L-Università ta' Malta
Faculty for Social Wellbeing

Peer-Led Training on Disability Rights

Research Project

Agenzija Sapport in collaboration with the Department of Disability Studies,
Faculty for Social Wellbeing at the University of Malta

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Peer Education Project

Collaborating with a social welfare agency like Agency SAPPORT is always very important because it is a mutual learning experience. This project is another loop in the endeavour of the Faculty to make this a better society by providing empirical research that supports policy recommendations. Once again the broad expertise of the Faculty, the diligent researchers and the support of the administrators in combination with the stakeholders is a perfect recipe to make this a successful project, with many more to come.

Prof. Andrew Azzopardi
Dean
Faculty for Social Wellbeing

Abbreviations

CBPR	Community-based participatory research
CRPD	Commission for Rights of Persons with Disability (Malta)
CoE	Council of Europe
ECHR	The European Convention for the Protection of Human Rights and Fundamental Freedoms
ECtHR	European Court for Human Rights
EU	European Union
HR	Human Rights
HRBA	Human Rights Based Approach
ICT	Information and Communications Technology
PRM	Person with Reduced Mobility
PWD	Person with disability
PWID	Person with intellectual disability
UDHR	Universal Declaration of Human Rights
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization

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Preamble

This report is being produced in the context of the Peer-Led Training on Disability Rights Project, a research study commissioned by Aġenzija Sapport and supported by the Department of Disability Studies within the Faculty for Social Wellbeing at the University of Malta. This project aims to pilot a developing rights-based approach to disability, by devising disability rights training for service users and measuring its effects. The specific objectives of the project are :

(a) Training (2) persons with intellectual disability in disability (PWIDs) rights and the UN Convention on the Rights of Persons with Disabilities

(b) Producing accessible information for the training together with the same PWIDs (within working groups);

(c) Passing on the above-mentioned training to other persons with ID through peer led education;

(d) Reporting findings of the process and documenting them.

The report is structured thus:

- Chapter 1 defines disabilities and explores specific barriers and risks for people with disabilities;
- Chapter 2 explores the international, European and national legal frameworks with a particular focus on the safeguards in place for people with disabilities;
- Chapter 3 details the methodology employed for data gathering, training delivery and impact assessment.
- Chapter 4 analyses the data gathered from the training and research study, including the outputs produced through the project.
- Finally, Chapter 5 concludes the report and provides recommendations for future initiatives.

Chapter 1

Disability: Issues and Challenges

The definitions of impairment and disability underpinning this research study are the following:

- Impairment: physical, sensory and intellectual difference to be expected and respected on its own terms in a diverse society.
- Disability: the loss or limitation of opportunities to take part in community life on an equal level with others due to physical and social barriers (Cameron 2008).

From these definitions we therefore see how disability is thus not just a health or medical problem, but rather 'a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers.'

CHALLENGES FOR DISABLED PEOPLE IN TERMS OF EQUALITY AND INCLUSION

Equality can be defined as the condition of being equal, especially in terms of political, social, and economic rights (Capaldi 2002). It results from absence of discrimination. To this effect, it requires dismantling societal and cultural barriers which hinder access to equal opportunities for certain disadvantaged and minority groups. This principle can be applied within various contexts, including education, employment and access to goods and services.

Discrimination results when a person is treated in a less favourable manner than another is, has been or would be treated in a similar situation. Discrimination may also be indirect, that is to say any treatment based on a provision, criterion or practice which would put persons at a particular disadvantage compared with other persons, unless this can be justified as appropriate and necessary on the basis of objective factors.

Every individual is entitled to live in an environment that promotes dignity, equality and respect for all. This notwithstanding, various forms of prejudice and discrimination are still widespread in our society. In order to redress this, both local and European legislation prohibit different forms of discrimination based on a number of 'protected characteristics'. These include sex; sex characteristics; marital or civil status; family responsibilities; pregnancy or maternity; gender identity; gender expression; sexual orientation; age; disability; religion or belief; race or ethnic origin; nationality; political opinion; and membership to a trade union.

> **Art. 2 of the UNCRPD defines 'discrimination on the basis of disability' as:**
> any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.

It formulates 'reasonable accommodation' as any 'necessary and appropriate modification and adjustment not imposing a disproportionate or undue burden' that are required to allow people with disabilities to fully enjoy their rights. It further specifies that 'universal design' stands for 'the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design'; and that 'communication' includes a range of means and methods such as languages, tactile communication, human-reader, accessible ICT and more. 'Language' encompasses spoken, signed languages and non-spoken languages.

Diversity can be defined as the 'the mix of differences, similarities and tensions that can exist among the elements of a collective mixture' (Roosevelt 2006); as well as in a human rights (HR) and more generally, professional context, as a 'feature of a mixed workforce that provides a wide range of abilities, experience, knowledge, and strengths due to its heterogeneity in age, background, ethnicity, abilities, political and religious beliefs, gender, and other attributes. It entails acknowledging, valuing and celebrating the different characteristics which belong to different individuals and/or groups. These differences may be visible or otherwise. Equality and diversity are not inter-changeable but they are interdependent. There can be no equality of opportunity if difference is not valued and harnessed.

Although often used in tandem with diversity, inclusion is a concept of its own. Inclusion, in fact, can be interpreted as 'the achievement of a work environment in which all individuals are treated fairly and respectfully, have equal access to opportunities and resources, and can contribute fully to the organization's success.' Therefore, diversity refers to 'the traits and characteristics that make people unique', while inclusion refers to 'the behaviours and social norms that ensure people feel welcome'. Inclusion is a critical factor which determines the success of efforts towards diversity.

BARRIERS AND DISCRIMINATION: THE EU AND MALTA

Despite various policy efforts spanning decades, the employment rate of people with disabilities remains low. Although increasing, it remains one of the lowest in the EU (29%). In the past few years, various efforts to improve the rate, such as pre-employment training, have been directed at employers. Since 2018 disability pensions continue to be paid when people with disabilities start working. A major issue in the Maltese context is that substantial investment in education does not translate in educational outcomes:

'Government expenditure on education in 2016, as a proportion of GDP (5.4 %) and of total public expenditure (14.1 %), is well above the EU averages (4.7 % and 10.2 %). However, the performance of Maltese students in international assessments remains poor, with major disparities linked to socioeconomic background and type of school as well as disability'.
Even more worrisome is the fact that poverty and social exclusion risks are high for people with disabilities living in Malta. Poverty risks are more moderate than in other EU MS, apart from what concerns people with severe impairments: In 2017 the disability pension for those who cannot work was increased. However, despite pension reforms the Severe Disability Allowance excludes groups with severe psychosocial, sensorial and intellectual impairments. Further, the existing household surveys miss a substantial number of people who are disabled.

BULLYING

Bullying is by definition a form of discrimination. The Center for Disease Control and Prevention (2014) defines bullying as 'any unwanted aggressive behaviour(s) by another youth or group of youths who are not siblings or current dating partners that involves an observed or perceived power imbalance and is repeated multiple times or is highly likely to be repeated' (para. 2). A commonly accepted definition for bullying is provided the book, Bullying at School: What We Know and What We Can Do (1993) written by Dan Olweus, creator of the Olweus Bullying Prevention Program: 'a person is bullied when he or she is exposed, repeatedly and over time, to negative actions on the part of one or more other persons, and he or she has difficulty defending himself or herself'.

