

Permanent Group on Disability Rights

REPORT

Fact-finding mission to Malta: independent living and community-based living schemes

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Meeting with representatives from public authorities

Dr Alistair De Gaetano – Directorate for Disability Issues (MIVC) (National Coordination Mechanism)

Mr De Gaetano presented the bodies currently working on disability in Malta as well as the legislative setting. There are three public authorities working on disability: the Directorate for Disability Issues within the Ministry for Inclusion, the Commission for the Rights of Persons With Disabilities (CRPD), and Aġenzija Sapport.

The Disability Directorate is the focal point for the CRPD and the National Coordination Mechanism. The Directorate examines all legislative proposals to ensure that they comply with the Convention and that they engage with disabled persons' organisations (DPOs). In addition, a screening of existing legislation has led to reforms such as the UNCRPD Act of 2021, applying the UN Convention to Maltese law; in the same year, the part of the Equal Opportunities Act referring to PWD was amended; in 2023, the Personal Autonomy Bill was adopted and the Protection of Adults in Vulnerability Bill and the Criminal Code were both amended.

The work of the Directorate has recently been focusing on the mental health and empowerment of people with autism, the accessibility of digital platforms, and digital skills for PWD.

Edwina Gouder – Directorate for Disability Issues (MIVC) (National Coordination Mechanism)

Ms Gouder outlined the main elements of the Malta Disability Strategy 2021-2030. The strategy represents a roadmap for the disability sector for the next 10 years. It is based on the principle of "Nothing about us without us" and is accompanied by the Autism Strategy 2021-2023. Objective 10 of the strategy deals with independent living, and Malta has developed six actions to achieve this: addressing gaps in services; strengthening personal assistance schemes and community living schemes; setting up a "Train the practitioner" unit; curtailing abuse; improving coordination among service providers; and de-institutionalisation.

Nicole Borg – Directorate for Disability Issues (MIVC) (National Coordination Mechanism)

Ms Borg presented the work done by the department on deinstitutionalisation. There are still some institutions on the island, but many resources are put into trying to transition to community-based care. For this purpose, a public-private social partnership has been established with NGOs. There are 13 agreements in place offering respite to parents. Most of the budget for carrying out these activities comes from the Ministry, not European funds (EUR 4.2 million). The department also supports the Maltese organisations representing PWD with a multiannual agreement and has increased the funds allocated.

Samantha Pace Gasan – Commissioner for the Rights of Persons with Disabilities

Ms Pace Gasan presented the preliminary findings of the study *Towards Deinstitutionalisation in Malta*. The aim of this study is to collect more data and information on how services for PWD work on a daily basis, as well as to integrate good practices from other countries, gather feedback from various stakeholders, and adopt recommendations. As part of the study, interviews were conducted with PWD living in institutions, including people with mental health problems, PWD living in homes run by NGOs, and members of the National Parents of PWD Society. The first such institution in Malta was Id-Dar tal-Providenza, which opened in 1960. Founded by a priest, its aim was to take children out from caves where their families were hiding them. This institution is still open, but since 2013 they have also started to run smaller group homes. The Deinstitutionalisation (D-I) process was described as fragmented and as being more focused on avoiding putting more people in institutions. As such, it is difficult to quantify its extent.

In 2014, a project was launched to provide support for independent living settings known as "Just Society".

According to the study's results, parents opt to put their children in institutions in response to a sudden emergency like sudden illness, old age, and death, or due to a lack of viable alternatives. People with mental health conditions coming from Mount Carmel Hospital are also often placed in institutions.

PWD living in institutions interviewed in the framework of the study responded that they wanted more choice on aspects of their life, including nutrition and how and with whom they spend their time. They complained about the lack of autonomy and privacy, while relationships with staff and other users were generally indicated as being good.

