

Multicultural Disability Advocacy Association of NSW

At MDAA we do **advocacy**. This means we work together with people with disability, families, and the community to promote, protect and secure the rights and interests of people from a non-English speaking background (NESB) with disability and their families and carers in NSW.

How we can help you and your family

Individual Advocacy: A worker, called an advocate, works with you when your rights are ignored. The advocate will 'stand beside' you and support you, so you can make your own decisions and get what you need. An advocate can help you stand up for your rights, for example, when you have problems with housing, immigration, work, school, and disability services.

How we can help your community

Advocacy Development: We work together with groups of people with disability and their families to learn more about standing up for your rights and needs. This can help you to have a say about the things that are important to you.

Community Development: MDAA can work with your community to increase knowledge and awareness about disability, disability services and the rights of people with disability.

Systemic Advocacy: We lobby politicians and government departments to make things better for people from a NESB with disability and their families.

Our advocacy and community development services are free.



Sophia Lindner

opening doors
Disability experienced
in Malta and Australia



Working for a NSW where the diversity of disability and culture is anticipated, supported and celebrated

Merrylands Maltese Seniors Group
(Merrylands Community Health Centre NSW)

The Rockdale Maltese Seniors Group
(St. George Migrant Resource Centre NSW)



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'opening doors' was undertaken by MDAA together with many individuals and organisations to increase the knowledge about disability in different ethnic communities.

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Disability experienced in Malta

This introduction focuses on experiences of disability for Maltese people and families. Some of the attitudes and beliefs discussed are also common to other cultures.

How we treated people with disability in the past

Malta was a colony of different rulers during parts of its long history, which resulted in rich and diverse cultures and traditions. In general, strong faith in the Catholic Church has influenced our values and behaviours and the traditional response to people with disability is based on care and support being provided by the family.



However, in the past disability was generally stigmatised and considered as taboo. We usually segregated people with disability from the rest of the community. When a child with disability was born the family sometimes felt ashamed. Being different from others was often seen as embarrassing and it was common to keep it secret and private. Thus many parents did not want to let the community know that one of their children had a disability and they hid the child at home. People with disability were usually not seen in public.

Having a child with disability would often lower their sisters' and brothers' chances of getting married. Usually people consulted the village parish priest before getting married to ask if the partner they intended to marry had any family member with disability. Due to a lack of education and knowledge – especially about mental illness and intellectual disability – we often feared that all kinds of disability are hereditary.

In general people made no distinction between mental illness and intellectual disability, seeing them simply as 'madness'. Physical and sensory disability were usually less stigmatised. Some children with a mild physical or sensory disability went into mainstream schools and were seen outside the family home. Sometimes they experienced violence and abuse and were often teased and made fun of. Parents usually thought that keeping a child with disability at home would protect them from being teased or bullied.

Guzeppi

Guzeppi had meningitis when he was a baby and he had difficulties hearing and speaking later on. Nevertheless his parents encouraged him to go to school with the other kids of the village and he finished every year as the best student in the class.

Karmena

Karmena was born with a vision impairment and should always have worn strong glasses. Her parents did not want her to wear glasses at school because they thought the family would get a bad reputation and other children would tease her. Karmena always had to sit in the first row or depend on the support of others to follow the lessons.

Family members with disability were sometimes regarded as a burden. We often thought they needed our protection forever and we used to decide everything for them. Because of a lack of support and services, the parents' biggest worry was who would care for their child after they passed away.

Parents, especially single parents, struggled to make ends meet and sometimes this forced them to abandon or give up family members with disability. People with disability, particularly people with mental illness or intellectual disability, were given

into the care of old peoples' homes or orphanages run by religious institutions. Before the 1950s we did not have special schools for children with disability.

What are the myths or beliefs about disability in Malta?

In the past, social stigma usually attached to disability, especially in regard to people with mental illness or intellectual disability. People often shunned people with mental illness or intellectual disability and perpetuated myths about them.

Maria

Maria was a woman with mental illness who lived with her parents in a small village. She was never seen outside the house, her parents did not let her go to church and some of her neighbours did not even know she existed.

We often thought having somebody with a disability in the family was a kind of disgrace or embarrassment for the family. As Malta is a very religious country, religion often influenced our beliefs about disability. It was common to think that having a child with disability meant that the family must have done something wrong in the past and was therefore being punished by God. Thus mothers having a child with disability sometimes walked on their knees to churches, asking God for help and forgiveness. On the other hand, disability was sometimes regarded as a 'gift from God' and the family treated children with disability with devotion.