This definition includes three important components:

1. Bullying is aggressive behaviour that involves unwanted, negative actions.
2. Bullying involves a pattern of behaviour repeated over time.
3. Bullying involves an imbalance of power or strength.

As Wallis (2010) points out, because bullying is often carried out by young people on young people, incidents which are against the law (such as physical assault, theft, racist taunts) tend not to be reported as crimes. Given that bullying may include physical or sexual harm, damage to property, may make the victim feel intimidated or afraid, or disrupt his or her daily life in a threatening way, in most cases it could be defined as assault or harassment and if reported would be punishable by law. In reality, according to Wallis (2010), bullying is hardly ever reported to the police and if reported at all to school staff or work employers or unions it is usually dealt with internally. The Times of Malta (May 18, 2010), quoting a research done by the British Council, reported that 62% of pupils in Malta consider bullying a problem in their school. If bullying is related to ethnicity, religion, gender identification, sexual orientation or disability, it could be classified as a hate crime.'

ACCESSIBILITY AND ITS IMPACT ON PHYSICAL AND EMOTIONAL WELLBEING

The main barriers to accessibility can be broadly summarized 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 scrutinized by experts on accessibility and the Commission for the Rights of Persons with Disability (CRPD, Malta) 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. Jobsplus, the national employment agency, 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 reliance on 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.

E-ACCESSIBILITY

When discussing barriers in terms of accessibility, one must not overlook the challenges posed by E-Accessibility, namely the use of ICT technology by people with disabilities. Very few websites take into account the specific needs of these individuals, which are complex and varied based on the specific features of each disability. For instance, persons with visual impairment require websites that incorporate programmes that can read text aloud and describe visuals; conversely, people with hearing impairments can be facilitated via combining audio content with text content. The importance of e-accessibility is stressed in the CRPD (Art.9), as well as in the World Wide Web Consortium's (W3C) Web Content Accessibility Guidelines, providing standards to ensure that online information is accessible to all. Similarly, a recent study commissioned by the Council of Europe (COE) as part of its Disability Strategy 2017-2023 – Human Rights: a reality for all provides information and guidance to governments and other organisations in order to ensure enhanced accessibility of information, communication and technology for people with disabilities.

Chapter 2

The International, European and National Legal Framework

The Second World War provided the impetus that resulted in the human rights movement, culminating in the adoption of the Universal Declaration of Human Rights (UDHR) in Paris by the United Nations General Assembly in 1948. This Universal Declaration provides a road map that seeks to protect and safeguard the basic and fundamental rights of individuals irrespective of origin, race or belief. Eleanor Roosevelt, chaired the UDHR drafting committee and has always been recognized as its main driving force. Hernán Santa Cruz of Chile, who was also a member of the drafting sub-Committee, wrote:

> *I perceived clearly that I was participating in a truly significant historic event in which a consensus had been reached as to the supreme value of the human person, a value that did not originate in the decision of a worldly power, but rather in the fact of existing—which gave rise to the inalienable right to live free from want and oppression and to fully develop one's personality. In the Great Hall…there was an atmosphere of genuine solidarity and brotherhood among men and women from all latitudes, the like of which I have not seen again in any international setting.*

With the implementation of the UDHR, the resolve to uphold citizen's rights, in absolute or relative terms according to the nature of certain rights, was formalised. States agreed, with the UDHR and other national legislative motions, to secure inherent freedoms and protections.

The principles on which these laws rests are aimed at ensuring people can benefit from free, safe lives, in equality with each other. 'All human beings are born free and equal in dignity and rights. They are endowed within reason and conscience, and should act towards one another in a spirit of brotherhood'.

Although not legally binding in itself, the UDHR is a document of importance, which provides guidelines, is generally regarded as a milestone in the history of human development, and represents a common standard of achievement. However, its encompassing stance has omitted one important element out of the population:

> *'Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.'*

Persons with disability were not included in the main human rights body – and due to the historical context and the mainstreaming of the biological model of disability, at the time of adoption, they were not at the forefront of the inclusive approach set out in UDHR.

THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITY

Progress found its way through with the UN starting with the 'Declaration on the Rights of Mentally Retarded Persons' (General Assembly, 1971). Whilst striving to reaffirm human rights and fundamental freedoms, a host of international organisations, including the WHO, sought to emphasize the need of dedicating special attention to persons with disability. Much of it, as it can be duly noted below, is still largely drawn up from the medical model: 'The mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.'

The bill's underpinnings are rather clear, and while it was in par with the knowledge base of the time, it did not provide sufficient tools to tackle intellectual disability. Nevertheless, it did offer provisions for ensuring adequate guardianship along with a focus on the severity of their 'handicap', which could have overridden some of the person's fundamental rights in case of restrictions.

'Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.'

Shortly after the 1971 Declaration, another General Assembly Resolution followed (XXX/75), which used the umbrella term of 'disability', thus recognizing its heterogeneity of and setting the basis for equalising PWDs lifestyle to that of a non-disabled person. However, the medical model's approach is still dominant. 'The term "disabled person" means any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capabilities' . For disability theorists worldwide, it is now well understood that the medical model alone cannot provide a functioning and dignified frame of reference for disability . Additionally, the General Assembly declaration from 1975 did not hold enough regulating power to safeguard persons with disability in practice.

Three decades after the creation of the Declaration on the Rights of Disabled Persons, a new legal instrument was adopted and enforced – the Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD, enforced in May 2008, stands out as one of the UN treaties with the highest number of signatories in history. It is, unlike its predecessors, a legally binding instrument, and represents an important paradigm shift in tackling the rights of persons with disability. Its ideological underpinnings lie in the social model of disability rather than the medical model. The emphasis falls on creating an enabling society, one that allows to the extent possible for the person to make his or her own choices, and views disability as an issue rooted in society's inclusiveness rather than on an individual's impairments. Although the idea is not new, it is a hallmark of the prevailing model of thinking for contemporary societies.

Some of the salient breaches of the Convention of Rights of Persons with Disability illustrate the paradigm shift, which marks new heights in disability human rights:

- inhuman, degrading or humiliating treatment;
- under-diagnosis;
- questions over their capacity to make decisions;
- lack of accessible information to make informed decisions;
- stigma in relation to sexual and reproductive health;
- difficulties in maintaining family life;
- poor physical access and inaccessible communications systems;

- institutionalised care with limited funding for independent living and community care.
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- lack of accessible information to make informed decisions;
- stigma in relation to sexual and reproductive health;
- difficulties in maintaining family life;
- poor physical access and inaccessible communications systems; and
- institutionalised care with limited funding for independent living and community care.'