The study contains several recommendations on completing the transition from institution to independent life in the community, which were outlined by Ms Pace Gasan. These include the need to:

- strengthen social welfare
- carry out a reform of the personal assistance (PA) scheme and promote PA as a career choice
- involve PWD and their organisations
- raise awareness of disability rights
- encourage and support the disability movement
- adopt a preventive approach
- stop opening new institutions
- reskill staff from institutions to enable them to work in day-care centres to promote and support independent living
- focus on transitioning people to independent living, with the appropriate budget
- encourage parents to form a cooperative to act as personal assistants for other PWD
- provide specific training on independent living
- present the report, lobby and advocate
- ensure mainstream services are fully inclusive and accessible

As regards data, the Commissioner explained that, in Malta, there are currently officially 25 000 PWD, but that the number is probably higher as the system for applying for disability status works on a voluntary basis. Currently, around 400 people receive subsidies of EUR 9/hour to pay for a personal assistant.

Oliver Scicluna – CEO – Aġenzija Sapport (national service provider)

Mr Scicluna presented the activities and programmes run by the agency. Aġenzija Sapport is the national agency providing professional and innovative services to enhance the quality of life of persons with disabilities. The agency's vision is to be the leader in guiding the community, promoting "ability" rather than "disability" and replacing care for PWD with support. The services offered by the agency include: assessment and intervention, community services, day services, residential services, respite services, sign language interpretation, and employability services, among other things.

Within the **Assessment and Intervention** team, social workers, physiotherapists, occupational therapists, and speech and language pathologists work with individuals with a disability and their families/guardians to provide support using a multidisciplinary approach.

As for **community services**, their aim is to assist persons with a disability to lead an independent life in the community, while at the same time enhancing the quality of life of both the service user and their family/guardians. The service may encompass interventions aimed at: improving personal care; assistance with learning and participation in housekeeping skills; community participation and social skills; engagement in leisure activities; and the prevention and management of behaviours of concern.

Day Services were assigned to Aġenzija Sapport in 2007 and currently there are thirteen day centres for persons with a disability in Malta and Gozo. The aim is to help persons with a disability continue to develop their potential through different types of activities, and to provide support to their families, so they can continue living within the community, without being socially excluded or institutionalised. The Day Services also aim to enhance each service user's independent living skills, thus empowering them to live as independently as possible, and to enhance the employability skills of each service user to their full potential and enable them to participate as active citizens within the community.

Where a family home environment is not possible or available, the **Residential Services** enable persons with a disability to live as independently as possible in the community. Such residential support is provided within small and personalised apartments and houses, which may be residences belonging to the agency, the home of the individual with a disability, or at another location acceptable to all parties but located in the area where Aġenzija Sapport operates. Residents gain skills in community living through individualised support plans.

The **Way to Work Service** assists persons with a disability in strengthening or gaining additional skills for employability. The aim is to complement other services and programmes in the sector in order to ensure that persons with a disability feel more confident about seeking employment and living more independently. The service includes training over a number of weeks on topics such as independent living skills, employability, boundaries in the workplace, hygiene, sexual health and boundaries, use of public transport, and how to present oneself with confidence during an interview.

Matthew Zerafa – CEO – Housing Authority

Mr Zerafa gave a presentation on the activities carried out by this organisation, whose function is to help persons with a disability adapt their homes to make them more accessible. The Housing Authority is also changing its offer to make it fully compliant with Article 19 of the UNCRPD (independent living).

The schemes currently available were presented, including: the New Hope scheme (not very popular); the Lift Installation scheme (at least one person in the building with mobility issues, financed by ERDF); the Sensibility scheme (for sensory conditions); and a scheme for PWD (to adapt bathrooms, etc.)

Meeting with representatives from organisations representing PWD:

Marthese Mugliette, President of the Malta Federation of Organisations of Persons with Disability (MFOPD), Venera Micallef, Secretary of the Malta Federation of Organisations of Persons with Disability (MFOPD); Catherine Vassallo, Secretary of the Mental Health Association Malta; Pauliana

Said, President of the Voice for Inclusion Gozo Association; Joanna Xerri, President of the Down Syndrome Association; Frank Turchett, President of the Malta Society of the Blind; and Marta Ruth Falzon from the Malta Dyslexia Association.

The organisations representing PWD (DPOs) in Malta that met during our mission felt that DPO involvement and **consultation** needed to be stepped up. Currently, DPOs are systematically consulted by the Ministry of Disability, but not by other ministries. The problem seems to lie in the implementation of Article 33 of the UNCRPD.