Superstition about disability was very common in the past. Due to the stigma and lack of knowledge about disability, we sometimes thought disability was contagious and people were generally afraid to touch a person with disability because this would bring bad luck or illness. Another superstitious belief was that some people had the 'evil eye'. These people could jinx

you when they looked at, spoke with or touched you and you would have bad luck or get an illness or disability from their 'evil eye'. This led to shunning and isolation of people with disability.

Nowadays we still sometimes attach stigma to some types of disability, especially mental illness and intellectual disability, but the myths and superstitious beliefs have given way to increasing awareness and more knowledge and acceptance about disability within the community.

Were there any events that changed attitudes to people with disability?



In Malta there have been huge changes to the ways we used to live, our beliefs and the way we generally saw people with disability. Along with television, radio and the Internet, education, information, knowledge and

awareness about disability have increased. Companies have started to hire people with disability and disability has become an important issue in the public, social and political arena.

The biggest influence in changing our attitudes to people with disability came about 40 years ago through Monsignor Mikiel Azzopardi, a Maltese priest. He tried to take away the stigma and embarrassment attached to disability, called people with disability 'my angels', promoted their rights and collected money for projects and for the opening of residential homes for people with disability.

Furthermore he was founder of '*Is-siegha tal-morda*' (*The Sick People's Hour*), a one-hour programme every Sunday on Rediffusion (the Maltese cable-radio of those days) dedicated to people with disability. This program was both humorous and religious, Monsignor Azzopardi told life stories of people with

disability, educated the community about disability and made disability a public issue in Malta, which changed attitudes towards disability.

With donations Monsignor Azzopardi founded the '*Id-Dar Tal-Providenza*' (House of Providence) in 1965, a residence for children and adults with different types of disability who live there in family-like groups. It provides workshops, runs an 'ability' centre and a gym and is rated as one of the best residential care homes in Europe. All residents go through an individually adapted programme, which aims for full integration into the community and the promotion of knowledge and self-esteem. Until his death in 1987, Monsignor Azzopardi was director of this house and he also opened other residences.



Since the 1990s these residences have followed the new approach of supported living. For example *Zernieq* is a self-contained house where former residents from the *House of Providence* live together with a support worker, attend school, go to work, attend ability promotion programmes and live independently, fully integrated into society.

Unfortunately the waiting list for all these residences keeps growing.

In 2003 Malta joined various European states in declaring 2003 as the *European Year of People with Disability*. Some major achievements for people with disability were made in this year, such as in the quest for equal rights and opportunities for people with disability.

Another important event, which changed the situation for people with disability, was the Maltese integration into the European Union in 2004. To become eligible to join the European Union, the Maltese government had to comply with a lot of requirements regarding rights for people with disability.

What role do families play in caring for people with disability?

Family has always been very important for Maltese people. Traditionally the family took full responsibility for the care of people with disability without using outside services and most people with disability lived with their families. Mothers were usually the main carers as there was mostly a lack of money to pay a carer or an institution.



In recent decades traditional roles have changed and more and more women have paid work. Thus nowadays fewer relatives care for family members with disability at home. The government wants to train more carers to meet this need. Also community and social care services have helped in this change.

Has the language we use to talk about people with disability changed?

Since gaining our independence from Great Britain in 1964, the Maltese language has become more important than English and has evolved very quickly. In the past we often used to talk about handicapped, retarded and incapacitated people and would nickname them. In recent decades, together with rising community awareness about disability, our language has become more sensitive and aware when we talk about people with disability. Now the everyday language, especially the language of the media, is about *'people with disability or special needs'* instead of *'handicapped'*.

Are there differences in the way city and country people respond to disability?

Malta is a small island state, thus all services and institutions for people with disability are near and in easy reach for people living in rural areas. In the past, people with disability usually had a harder life and more hurdles to manage in rural areas than in cities. Nowadays the situation for people with disability has improved, no matter where they live. Cities and villages have better infrastructure and services for people with disability are available in both of them.

The situation for people with disability from Gozo, the smaller and more rural island next to the main island of Malta, generally improved later. In the past, life for people with disability on Gozo was often harder than on mainland Malta due to the poor infrastructure, difficult access to services and insensitive attitudes towards disability.