Additionally, the UNCRPD is a legally binding instrument for all the countries that signed the Optional Protocol. The Protocol establishes a committee, which receives individual complaints wherein State Parties might not be respecting sections of the Convention:

> *A State Party to the present Protocol ('State Party') recognizes the competence of the Committee on the Rights of Persons with Disabilities ('the Committee') to receive and consider communications from or on behalf of individuals or groups of individuals subject to its jurisdiction who claim to be victims of a violation by that State Party of the provisions of the Convention. (Section 1, Article 1, UN CRPD Optional Protocol).*

In effect, the Optional Protocol, to which Malta is a signatory, is the executive arm of CRPD and its committee has the power to sanction duty bearers for not respecting the disability rights. There are eight guiding principles that underlie the Convention and each one of its specific articles:

'1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
2. Non-discrimination
3. Full and effective participation and inclusion in society
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
5. Equality of opportunity
6. Accessibility
7. Equality between men and women
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities'.

COUNCIL OF EUROPE DIRECTIVES

In 2000 two main Directives in the field of equality were adopted. Council Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation lays down its purpose in Article 1 which states:

> *The purpose of this Directive is to lay down a general framework for combating discrimination on the grounds of religion or belief, disability, age or sexual orientation as regards employment and occupation, with a view to putting into effect in the Member States the principle of equal treatment.*

Presently there is no Directive in force protecting from discrimination on the grounds of religion or belief, age, sexual orientation and disability outside of the field of employment. In 2008 the Commission presented a proposal for the adoption of Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation. This draft Directive is known as the 'Horizontal Directive' and its aim is to extend protection on the afore-mentioned grounds to the area of accessing goods and services.

THE EUROPEAN CONVENTION FOR THE PROTECTION OF HUMAN RIGHTS AND FUNDAMENTAL FREEDOMS (ECHR)

The ECHR was adopted by the Council of Europe Member States in order to realize the aims of the Council of Europe, namely to promote the rule of law, democracy, human rights and social development. The ECHR legally binds its members to guarantee a list of human rights to everyone within their jurisdiction. The European Court of Human Rights, situated in Strasbourg reviews the implementation of the ECHR.

The ECHR goes beyond the list of protected grounds listed in the Directives. Article 14 of the ECHR, which prohibits discrimination, states that: 'the enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.'

The European Court of Human Rights (ECtHR) has interpreted the category of 'other status' to include those grounds that are expressly protected by the non-discrimination directives, which are disability, age and sexual orientation.

THE EU CHARTER OF FUNDAMENTAL RIGHTS

Article 21 of the EU Charter of Fundamental Rights also prohibits discrimination. The EU Charter of Fundamental Rights, apart from binding the institutions of the European Union also applies to Member States when the latter are applying and interpreting EU Law. Article 21 of this Charter states the following:

> *Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited.*

THE NATIONAL LEGAL AND POLICY FRAMEWORK

Malta Equal Opportunities Act / National Disability Policy

Malta signed the UNCRPD and its Optional Protocol in 2012. In the preceding years, it had already set the foundation for its current models of care. Notably, there are several entities and legal instruments that Malta has relied upon over the past few decades to ensure access to social support for persons struggling with disability. 1987 marked an important milestone in the development of a rights-based approach in Malta: the Kummissjoni Nazzjonali Persuni b' Diżabilità (KNPD) - now the Commission for the Rights of Persons with Disability (CRPD Malta) - was founded and implemented a Social Model (Rights-based) approach. Its immediate priorities focused on giving a voice to PWDs and their caregivers, as well as keeping PWDs in mainstream education. Several achievements in terms of inclusive education have been secured since the establishment of the KNPD, and other auxiliary entities have sprung up as a result of an increasing desire for greater inclusiveness.

The centrepiece of Malta's local legislative framework is the Equal Opportunities Act (413/2000), which recognises PWDs' vulnerable position in society and strives to introduce corrective measures. It regulates anti-discriminatory procedures concerning education, employment and housing, and defines complaints procedures in the case of individual acts of discrimination. 'The Commission may itself initiate investigations on any matter involving an act that is allegedly unlawful under any of the provisions of this Act.' (Part IV, Art 1, Act 413/2000).

The Equal Opportunities Act also develops a framework for anti-discrimination which recognises multiple discrimination. For instance, women with various forms of disability or disabled asylum seekers are particularly exposed to oppression and subsequently vulnerable to abuse and compounded discrimination. The recognition of such vulnerability in a legal instrument adds supports the creation of an inclusive society: '(1) A person discriminates with another person in a multiple manner if apart from the disability there exists discrimination inter alia due to gender, age, civil status, sexual orientation, race, ethnicity, beliefs, skin colour, trade union affiliation or political belief'(Part III, Art 1, Cap. 413/2000).

The Constitution of Malta

Article 45 of the Constitution of Malta deals with the principles of equality and non-discrimination and relates to the protection from discrimination on the basis of 'race, place of origin, political opinions, colour, creed or sex' . Furthermore it stipulates that no law shall make any provision that is discriminatory either of itself or in its effect.

In addition, the Employment and Industrial Relations Act, 2002 (Cap. 452) defines discriminatory treatment as: 'any distinction, exclusion or restriction which is not justifiable in a democratic society including discrimination made on the basis of marital status, pregnancy or potential pregnancy, sex, colour, disability, religious conviction, political opinion, or membership in a trade union or in an employers' association.' The Act also provides protection from victimisation and gives complainants the right to lodge their complaint to the Employment Tribunal within four months of the alleged act of discrimination.

The Equal Treatment of Persons in Employment (Legal Notice 461 of 2004, Subsidiary Legislation 452.95), provides additional protection in so far as these regulations offer protection on the grounds of racial or ethnic origin and also religion or religious belief, disability (emphasis added), age and sexual orientation from direct and indirect discrimination, and harassment. In addition these regulations deem an employer or any person or organisation to have discriminated against a person if they provide instructions to discriminate or neglect their obligation to suppress any form of harassment at the workplace.

Bullying, Violence and Harassment: The Criminal Code and The Equal Treatment of Persons Order

The Maltese Criminal Code does not define harassment, but Article 251A of Chapter 9 of the Laws of Malta (Criminal Code) mentions harassment, without strictly defining it:

‘(1) A person who pursues a course of conduct:

- (a) which amounts to harassment of another person, and
- (b) which he knows or ought to know amounts to harassment of such other person, shall be guilty of an offence under this article (p. 111)’ .

The law, under the same Chapter, Article 251C, also provides that harassment includes ‘alarming a person or causing them distress’. The Black’s Law Dictionary (2009) defines harassment as: ‘words, conduct or action (usually repeated or persistent) that being directed at a specific person, annoys, alarms or causes substantial emotional distress in that person and serves no legitimate purpose’.

In Maltese law a definition of harassment is also found in The Equal Treatment of Persons Order (2007) , which ‘means to subject the person to any unwelcome act, request or conduct, including spoken words, gestures or the production, display or circulation of written words, pictures or other material and to ‘harass a person’ shall be construed accordingly’ (Article 2, p. 1).This law implements the provisions of the Council Directive 2000/43/EC of 29 June 2000 and in particular, the principle of equal treatment between persons irrespective of racial or ethnic origin.

As stated by the UN Secretary General in 2006 ‘in most countries children spend more time in the care of adults in education settings than anywhere else outside of their homes. Schools have an important role in protecting children from violence.’ It is therefore important to use these definitions to set the parameters for action required to be taken in educational settings.