As regards the **educational system**, the organisations were of the opinion that the system was not adequately preparing children, especially those with intellectual disabilities, for life and work. Skills for independent living should be taught from a young age. The current system in Malta provides that schools should be inclusive until students are 16 years old, at which stage they can only go to a resource centre until the age of 21. Resource centres are often isolated and do not offer training in skills that are useful to help people enter the labour market. In Gozo, the situation is even worse, as there is no resource centre and young PWD have no choice but to stay at home after the age of 16.

The **employment** rate for PWD in Malta is low, mainly because PWD lack sought-after skills, namely in digitalisation. People with mental health conditions are more affected than those with physical disabilities. There is quota system of 2%; however, many employers prefer to pay a fine instead of employing PWD. The situation on the smaller island of Gozo is even worse. PWD receive a disability allowance, which they do not lose if they find a job; however, if they do not find a job they keep only the allowance and not the minimum income, which is double the disability allowance. This penalises PWD. People with less severe mental health conditions do not receive the disability allowance if they work; they are therefore not incentivised to stay in the labour market.

PWD in Malta do not have equal **access to leisure** activities; there is need for a common social space that is accessible to everybody.

One major problem is the **availability of personal assistants (PAs)**; there is an alarming shortage. The role of PAs is often performed by family members. Their role and their rights also need to be formally recognised. DPOs also pointed out that assistance and services for PWD are very expensive, which is why many families apply to put their children in day-care centres or in institutions like Id-Dar tar-Providenza.

As for **living in the community**, small group houses (up to 10 people) have been opened in the past few years; however, the way PWD live there is no different from life in a big institution, as they lack autonomy and choice. The situation is also difficult for PWD living with their parents as receiving adequate services and assistance is problematic. PA schemes need to be reinforced as they are an essential tool for independent living; however, they must be accompanied by accessible services and infrastructures. This is still not the case in Malta.

In the field of mental health, the medical model of managing disability is still prevalent, while in the case of physical disabilities there has transitioned to a social model.

Day-care centres are managed by Aġenzija Sapport. PWD spend most of the day doing crafts. The centres are mostly full and there are long waiting lists to enter. There are some programmes, such as the one managed by the Maltese Association for Supported Employment, which, after a one-year training course, succeeded in giving employment to 14 people, of which one was in a secretarial position and the rest in supermarkets or in the public sector. However, in general, DPOs felt that the day-care centres are not an optimal solution, as people stay there for too many years without being able to enter the job market. For example, in Sliema, the skills space managed by Aġenzija Sapport, which was intended to teach PWDs skills to help them find employment, has become a day-care centre.

Meeting with service providers

- Martin Micallef, Director; Nadine Camilleri Cassano, Administrator; and Remona Cuschierid, Service Coordinator, Id-Dar tar-Providenza
- Paula Doumanov, Chief Quality Officer at Inspire – the Foundation for Inclusion
- Elena Tanti Burlo', Director of Services and Vice-President of the Equal Partners Foundation

Id-Dar tal-Providenza is a large residential institution run by the Roman Catholic Church, located away from the community in an isolated area, with around 95 residents. It was founded in 1968 by a local priest who received the land as a donation. At the time, the institution welcomed children with disabilities who lived segregated lives at home, some even locked up in a cellar or a cave. The original residents remained over the years and now most of them are 40-60 years old, along with one child with multiple disabilities and a 29-year old. There are also around 20 residents aged 60-80 years old for whom geriatric care is necessary. They all have mental health problems and multiple physical disabilities. They live in shared flats (around 10 people per flat), each of them with carers. Around 300 people, including carers and other staff work in the institution. Residents usually take part in external activities in the morning (work or in day centres) and in the flat in the afternoon. Several recreational activities are organised on a weekly basis.

Changes have been introduced over the years and residents are now encouraged to develop their autonomy. Four small community-based homes for disabled people were opened, thus moving away from the notion of institutionalisation. Such group homes house a maximum of four people living together.