What services are there for people with disability?

As our community became much more aware of and educated about disability, the number and range of services for people with disability increased significantly. Today we have services in almost every town and suburb, which are run by the government, the church and various voluntary non-government organisations. These agencies provide support, assistance and social care for people with disability. They offer counselling, day treatment, therapy, community education, vocational rehabilitation, sheltered employment, meals-on-wheels and referral networks for people with disability and their families.

Many services are substantially subsidised by the government and the general aim is to move people with mental illness or intellectual disability out of institutions. However, we still lack services for long-term support for young people with disability and the waiting lists for some of the specialised services are long.

A well-known example of a non-government organisation is *Razzett tal-Hbiberija*, a rehabilitation service for people with disability, which opened 15 years ago and which provides free leisure, educational and therapeutic programmes, fitness training and social activities to people with disability to improve their quality of life.



Nowadays our social security system is very well established and the Maltese government issues disability support pensions. The *National Commission for People with Disability (NCPD)*, a government-funded organisation, coordinates the numerous NGOs and issues a *Special Identity Card*, which gives people with disability access to a number of specialised services. The *Department for the Elderly and Community Services* offers people with disability a home assistance service to complement familial help. The aim of this service is to allow people with disability to keep on living in the community and to improve their quality of life.

The *Education Division* of the *NCPD* offers education services for children with emotional, physical, intellectual or social impairment. Moreover we have several special schools for children with disability and the Maltese government promotes integration classes where children with disability attend school together with other children. This helps children to learn to understand each other's needs, to respect each other no matter what differences and to get prepared for tertiary education or employment.

In the past 15 years massive improvements, such as ramps, lifts and wider pavements, have been made to the accessibility of public places, buildings and educational institutions. Since 2000 public places can only be built with a recommendation of the *NCPD* as being accessible to everyone. However, our public

buses, some of the old buildings and many multi-storey buildings are still hard to access for people with disability.

What does the community know about the rights of people with disability? How has this changed over the years?

Our understanding of people with disability has grown in the past four decades. Disability has become a much more open topic, the government made it an issue and we have a lot of discussion about it in the media. The rights of people with disability are also protected by general legislation and the law guarantees them financial security and employment.

Since 1969 the *Employment Act for People with Disability* has tried to ensure that companies with more than twenty employees include 2% of employees with disability. The *Employment and Training Corporation* administers this law and assists people with disability by offering them training and finding and keeping work. Unfortunately only 20% of all people with disability are permanently employed.

The *NCPD* was established more than fifteen years ago. It is government-funded, does research about disability and coordinates NGOs, which work with and advocate for people with disability. The Commission's aim is that people with disability are able to live independently and contribute fully to Maltese society. Its campaigns support people with disability to have the least restrictive environment, equal opportunities in all sections of society and inclusive education. To achieve these aims the *NCPD* tries to ensure that society eliminates all forms of discrimination against people with disability and their families, while providing them with the necessary assistance, support and information. PEKTUR, the '*Continuing Education, Training & Research Programme*' (*Programm ta' Edukazzjoni Kontinwa, Tahrig u Ricerka*) is run by the *NCPD*, supports

projects on education, training and research within the disability field and organises training courses for activists with disability and parents of children with disability

In 2000 the Maltese Government enacted the *Equal Opportunities Act for People with Disability* that aims to eliminate discrimination against people with disability, and prohibits discrimination in employment, education, access, accommodation and insurance. In addition, the *National Commission for Mental Health* will draw up new legislation for mental health and the new EU human rights agenda in Malta deals exclusively with the rights of people with disability.

Today our community has much more compassion towards people with disability and increased awareness about disability. We know that people with disability would like to lead interdependent lives, such as being part of the workforce, having their own space, having a voice and participating fully. Despite these advances, there is still a lot of room for improvement.

Web Sites used in writing this document

<http://www.diversityinhealth.com/regions/europe/maltese.htm>

<http://www.eumap.org/library/?trexp=&countries=470&topics=1461&categories=576087290&ftext=>

<http://www.independent.com.mt/daily/newsview.asp?id=22357>

http://www.knpd.org/pubs/pdf/selfadvocacy_e.pdf

<http://www.knpd.org/pubs/pdf/servbene.pdf>

<http://www.maltatoday.com.mt/2002/0728/people2.html>

<http://www.euro.who.int/document/e67140.pdf>

Disability experienced in Australia

What is Disability?