Victims’ Rights: The Victims’ Rights Directive

In 2015, Malta transposed Directive 2012/29/EU of the European Parliament and of the Council of 25 October 2012 establishing minimum standards on the rights, support and protection of victims of crime into national law with the Victims of Crime Bill . Directive 2012/29/EU explicitly acknowledges the needs of people with disabilities, particularly with regard to guaranteeing accessibility to premises where criminal justice proceedings are taking place; ensuring effective communication and information provision; conducting tailored individual assessments; considering the enhanced risks of repeat or secondary victimisation to which people with disabilities are exposed; safeguarding the right to understand and be understood for people with disabilities; and recognising the severity of crimes against people with disabilities because of their disabilities.

Regrettably, the Maltese Victims of Crime Bill remains silent on all these matters, with the exception of the Right to be Understood, formulated as follows:

> *‘(1) In relations with any competent authority in the context of criminal proceedings, all communications between the said authority and any victim shall be conducted in simple and accessible language, orally or in writing. Such communications shall take into account the personal characteristics of the victim including any disability which may affect the ability to understand or to be understood’ (Art.3)*

The lack of depth and breadth of the Victims of Crime Bill, as opposed to the preceding EU Directive hints to non-negligible risks of human rights breaches for victims of crime with disabilities.

Despite these evident gaps in the existent legal framework, a noteworthy development is the establishment of the Victim Support Unit within the Malta Police Force. The Unit started functioning in January 2017 and was officially launched by the Ministry for Home Affairs and National Security on 19 April 2017. The Malta Police Force website describes this development as 'part of its transformation process.'

The functions of the Victim Support Unit are to:

> *'provide a single point of contact for victims of crime, especially the most vulnerable victims, shortly after lodging a police report; provide crisis counselling services to victims of crime, depending on the nature and severity of the particular case; implement tools and procedures that will help police officers to provide for the minimum standards on the rights, support and protection to victims of crime; facilitate effective and timely referrals to other support services; monitor the number of victims that are accessing their rights and victim support services provided by the Police Force; deliver appropriate and ongoing training on victims-centred practices; establish an effective communication and working relationship with key stakeholders, both government and non-governmental agencies'* .

The Victim Support Unit assists victims with their needs and concerns and provide them with adequate support:

> *'The services offered within the Unit will help to minimize the adverse emotional and psychological stresses of victims of crime and also caters for the various police obligations emanating from the Victims of Crime Act, Chapter 539 of the Laws of Malta. Amongst others, Chapter 539 requires the Executive Police to provide victims with written acknowledgement of receipt of complaints, information about non-institution of criminal proceedings, and referral to victim support services'* .

The Victim Support Unit also published a Victims of Crime leaflet, containing standard police procedures to be implemented in all police districts/ branches. This leaflet includes a 'Report Acknowledgment' section which should be filled in by the Police officer taking the report and given to the victim. Moreover, it informs victims that they may wish to opt for support immediately or receive such support at a later stage. The leaflet states that victims 'will be informed with the outcome of the police investigation' and describes the information that they should expect.

Another interesting development of 2017 was the launch of the Victim Offender Mediation Service by the Department for Probation and Parole within the Ministry for Home Affairs. This is a voluntary process consisting of a number of meetings between the parties, led by a specially trained person, with the aim of reaching a compromise that is satisfactory to both sides. Eligible cases may be referred to the Mediation Committee by the Courts, the Parole Board, the Offender Assessment Board and the Remissions Board. The Committee has a duty to analyse all cases referred to it and decide if these merit mediation .

In this regard, the Department of Probation and Parole has organized mediation training, which was accredited by the University of Malta, thus ensuring that mediators are recognized as such in the field of Restorative Justice. Nine probation officers received this training. Moreover, a Victim's Charter has been drafted – it includes information about services offered by the Department of Probation and Parole for victims, as well as information about victims' rights.

With specific reference to child victims, in 2017 the Ministry for the Family, Children's Rights and Social Solidarity, published the National Children's Policy . An important legislative development in 2017 was the enactment of The Child Protection (Alternative Care) Act, 2017 (Chapter 569), the result of a revision of existing child-related regulations in Malta that aimed to create a coherent legislative framework. The Child Protection (Alternative Care) Act, 2017 defines 'significant harm' as: 'abuse, neglect, ill treatment, exploitation, abandonment, exposure, and trafficking'.

It introduces the concept of mandatory reporting of such 'significant harm' to the Director responsible for Child Protection or the Police, and criminalises failure to report with a sanction of imprisonment for a term of four months to one year or to a fine not exceeding €5,000, or to both such fine and imprisonment. Article 8 of this Act places the obligation to report on 'any person', including professional workers and volunteers, who come in contact with a child who is suffering or likely to suffer harm; however sanctions are applicable only against persons who fail to report harm which they come across in the context of their work (whether paid or voluntary) . Upon receipt of such a report, the Director is obliged to conduct an investigation and assessment to determine whether the child is in need of care and protection and take appropriate action, as required. In such cases the Director may:

> *Recommend and/or enforce the provision of support services for the child, taking into account the particular needs of the child; recommend and/or enforce the provision of support services for the child's parents or to any such other person who appears to have responsibility for such child; Issue parent responsibility guidelines; apply to the Court to make an emergency order; apply to the Court to make the appropriate child protection order; submit a report to the Executive Police for further investigations in all cases involving child abuse or neglect; give information to the Police regarding any offence liable to prosecution by the Police in accordance with the relevant provisions of the Criminal Code* .

Moreover, the Director is granted an array of powers to exercise his functions.

Remedies and Access to Justice

In the light of the above discussions and the assessment of the current status quo pertaining to the situation of persons with disabilities, the disparity between law in the books and law in practice becomes apparent. To this end, one would need to turn to the notion of access to justice. Access to justice is a fundamental right, as well as a prerequisite for the protection of all other human rights. Norms and standards relating to access to justice for persons with disabilities are set out in a series of binding instruments at international and regional levels. Despite this, across the world, persons with disabilities face considerable obstacles in terms of access to justice. Barriers can be encountered in a country's national laws that do not adequately consider the rights of persons with disabilities. Barriers can also be faced in the country's institutional justice framework, which includes law enforcement and courts. In addition to being a fundamental right in and of itself, access to justice is also essential in terms of development and poverty reduction, as well as in the protection and enjoyment of other rights.

One of the ways to achieve access to justice is via Legal Aid. Legal Aid allows people with limited to no resources to prepare their defense, lodge claims or otherwise engage with the justice system. It may take several forms and modalities, such as a government subsidy for the use of a specific lawyer, in-kind service provided by the government, legal advice centres, websites or also telephone services. The right to legal aid is inexorably linked to the right of access to justice, the right to an effective remedy and the right to a fair trial.

Many can point to a situation where they, or somebody close to them, was treated unfairly by government authorities. However, most people don't realize that these issues often involve human rights concerns. Some of the worst human rights breaches have happened to ordinary people. Human Rights Law helps us to ensure that our human dignity is always respected – no matter who we are, where we live, or what we do.