However, because of the high cost of services and therapies and the shortage of staff, as well as the good reputation of the institution, Id-Dar tal-Providenza has a long waiting-list of families asking for their children to be admitted. In the care sector, there is high demand and limited availability; workers are mainly migrants, which also poses the issue of the language barrier (Maltese not spoken).

A change in the approach to disability, both by families and workers in the care sector, is needed in order to shift from care to support.

D-I was pushed, but without having in place adequate available and accessible community-based schemes and services. The institution is forced to admit new residents as there are not enough group homes available. It was felt that the government should do more.

Inclusion of PWD in schools is not a reality. According to legislation, learning support educators (LSE) are assigned to help students with disabilities. However, difficult cases are often given to newer and less experienced LSEs, who have more difficulties in managing them. Parents sometimes prefer to send their child to a resource centre where they have the impression their child will feel more included. The whole educational system in Malta is very selective from a young age. This should be changed using a synergy-based approach, with a team of people who would support the teacher and monitor the progress of the students with a disability. Each teacher should learn braille, sign language and receive universal training. However, teaching unions are against teachers being given any new tasks.

Tuesday 21 March 2023

Visit to San Andrea School

San Andrea is an independent private school in Malta. In the mid-1980s, a group of parents got together to share views on a common educational situation. They were concerned about the educational future of their young children, as private schooling at the time did not offer enough choice of schools to parents. The solution they settled on was to set up an independent school, financed by the collective effort of the parents. The school seeks to celebrate inclusion and diversity holistically as well as to deal with social, emotional, cognitive, existential and identity-related difficulties from a mental health perspective. The school teaches the values of sharing and respect for diversity. It

currently has 1200 students, of whom around 250 have some type of disability, including mental health conditions.

The school offers plenty of activities, such as theatre, pet therapy through a therapy dog and a cat in the science lab and rabbits in the garden, various playgrounds, a swimming pool, and multisensory rooms.

In class, children can choose the type of chair they prefer and when they have finished their tasks they can select a book from the ones available and read.

Skills are taught throughout secondary school, from 12 to 16 years of age.

Visit to the Skills Space Centre run by Aġenzija Sapport in Sliema

The centre was opened in 2017 with the aim of promoting inclusion and training disabled people to live independently.

The new centre features specially designated areas where people with different abilities receive instruction on basic home living skills, including how to prepare meals and operate appliances such as vacuum cleaners and washing machines. In addition, they can choose other activities such as theatre, baking and crafts. They also volunteer in the community with older people, clean litter from the street and help in animal shelters.

Relatives are able to observe and follow the training from behind two-way mirrors, easing fears many families often have when leaving their loved ones in the care of professionals.

The centre currently welcomes 40 people aged from 18 to 60 years old. Most of them stay for years, although a minority do find a job.

CONCLUSIONS AND RECOMMENDATIONS

- The involvement of PWD and their organisations in designing, implementing and monitoring each policy and measure needs to be stepped up, especially for those measures which are adopted by ministries other than the Ministry for Inclusion.
- The disability movement should be supported with adequate resources.
- The transition from institutions to independent life in the community should be accompanied by better availability of social services provided IN and BY the community.
- No new institutions should be opened.
- The shortage of professionals working in the care sector and of personal assistants (PA) should be addressed by carrying out a reform of the PA scheme, promoting being a PA as a career choice with adequate salaries and working conditions, and improving working conditions across the whole care sector.
- Parents of children with disabilities could be encouraged and supported to set up a cooperative where they could offer their services as PAs to other families in need.
- The budget allocated to PWD to hire a PA should be increased to cope with increased cost of living.
- Staff currently working in institutions could be employed in day-care centres, provided they receive appropriate training that focuses on promoting and supporting independent living.
- The approach to disability taken both by families and workers needs to shift from care to support.
- Children with disabilities should receive training on living independently from a very young age both in their families and at school.
- Ensure that mainstream services are fully inclusive and accessible.
- The educational system should be adapted and made less competitive; all teachers should be trained in basic braille and sign language and be supported by a team of professionals in order to ensure the inclusion of students with a disability in the class.