment and genetic counseling. Furthermore Physio, occupational and speech therapy as well as assessment for children at the Child Development and Assessment Unit (CDAU) with regular review are provided free of charge.

There are some private organisations, such as the Razzett tal-Hbiberija that provide an add-on free therapeutic service to persons with disabilities. Often persons with disabilities attend

hydrotherapy at this facility after they have been discharged from hospital or the physiotherapy department. Often the rehabilitation programmes are interrupted with the realization that disability may be permanent (Satisficing).

Other organizations such as Dar tal-Providenza, provide institutional care and medical treatment whilst other more specialized therapies can be obtained against payment from organisations like the Eden Foundation.

Special schools with severely disabled pupils provide daily physiotherapy programmes through in-house therapists or specialized carers. San Miguel School also has a small hydrotherapy pool which is surprisingly well used.

Other self help groups and service providers set up activities to help rehabilitate persons with acquired disabilities; however these are few and not staffed by professionals.

3. “States should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to their level of independence in their daily living and to exercise their rights”.

There are an array of support services for persons with disabilities in Malta, many of which are government initiatives. The prime responsibility for support services is Agenzija Support. (Support Agency). This agency has the primary aim “of providing community and residential services so that persons with disabilities can exercise their right to participate fully in community life”. Support Services aims to promote deinstitutionalization and community inclusion.

FITA assist disabled persons with ICT whilst the numerous employment and training courses available through the Education Department and the Employment and Training Corporation are accessible to persons with disabilities.

4. “States should recognise the overall importance of accessibility in the process of equalisation of opportunities in all spheres of society... through the introduction of programmes of action to make the physical environment accessible; and undertake measures to provide access to information and communication”.

The KNPD set up the Accessibility section within its operation to ensure that physical access is considered in all new development, and to investigate issues of non-compliance. The KNPD rubber stamps any MEPA application after scrutinising access for disabled persons. FITA are providing training programmes for ICT access, and the MITI are developing community-based training facilities on ICT, some of which will be completely accessible (Such as the one planned at the Razzett tal-Hbiberija).

5. “States should recognise the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated studies. They should ensure that the education of persons with disabilities is an integral part of the education system”.

The Education Division offers education services for children who have a disability or emotional, physical, intellectual or social impairment of whatever degree. A Statementing Moderating Panel determines the assistance required by each individual.

The Foundation for Educational Services of the Ministry of Education (MOE) is working closely with the Ministry for the Family and Social Solidarity (MFSS) to ensure that the educational needs of persons with disabilities are met. The Education division provides in-class facilitators to children with learning difficulties in mainstream, whereas those with more severe learning disabilities attend special schools.

Other organisations such as Equal Partners and the Eden Foundation provide facilitators to schools. The Razzett tal-Hbiberija provides Leisure Education services to school children in a unique (out of school) setting using activities such as horse-riding and drama to teach skills. Only the first two are funded by the education division.

Where issues of disability overlap with other disadvantages such as low income, literacy and broken home settings, other initiatives such as “Assist” APPOGG and other ESF funded initiatives for improving literacy and education exist.

6. “States should recognize the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of employment. In both rural and urban areas, they must have equal opportunities for productive and gainful employment in the labour market”.

“In order to find a job, a person with disability can register with the Employment and Training Corporation (ETC), as provided by the 1969 Employment Act (Persons with Disability). This Act provides that those companies employing twenty or more employees have to include 2% of the employees who are registered as persons with disability”.

The above statement should ensure that in larger companies either 2% of the workforce is composed of persons with a disability, or if not, that there aren't enough employable persons with disability in Malta. One must determine what combination of the above two is slowing the uptake of persons with a disability in the workforce and make a better goalpost for the state to tackle.

The ETC offers financial incentives to employers, provides training and provides job coaching to ensure that not only are jobs found, but kept. Through cooperation with the Eden Foundation and the Richmond Foundation, persons with disabilities can be further trained and prepared for working life.