Human Rights legislation entails, inter alia, the European Convention of Human Rights, which secures the protection to an individual's right to life, the right to a fair hearing, the right to respect for private and family life; freedom of expression, freedom of thought, conscience and religion; and the protection of property. The Convention further prohibits practices which impinge on such fundamental human rights, such as torture and inhuman and degrading treatment or punishment and discrimination in the enjoyment of the rights and freedoms set out in the Convention, amongst others.

ADVOCACY AND EMPOWERMENT: DISABILITY AND THE HUMAN RIGHTS APPROACH

A structured legislative framework is a tool to combat oppression, as it sets common standards for all individuals groups, including those with vulnerabilities, but it often fails to grasp the backdrop of inequality (Young and Quibell 2010). Research has shown that simply providing a legal response is not sufficient to achieve a true rights-based approach, as rights and empowerment are inextricably linked (Worthen et al 2010).

Empowerment has recently become a buzzword used by an array of agencies, entities and social justice stakeholders to refer to a set of attitudes and beliefs to self-advocate, assume a stance of self-confidence, maximise one's own abilities and diminish oppression, as well as being active towards achieving one's own realization of rights. Creating the space for empowerment and a rights based approach in the case of disability (particularly intellectual), means creating a shift in terms of social development towards PWDs as rights holders rather than charity recipients. As illustrated in the previous chapter, charters and legal frameworks have been created to support such a shift.

Research suggests that even when organisations are aware that they have a legal obligation to comply with human rights, most are yet to fully realise the benefits that can be gained from mainstreaming human rights within community care. Some of the most salient benefits for human rights being used proactively with vulnerable groups in health settings include improved decision-making, which is better reasoned and properly recorded, as well as improved effectiveness in handling complex issues around people's rights. From the service user's perspective, involvement in all aspects of the decision-making process enhances their wellbeing and ability to claim rights.

In relation to intellectual disabilities, developing a strong rights-based approach might prove challenging. As with mental health problems, there are tensions and dilemmas which stem from the disjuncture between the level of ability of people with ID have and the individual capacities of 'conscience and choice' the rights discourse presumes. Neoliberal discourses generally emphasizes the importance of self-advocacy, informed decisions and consent. However, there is a strong debate over the boundaries between the capacity to make informed decisions and the caregiver's obligation to safeguard the person with disability.

In order to shed light on this debate, two instrumental cases from the UK shall be brought to the fore. Both refer to the limit at which safeguarding may be considered a right and where it becomes a privation of liberty as described both in the Convention for Rights of Persons with Disability and the European Court for Human Rights. The 'Bournewood Case' (HL vs. United Kingdom, 1997) refers to the unlawful detention of a person with disability under the umbrella of mental capacity. HL is a nonverbal autistic man with challenging behaviour, who was informally admitted to a psychiatric hospital due to an episode which occurred while HL was attending his day service. His lack of protest was considered 'compliance' and therefore consent. Under Britain's Mental Health Act of 1989, he was declared non-compus menti and withheld at the hospital against his will, while his carers were refused visitation privileges. Only when the ECHR ruled that it was an unlawful violation of Art 5 ('Right to freedom') was he eventually released from the psychiatric hospital .

In Hoskin v. Stewart (2007), S. Hoskin, an adult with learning difficulties (testing placed him at the bottom 0.4% of UK's population) was the target of exploitation and eventually murder at the hand of D. Stewart, a person he considered a friend. According to the case review, Hoskin's life spun out of control under Stewart's care. However, Steven Hoskin had deliberately 'chosen' to discontinue availing himself of social services, opting to maintain as little contact as possible with the health and social care sector . A month after the social visits were discontinued, Hoskin's body was discovered at the bottom of a 30m drop, showing signs of hours of torture prior to his death . Stewart and his girlfriend were convicted of murdering Hoskin, after months of exploitation and financial abuse. The case was instrumental in introducing additional safeguards for PWIDs. The Hoskin case is a case rife with ethical and practical debates over the measures agencies should have taken as a response of a potentially vulnerable situation.

The two cases illustrate two very conflicting outcomes and procedures over two of the main pillars of the human rights approach: choice and consent. As such, developing a functioning rights-based approach must bear in mind the equilibrium, which must be met in order to respect a person's undisputable right to freedom and choice, whilst recognising the vulnerability inherent to belonging to a disadvantaged group. Namely, developing a Human Rights Based Approach (HRBA) requires solid conceptualisation, or it may yield lax results .
Implementing an HRBA requires a certain degree of negotiation between the duty of care and the dignity of risk. The dignity of risk refers to the acceptance of inherent risks that accompany freedom of choice. The United Kingdom National Health Service (NHS) argues that there is a constant push-pull between the duty of care and the dignity of risk, which may lead to a complete standstill. Risk management is built into an HRBA as part of the development training. The purpose of this project is to provide a piloting exploration of the issues surrounding Intellectual disability in Malta and to suggest some fruitful alternatives. These alternatives will advocate for a broadening of rights to facilitate understanding for right holders and Agency staff as the primary duty bearers. A secondary goal of the project is to create an active engagement not only with the human rights, but with the notion of empowerment as well. As such, it seeks to measure practical changes in experiential knowledge about learning and teaching human rights and daily behaviours, which point towards a choice oriented approach.

Chapter 3
Methodology

THEORETICAL UNDERPINNINGS: THE SOCIAL MODEL OF DISABILITY

This project draws on the Social Model theory of Disability studies, which seeks to put an end to disabled people's exclusion and oppression. The Social Model is rooted in the 'Disability People's Rights Movement' of the 1960s and 1970s, which sprung up at the same time as the civil rights movements of the time. Activists who were involved in the movement re-conceptualised disability as a civil rights and equality issue, moving away from the interpretation of disability as a medical or charitable issue. They began campaigning for equal rights and laid down the 10 pillars of independent living:

> *appropriate and accessible information; an adequate income; appropriate and accessible health and social care provision; a fully accessible transport system; full access to the environment; adequate provision of technical aids and equipment; aavailability of accessible and adapted housing; adequate provision of personal assistance.*

The social model, developed and refined over the past 40 years, opposes the medical and charitable models of disability, which focus on the person's impairment, diverting the attention away from the barriers and mechanisms of exclusion which engender disability. These barriers include attitudinal barriers, such as cultural and social norms which give rise to prejudice and discrimination, physical barriers, such as steps, staircases and other, and information and communication barriers, like the lack of Sign Language Interpreters. The Social Model therefore privileges the use of the term 'disabled people' to 'people with disabilities' in an attempt to emphasize the role of society in impairing individuals and groups through exclusion and marginalization.

In a similar manner, this project is rooted in a logic of empowerment, evident at various stages of project implementation. More specifically, the project team created a safe space for people with disabilities to give voice to their lived experiences of exclusion and discrimination, as well as voice their opinion and reflect on what it means to be a rights holder. The various moments of dialogue and reflection that took place in the context of the project, effectively constituted a research phase, aimed at gathering relevant information on disability and human rights in Malta. PWDs themselves took on the role of trainers, co-investigating the issues at hand in their role as insiders. They identified accessible information on rights and mechanisms for redress that can become the foundation of subsequent training for other service users and support workers. By seriously taking stock of service users' narratives, project partners will be able to pinpoint extant societal shortcomings in recognizing and accommodating the needs of people with disabilities, which hinder the full realisation of their potential. By being aware of their rights, beneficiaries will also be able to question and challenge certain practices which are discriminatory and which are affecting their economic and social progress.