A disability is something that stops a person from doing things they want to in their day-to-day activities. At least 19%, or one in five people in New South Wales, will experience one or more of the following:

- blindness or vision impairment (even when wearing glasses or contact lenses)
- deafness or hearing impairment (even when fitted with a hearing aid)
- chemical sensitivity
- speech difficulties in their first language
- blackouts, fits or loss of consciousness
- disorientation in unfamiliar environment
- slowness at learning or understanding
- acute anxiety
- difficulty making decisions
- incomplete use of hands or arms
- difficulty in gripping or holding or carrying small objects
- physical weakness over distance or long waiting periods
- lack of balance and coordination
- incomplete use of feet or legs
- difficulty walking on uneven ground, stairs and slopes
- pain, fatigue and discomfort
- difficulty breathing

- long term illness
- medical conditions and/or physical trauma leading to one or more of the above

In Australia disabilities are often categorised into different types, such as: physical disability (e.g. polio, arthritis, burns, obesity, broken bones, amputation), intellectual or learning disability (e.g. autism, down syndrome, attention deficit disorder), psychiatric disability or mental health problem (e.g. post traumatic stress disorder, schizophrenia, depression), sensory disability (deafness, blindness) and neurological disability (e.g. brain injury, spinal injury – paraplegia and quadriplegia, cerebral palsy, Parkinson’s, multiple sclerosis).

A disability can be permanent or temporary. Many people with disability say that what usually stops them from fully participating in the community is not their disability, but the barriers put up by society and the negative attitudes of the community.

What support can people with disability get?

In Australia people with disability have the same human rights as other people. This includes having the right to be part of the community, make their own decisions and receive services that assist them to have a reasonable quality of life.



People with disability have the right to all the services people without disability can get. General community services need to provide services to people with disability. Just because somebody has a disability should not mean that they cannot get general services. In many instances people with disability can get support and assistance from the same places as people without disability.

However, to ensure that people with disability have the same opportunities there are specialist services available only to people with disability. These services include:

- Services assisting you to get a job or more training such as *Employment and Vocational services*.
- Services assisting you and your family to have a break from each other such as *Centre-based and In-Home Respite Care*.
- Services assisting you with your personal care such as *Attendant Care Services*.
- Services assisting parents when you first find out that your child has a disability such as *Early Intervention Services*.
- Services assisting mainly younger people with disability to learn more skills such as the *Transition to Work Program, Community Participation Programs, Community Access Services or Day Programs*.
- Services assisting you to live in the community with support such as *Accommodation Support Services*.
- Services assisting you with technology, equipment, therapy and para-medical specialist services, such as *PADP (Program of Appliances for Disabled People)*.
- Services assisting you to have your rights respected and to get information, such as *Advocacy and Information Services*.

How to find out more about services for people with disability

While there are many services for people with disability, it is not easy to find out about them or find out what the right service is for you. Also sometimes the services are full and have a waiting list, or sometimes you don’t know who to ask and what service to ask for.

Here we have listed only a few services, services that say they will organise an interpreter if you need one:

The Translating and Interpreting Service (TIS) of the Department of Immigration and Multicultural and Indigenous Affairs is available to any person or organisation in Australia requiring interpreting services. TIS is available 24 hours a day, 7 days a week.

TIS phone: 13 14 50

You might have to pay a fee depending on the circumstances and depending on whom you are calling.

One good starting point to find out about things is Centrelink.

Centrelink phone: 13 10 21

Centrelink Multilingual Call Centre phone: 13 12 02

TTY phone: 1800 810 586

If you can go to your local Centrelink office, one good person to talk with is the Disability Officer.

Also a good place for you to start is the Commonwealth Carelink Program.

Commonwealth CarelinkCentres phone: 1800 052 222

TTY phone: 1800 555 677

Speech-to-Speech Relay phone: 1800 555 727

Another disability information service is IDEAS.

IDEASphone: 1800 029 904

You can also call the Multicultural Disability Advocacy Association (MDAA) which promotes and protects the rights of people from a non-English speaking background (NESB) with disability and their families and carers.

MDAA phone (02) 9891 6400 or 1800 629 072