Some new schemes further encourage persons with disabilities to become self employed. Rare but true success stories are an example to others.

7. “States are responsible for the provision of social security and income maintenance for persons with a disability”.

Means-tested measures have been introduced. However there is an array of social benefits for persons with a disability. Some time ago the Ministry for the Family and Social

Solidarity (MFSS) distributed a certain amount of money in disability pensions, allowances for children with disabilities, injury pensions, carer's pensions and chronic illness allowances. The average pension is Lm 30-Lm 40 a week.

The relative high value of the pension compared to the minimum wage structure often acts as a deterrent to employment. Even more so when payment 'off the books' is still a common occurrence in Malta. Aside from the psychological benefits of work, some see gainful employment as "not worth it" (Insight from Personal experience).

8. "States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood".

Little is being done by the state to develop the above issues. In recent months the social workers and social administrators have recently achieved professional status and independence as a profession. This change will give more liberty and autonomy to social work, amongst others in the field of disability. There is hope that issues such as these will be addressed.

The National Council of Women organised a conference on the Sexuality of the Disabled Person to further investigate what is being done to educate parents and carers on these issues. The findings, in general, were that there is a huge need to address these issues, partly due to the fact that Sexuality is still considered a taboo subject when involving persons with intellectual disability, and therefore as a consequence marriage and parenthood as well.

To my knowledge, there has been no solid follow-up to these investigations; however support services and KNPD will assist and provide counseling if asked. Not the most proactive of activities, to say the least.

9. "States will take measures to ensure that persons with disabilities have equal opportunities for recreation and sports".

There are no state organised activities for persons with physical disabilities. Youth with intellectual disabilities are invited to participate in Skola Sport, a government initiative to encourage active lifestyles. There are one or two qualified trainers helping on this scheme but participation is poor.

Special Olympics participation is left in the hands of a private organisation and open to the select few that can afford the programme.

The Malta Wheelchair Dancing Association is one of the few active organisations promoting disabled sports and participates in international competitions. The recent European championships of the sport were hosted and organised successfully by the MWDA late last year.

The Torball association for the blind organise torball sessions once a week but have problems with an adequate venue. They also organise tandem cycling and participated in a Triathlon organised by the Razzett tal-Hbiberija in 2004.

The Physically Handicapped Rehabilitation Fund used to be a very active group (Based in Corradino) mainly comprised of people afflicted by Polio. They participated in Paralympics and international competitions but have been dormant aside for sporadic participation by one or two individuals in the Malta Half Marathon and the Olympic Day Run.

The Malta Sports Council attempted, in vain, to set up a federation of organisations for disabled sports. The Razzett tal-Hbiberija and Pippa Roberts (Wheelchair Dancing Association) are the representatives of the Paralympics Games in Malta, however there are no budgeted funds from the state to assist in the development of an (Ideal) National Paralympics Centre. Discussions between the MOE and Razzett tal-Hbiberija ensue.

10. “States assume the ultimate responsibility for the collection and dissemination of information on the living conditions of persons with disabilities and promote comprehensive research on all aspects, including obstacles that affect the lives of persons with disabilities”.

Aside from the National Statistics office, the KNPD organise surveys to collect demographic and economic information from persons with disabilities. Retrieval and participation is poor and the figures are therefore at best, approximate.

MOE created a focus group, and now a working group to gather information on disability issues, primarily to revise the special education operation.

11. “States have the financial responsibility for national programmes, (Economic policies) and measures to create equal opportunities for persons with disabilities”.

Again, KNPD is funded by the state to ensure the above is maintained. The NGO unit of the MFSS budgets Lm750,000 annually for NGOs to develop programmes on welfare and social services, part of which involve organisations working with disabled persons or therapeutic, employment and social issues.

The MOE budgets Lm220,000 annually for the provision of add-on services to assist the needs of students with special needs. To date, this fund is entirely absorbed by the Eden Foundation.