The Medical Model of Disability

This is a diagram of the traditional Medical Model of Disability, which the Social Model was developed to challenge.

The Social Model of Disability

The Social Model of Disability states that the oppression and exclusion people with impairments face is caused by the way society is run and organised.

Photo credits: Inclusion London

RESEARCH APPROACH

Partnership, collaboration and power, three elements which interact at varying levels within the framework of the current social model of disability, at a confluence of political, biomedical and social influences. Simply understanding the human rights paradigm in the context of disability isn't sufficient. Researchers are traditionally 'outsiders' and power-holders within the research relationship, due in large part, to the academic knowledge they possess. Post-colonial feminist research aims to deconstruct the boundaries, which define subject and object of research. This project will embrace a community-based participatory research (CBPR) approach, in an attempt to move away from the 'outside expert' role, placing emphasis on negotiating and developing relationships in specific cultural/spatial/political/historical contexts. In CBPR, women, sexual minorities, people with disability, indigenous people and any others confronting structural inequalities are sought out as partners, as a means to bridge the gap. CBPR raises the challenge of extending rights to groups or communities.

Although CBPR is hailed as the most inclusive approach, developed as a response to imbalanced power dynamics, which inherently arise from the researcher – subject dyad when the subjects belong to vulnerable groups, it is not infallible. The most salient caveat concerns defining what counts as a 'community' and the potential for conflict between individual and group interests. Further complexity is added if the topic is controversial and opinions are divided within a 'community'/group. While embracing the CBPR methodology, researchers and trainers gave space and voice to the individual narratives of all participants, through reliance on techniques that can elicit dialogue and discussion in a group setting whilst also keeping disruptive tendencies (e.g. dominance of one or more individuals over the others; uncomfortable atmosphere etc.) at bay.

AIMS AND OBJECTIVES

As previously discussed, this study aimed at:

- piloting a train-the-trainer disability rights course with persons with intellectual disabilities
- evaluating the trainees' understanding of such research and training
- evaluating the impact of the training on the trainees.

The original aims of the trainees conducting peer-led disability rights training could not take place due to the COVID-19 pandemic. In lieu of such training, in-depth interviews were conducted with the trainees, who also recorded video messages on disability rights. This does not exclude the possibility of the trainees conducting peer-led training at a later stage (not as part of this study).

METHODOLOGY

Recruitment of Participants (Trainees)

The research team consisted of 1 University of Malta (UM) Research Officer, 3 persons from the Aġenzija Sapport Research Department (with a lawyer also being present in some of the training sessions), and 2 intellectually disabled persons. The latter were selected by Aġenzija Sapport from previous trainings and work experiences. One of the participants (trainees) faces discrimination on the ground of sexual orientation as well as disability. The trainees were able and willing to participate in the training, with the aim of conducting such training themselves at a later stage.

Once the trainees were identified, their transport and attendance needs were defined together with their home leaders. An initial discussion (pre-session) with all the research team was conducted, to ascertain trainees' receptiveness to study, training and topics covered; their choices of involvement; their knowledge of their rights; and their expectations of the study and training. An Easy Read Information Letter in Maltese (see Annexes) was also presented – and explained – to the trainees. The group put together a set of ground rules to be followed during the training, which were then transformed into an Easy Read PowerPoint presentation in both English and Maltese (see Annexes).

Training

The training was conducted over five face-to-face sessions over the course of six weeks, during the months of July and August 2020. The trainer, an Aġenzija Sapport staff, conducted the training in English while another staff translated into Maltese. The Research Support Officer conducted note-taking during every session and observed how the trainees were responding to the training in terms of content and delivery. These research notes, together with the interviews carried out with the trainees and the video messages they recorded, provided the basis for the analysis provided in the current report. An Easy Read version of the report was also developed.

The training – which was developed based on the topics which the trainees consider most pertinent to their lives – covered the following topics:

- What are human rights? Introduction to UNCRPD - including Easy Read UNCRPD
- Human rights issues across the globe
- Discussion on various human rights topics and their impact on everyday life (including the meaning of informed consent and decision-making)
- Discussion on the research design, agreeing on what is to be included in the final research report
- Overview of training material, revising and reviewing training supports; piloting consent forms
- Devising the training and providing trainer guidance.

These topics do not correspond to single training sessions: the training followed the trainees' needs and aspects brought up by them during the sessions. Thus the topics mentioned above were covered over more than one session and did not necessarily follow the order in which they are listed. Below is a brief description of the content covered in each of the sessions:

TRAINING SESSION 1

Part 1

- Discussion on the project, training content and its evolvement over the course of six weeks.
- Discussion of logistics such as transport to Day Centres (where peer-led training was to be held).
- Recalling of ground rules laid down in the pre-session.
- Discussion of trainees' concerns regarding potential challenges (e.g. people's perception of gay persons)
- Signing of Consent Forms
- Discussion on women's rights
- Introductory game: helping trainees get to know each other better.

Part 2

- What are human rights?
- Human rights in different countries
- Introduction to the UNCRPD Easy Read Version
- The Social Model of Disability
- Discussion on illegal acts and rights
- Lawyer present to answer trainees' questions.

TRAINING SESSION 2

- Practical scenarios (brought up by participants) involving human rights and ethical considerations
- Discussion on rights and expectations of persons with disabilities in residential homes
- Discussion on children's rights.

TRAINING SESSION 3

- Disability rights and accessibility when travelling (at airport, on plane, support / guidance in country of destination, etc.)
- Difference between rights and responsibilities.

TRAINING SESSION 4

- Rights of persons with disabilities in institutions
- Right to freedom from exploitation and abuse.

TRAINING SESSION 5

- Revisiting Disability rights
- Revisiting the Social Model of Disability
- Conclusion.

Various resources were used by the trainers during the sessions, including Easy Read PowerPoint slides, pictures and videos, which were mainly compiled together with the trainees themselves.

Research Methods

The study employed a qualitative approach and included elements of participatory research. While the participatory aspect was intended to comprise a larger part of the research approach, in view of the fact that the peer-led training did not take place as part of this project, there was no scope for the trainees to develop the training they would have facilitated with their peers. Nonetheless, the project was participatory in basing the training content on issues pertinent to the trainees themselves, in compiling the training material (including ground rules) with the trainees, and in enabling the trainees to produce recorded messages for their peers and society in general (see below). In this way, not only did the trainees use the knowledge they gained through the project but they were also involved in disseminating the project outputs in a manner which is accessible to them as well as to other persons with intellectual disabilities.

Following the training course, the trainees were supported in developing key messages for their peers, based on the learnings they had acquired from the training and the project in general. These messages on disability rights (see Outputs section) were recorded as short video clips, thus enabling their easy dissemination and viewing. The research officer then conducted in-depth semi-structured interviews (see Interview Guide in Annexes) with the trainees. These were conducted in their language of choice, i.e. Maltese. Semi-structured interviews were used in order to enable the interviewees to talk about their own thoughts and ideas (Willis 2006), while at the same time targeting the areas relevant to the research through the guide. Thus the trainees were given the opportunity to elaborate on aspects which are important to them, and which the interview might otherwise not have explored.

Once the interviews were transcribed, they were analysed together with the field notes taken during the training sessions as well as the video messages. This was done through coding methods used in Grounded Theory methodology, where a theory is generated from the data collected (Tie et al 2019). In this case, the researcher read the interview transcripts, field notes and video messages scripts, and identified concepts and links between various components of the texts. The transcripts were then coded, that is, “segments of data” were named “with a label that simultaneously categorizes, summarizes, and accounts for each piece of data” (Charmaz 2006, 43). Based on this analysis, the research report was then developed.

Ethical Considerations

The trainees, after having understood the objectives and procedures of the research study and training – with the help of an Easy Read Information Sheet – signed the Consent Forms, also in Easy Read and in Maltese (see Annexes). The Information Sheet (as well as the Consent Form) explained the objectives of the research and training, note-taking and report-writing, as well as ethical considerations including the disposal of information upon termination of the study, anonymisation of names, protection from harm, possibility of leaving the project whenever the participant wishes to, possibility of asking questions, and where / how to ask for more information.

OUTPUTS

Video Message 1: Accessibility

In this video, the trainees talk about various accessibility rights for persons with different disabilities, including persons with visual, hearing, physical and intellectual impairments. The message discusses the capabilities of persons with disabilities, the need for society to adapt and the need for provision of information in Braille, sign language, guide dogs, accessible buildings, job coaches, and why these are necessary and how they support persons with disabilities. It also relays information on where to file a complaint if such rights are not respected.

Video Message 2: Relationships

In this video, the trainees talk about the right of gay persons with disabilities to live like everybody else, their right to be treated like other disabled persons, as well as their right to be free from violence and abuse.

Chapter 4
Analysis

As mentioned earlier, the aims of this project were two-pronged: on the one hand, it involved training persons with intellectual disabilities with the original aim of the trainees implementing peer-led training; on the other hand, it aimed at evaluating the impact of such research and training on the participants (trainees) and their understanding of research. The following analysis looks at these concepts from multiple angles while evaluating them in light of current pertinent literature and national, regional and international disability policies and strategies.

REASONS FOR JOINING THE PROJECT AND FUTURE OPPORTUNITIES

For both trainees, this was the first time joining such a project and both enjoyed the training course: Michael was happy to be given the opportunity to participate in such a project, in order to be able to help others. Both Michael and Tania would join similar projects if given the opportunity in the future, while Michael would also tell his friends to join if possible.

UNDERSTANDING THE CONCEPT AND IMPORTANCE OF RESEARCH

Nonetheless, none of the participants truly comprehend the meaning of research. For Tania, for example, research is an activity that is carried out to find out one's genealogy. Interestingly, neither Michael nor Tania knows what will happen with the research project once it is finished.

Such findings underscore the need to perhaps make clearer the objectives of such research studies through means which are accessible to persons with intellectual disabilities. Relatedly, the importance of rendering the research results and reports accessible to participants with intellectual disabilities – even those with 'less severe' intellectual impairments as the trainees in this study – emerges through Michael and Tania's responses. As Bigby et al (2014) maintain, there is a need for those involved in inclusive research with persons with intellectual disabilities to reflect deeply on the knowledge emerging from such research, and attempt to find different means of gauging its value / contribution towards social change. These aspects, according to Bigby et al, also need to be considered as part of the dissemination stage of the research.

EVALUATION OF TEACHING CONTENT, METHODS AND TRAINERS

While both Michael and Tania liked the training overall (with Michael stating that he would not have changed anything, given the opportunity), Tania observes that she would have liked the content to put more emphasis on regulations regarding disability and gay rights.

Both trainees were satisfied with the teaching methods, with Michael especially enjoying the use of pictures. Tania focuses on the fact that she learnt a great deal on disability rights through the questions the trainers posed to her and the answers she gave:

> *U tgħallimt ta, jiġifieri! Għax tgħallimt ukoll fuq id-drittijiet. Hawn min, jiġifieri persuni b'diżabilita', ma jafx x'inhuma dawn l-affarijiet.*
>
> *And I learnt! Because I also learnt about rights. There are those, meaning persons with disability, who don't know what these things are.*

Nonetheless, when exploring such views, care needs to be taken with regard to the argument, put forward by various scholars (see, for example, Marinos et al 2009, 139; Laws and Radford 1998, 82; Stalker 1998, 6), that persons with intellectual disabilities might be used to complying with what other people – especially 'authority figures' – request of them, either because of the large amount of control exercised by others over their lives, or because of fear of consequences.

EVALUATION OF OUTPUTS (VIDEOS)

Both Michael and Tania enjoyed recording the video messages and would like their friends to see the video clips; while Tania considers them to be important for those who do not know about disability rights: such messages give them the opportunity to learn from others' experiences such as hers. Nonetheless, she observes that there are persons who, because of their disability, would not necessarily understand the messages, hence the need, as mentioned earlier, of reflecting on the dissemination and accessibility of research results and outputs, especially for persons with ('severe') intellectual disabilities.

UNDERSTANDING OF DISABILITY RIGHTS

In their understanding of disability rights, one of the topics that stood out for both Tania and Michael is accessibility rights, especially physical accessibility (e.g. ramps) for persons using a wheelchair. The focus on such rights supports the emphasis placed on accessibility in the National Disability Strategy . The Strategy – still a consultation document at the time of writing in the spring of 2021 – dedicates a whole objective (Objective 2) from its 13 Objectives to accessibility in its various forms. The Strategy recognises the importance of accessibility in the enablement of independent living. Furthermore, it also deals with accessibility in other objectives such as the one dedicated to legislation and access to justice. Thus, the trainees' understanding of accessibility as a key component of disability rights is important in not only increasing their knowledge of such rights but also in their passing on the message to their peers.

Tania also emphasises the importance of the rights of persons with disabilities who are also on the LGBTQI spectrum, especially with regard to their protection from violence and abuse. This topic, together with accessibility, forms the key messages in the recorded video clips (see Outputs section).

Other disability rights which stood out to Tania include the right for persons with intellectual disabilities to manage their assets, including the right to be protected from possible abuse of one's assets by a procurator. This topic is of the utmost importance with regard to persons with intellectual and psychosocial disabilities' right to independent living: the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) , in its Article 12, states that people with disabilities have the right to "enjoy legal capacity on an equal basis with others in all aspects of life" and that they should control their own financial affairs and "are not arbitrarily deprived of their property." However, in Malta, while a Personal Autonomy Act which would enable supported decision-making (instead of substituted decision-making) has been announced, it is yet to be published and enacted. Meanwhile, the Maltese Parliament enacted an Act to amend the Code of Organization and Civil Procedure and the Civil Code for the purpose of providing for Guardianship in order to be compliant with the UNCRPD. The Act states that persons who cannot exercise their legal capacity to the full will be provided with the option of guardianship, instead of the interdiction and incapacitation options. However, the Mental Health Act still permits interdiction and incapacitation. Thus, the fact that Tania is aware of such rights and can contribute towards lobbying for their implementation and to relevant discussions marks progress in the dissemination of knowledge of disability rights and advocacy.