12. “States should recognize the right of the organisations for persons with disabilities to represent persons with disabilities at national, regional and local levels. States should also recognise the advisory role of organisations of persons with disabilities in decision-making on disability matters”.

The International Development Disability Consortium (IDDC) is a self-managing group currently consisting of 16 international non-government organisations supporting disability and development work in over 100 countries globally. IDDC's aim is to more effectively

and efficiently promote the rights of disabled people through collaboration and sharing of information and expertise.

An attempt was made to form a Federation of Organisations for Persons with a Disability, but the function of this Federation has been seriously impaired by internal politicking. Splintering of such groups is common-place. An attempt to create a federation for sports associations for disabled sports also failed to take off.

The Malta Council for Persons with a Disability, and the National Federation of Parents of Persons with a Disability are representative groups nearly entirely comprised of disabled persons. Although in principle, self-representation is ideal, often expertise is shunned due to the fact that interested parties do not have a disability or are not parents of persons with a disability. In a recent move, organisations working with disabled persons were prevented from being on the core committee of the NFOPD due to the above criteria, even though their entire existence was to support persons with a disability.

13. “States are responsible for ensuring the adequate training of personnel at all levels, involved in the planning and provision of programmes and services concerning persons with disabilities”.

There is a diploma in individual educational needs that trains facilitators to work with children in schools. There is a diploma and degree of Occupational and Speech and Language therapy that includes training on disability issues. There is a Masters degree in psychology that trains in further clinical & educational psychology that can be used in the field. A Masters in Special Educational Needs Co-Ordinators (SENCO) is new and aimed at overseeing and co-ordinating the work of facilitators in schools. The ETC trains Job Coaches to assist disabled persons in new employment.

There is a lack of Early Intervention Educators and training is not available in Malta today. There is also no training available for carers to assist disabled adults.

14. “States are responsible for the continuous monitoring and evaluation of the implementation of national programmes and services concerning the equalisation of opportunities (as above) for persons with disabilities”.

KNPD is responsible for ensuring that the national programmes and services are implemented. There is some doubt whether KNPD is effective in ensuring full provision of services. The MOE has set up a New Working Group on Inclusion, primarily to assess inclusion in schooling; however this may or may not extend to social inclusion.

It is important to note that in the latest Education Act (albeit dated 1988) Part 1 General Provisions, it is provided that:

“It is the right of every citizen of the Republic of Malta to receive education and instruction without any distinction of age, sex, belief or economic means.”

There is no mention of disability!

These conflict with the United Nations Convention of the rights of the child, disability is included. This discrepancy needs to be addressed.

15. “States, both industrial and developing, have the responsibility to co-operate in and take measures for the improvement of the living conditions of persons with a disability in developing countries”.

Aside from individual private activities such as the recent efforts to assist the Tsunami victims, there seems to be little provided by the State to developing countries aside from the contributions imposed by EU. (Possibly the commonwealth and United Nations?)

A number of NGOs raise funds locally to support initiatives in Sub Saharan Africa, Albania, Peru and Brazil, however these are not strictly for, but do include persons with disabilities.

Conclusion

The above is an overview of issues related to Equality pertaining to disability. We have seen a solid investment to educate and de-stigmatise disability in Malta, however little is being done to assist disabled persons to become self-sufficient and an integral part of society. There is still heavy dependence on the state for pensions and funds.

This dependence drains financial resources that could be invested in further ICT development, stronger support for employment and tertiary education, so this vicious cycle needs to be broken.

We also need to investigate further issues such as sexuality and parenthood. Our culture is such that makes us less vocal on issues of sexuality, and it is often left in the hands of poorly educated or old fashioned parents and carers to determine the best practice for the disabled persons in their care.

Overall, there is more acceptance, accessibility and education on disability issues, and investment of time and resources must be weighted against those issues we are slacking in. Accessibility and enforcement of the rights of the disabled seem to be the predominant achievers in the above list. We need to make an effort to improve on the rest.

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