In the interview and video message, Tania also talks about other important disability rights such as protection and support, independent living and employment rights. The significance of providing persons with intellectual disabilities with a job coach, for instance, is one of the key messages emerging from the video clip which the trainees produced on accessibility. Job coaching is compatible with the UNCRPD (Article 27), which states that persons with disabilities have the "right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities." This includes the state's responsibility to provide "assistance in finding, obtaining, maintaining and returning to employment." Thus as Tania rightly states in the video clip:

> *Mhux kulħadd jifhem l-affarijiet bl-istess mod, u għalhekk, job coach jista' jgħinna sabiex naħdmu fuq l-istess livell bħal persuni li m'għandhomx diżabilità, u sabiex ikollna sapport addattat għalina.*

Not everyone understands things in the same way, and therefore, a job coach can help us to work on the same level as persons who do not have a disability, and for us to have support which is adapted to our needs.

Such messages bring home the importance of supported employment – as against sheltered employment – in the open labour market for persons with disabilities. While job coaching in Malta is provided by such entities as the Lino Spiteri Foundation, sheltered employment still exists and is endorsed by the National Employment Policy, despite the fact that the UN Committee on the Rights of Persons with Disabilities notes the incompatibility of sheltered workshops with the UNCRPD and recommends measures to support persons with disabilities within the open labour market.

POSSIBILITY OF PEER-LED TRAINING

When asked about the possibility of teaching other persons with disabilities what they learnt during the training, Michael is very keen to teach the others at Day Centres, and feels prepared to do so:

> *Sakemm jaqbdu naqra ir-ritmu l-ewwel darba… għax nispjegawlhom naqra… [id-] Day Centre, ikolli il karti fuqi… jiġifieri dak ħa jkun miegħi.*

Until they get into the rhythm the first time… because we'll explain to them a bit… [at] the Day Centre, I will have the papers with me… so they will be with me.
Indeed, Michael feels his friends need to know about disability rights, so that they can learn how to respect and help others. He would also like the video messages to be shared and disseminated. Similarly, Tania feels proud that she was able to teach others – through the video clips – and that others will learn from her experiences.

In this regard, the training was quite successful in enabling persons with intellectual disabilities to share their lived experiences as well as the knowledge gained. Through the video clips, such messages can also be disseminated to a wider audience than that which would have been present at peer-led disability training held solely in one or two Day Centres. Nonetheless, there is room for improvement in both the training conducted as well as its outcomes, as discussed in the concluding section of this report.

Chapter 5

Conclusions and Recommendations

As discussed in the previous chapters, the training conducted as part of this project was partially successful in enabling two persons with intellectual disabilities to be familiar with the UNCRPD and thus with the rights of persons with disabilities. It also provided the trainees with the opportunity to share the knowledge they acquired through two video clips which can be easily reproduced and disseminated. Throughout the research project and training, participatory elements were interwoven with traditional research and training methods. This project was therefore a step forward in disseminating and raising awareness of disability rights and empowering persons with intellectual disabilities, who often encounter barriers in accessing much needed information.

Positively, this research project also resulted in tangible outcomes in that the two trainees produced video messages - targeted at their peers and the public in general - on various disability rights. Such ouputs are useful not only in the messages they put across, but also in the fact that videos are easily disseminated and can be used - together with the documents and notes used during the training - by the trainees themselves in future endeavours. Thus the results of these training and research processes were immediately available to the trainees (research participants) in a manner which is accessible to them and other persons with intellectual disabilities.

Nonetheless, as with any research study / training course, there is room for further development. Below are recommendations aimed at improving related future initiatives:

- Training sessions would benefit by being conducted in the primary language spoken by the trainees. Interpreting the whole training session from English to Maltese is time-consuming (also reducing the time which could be spent on actual content) and tends to result in loss of attention or confusion from the trainees' side.
- Relatedly, in future initiatives, such training sessions would benefit from being shorter and being punctuated by more frequent breaks in order to enable the trainees to keep more focused and engaged in the training.
- Refreshments could be left on table to enable the trainees to get up and access them whenever they feel the need to. This would also allow more movement and help retain the trainees' attention.
- Training content format could benefit from being more interactive – rather than the trainer teaching mainly through slideshows – and include formats which engage participants' attention such as more videos, games and discussions.
- In order to maximise the benefits of such training courses, increasing the number of trainees might help in reaching more persons with intellectual disabilities, thus increasing knowledge of disability rights. While it is acknowledged that the number of trainees needs to be kept small in order to meet the trainees' needs and ensure their learning, two might be too small a number to justify a research team of four persons (not including the lawyer) working on the project.
- Finally, more reflection needs to be put into the trainees' understanding of research processes and their involvement in it, including the dissemination phase and its accessibility to persons with intellectual disabilities.

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ITTRA TA' STEDINA

INFORMATION LETTER

FORMOLA TA’ KUNSENS

CONSENT FORM

REGOLI TAL-GRUPP / GROUND RULES

INTERVIEW GUIDE – MALTESE

1. Inti li kont involut/a f’din ir-riċerka, issa x’tifhem bil-kelma riċerka?
2. Għalfejn taħseb li hi importanti?
3. Inti għalfejn iddeċidejt li tieħu sehem?
4. Kienet l-ewwel esperjenza tiegħek?
5. X’taħseb li jsir minnha r-riċerka?
6. Kieku kellek tagħti xi suggerimenti dwar kif saret din ir-riċerka li ħadt sehem fiha, jew tbiddel xi affarijiejt, xi tbiddel?
7. Titħajjar terga’ tieħu sehem f’riċerka?
8. Tħajjar lil sħabek jieħdu sehem f’riċerka ? Kieku x tgħidilhom?
9. Kif ippruvaw jgħallmuk dwar id-drittijiet tal-persuni diżabbilta’?
10. X’għoġbok l-aktar mill-mod ta’ kif ippruvaw jagħllmuk? X’ma’ għoġbokx?
11. Tbiddel xi ħaga kieku?
12. Liema drittijiet tal-persuni b’disabbilta’ taħseb li huma l-aktar importanti?
13. Liema drittijiet tiftakar l-aktar?
14. Liema drittijiet huma l-aktar importanti ghalik personali?
15. Hadt pjacir tiehu sehem fil-videos? Tħossok li għaddejt messaġ lill-persuni oħra?
16. Taħseb li sħabek ser jieħdu gost jaraw dawn il-videos? Tixtieq li jarawhom?
17. Kif tħossok dwar il-fatt li ngħatajt l-opportunita’ li titgħallem u li tgħallem?
18. Min għandu bżonn jitgħallem aktar dwar id-drittijiet tal-persuni b’diżabbilita’?

INTERVIEW GUIDE – ENGLISH