



L-Università ta' Malta
Faculty for Social Wellbeing

Systematic Review

Postgraduate Dissertations on Disability in Malta

Commissioned by the Commission on the Rights of Persons with Disability
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Table of Contents

| | |
|--|----|
| Abbreviations | 6 |
| Forward | 7 |
| Acknowledgements | 8 |
| INTRODUCTION | 9 |
| Methodology | 9 |
| Identification of Dissertations | 9 |
| Selection of Dissertations | 9 |
| Review of Dissertations | 10 |
| Review Outline | 10 |
| Limitations | 11 |
| REVIEW | 13 |
| Human Rights and Legal Aspects | 14 |
| Disability Movement | 14 |
| Disability Rights & Non-Discrimination | 14 |
| ‘Legal Insanity’ and Legal Capacity | 18 |
| Legal ‘Insanity’ | 20 |
| Legal Capacity | 20 |
| Bioethics and Genetics | 22 |
| Life Areas | 25 |
| Education | 26 |
| Students with Dyslexia | 26 |
| Students with ADHD | 26 |
| Students with SEBD | 27 |
| Students with Severe Disability | 30 |
| Students with High Ability | 30 |
| Perceptions and Attitudes towards Students with Disability | 31 |
| The Role of the INCO | 32 |
| The Transition to Secondary Education | 32 |
| The Transition to Post-Secondary Life and Beyond | 33 |
| The University Experience | 34 |
| Employment | 34 |
| Information and Computer-Based Technology | 37 |
| Leisure, Culture and Sport | 39 |
| Leisure and Culture | 39 |
| Sport | 40 |
| Intimate Relationships and Sexuality | 41 |
| Services | 43 |
| Community Services | 44 |
| Residential Settings | 44 |
| Psychological and Counselling Services | 45 |
| Stages of Life | 49 |
| Children | 50 |
| Youth | 50 |
| Families | 52 |
| Families and Couples | 52 |
| Parents | 53 |
| Siblings | 55 |
| Impairments | 57 |
| The Deaf Community | 58 |
| Persons with Intellectual Disability | 58 |
| Persons with Mental Health Issues | 59 |
| Mental Health and Hospitalisation | 60 |
| CONCLUSION | 63 |
| List of Dissertations | 65 |



Acronyms

| | |
|--------|---|
| AAC | Augmentative and Alternative Communication |
| ADHD | Attention Deficit Hyperactivity Disorder |
| AT | Assistive Technology |
| CRPD | Commission for the Rights of Persons with Disability |
| ECHR | European Convention for the Protection of Human Rights and Fundamental Freedoms |
| EOA | Equal Opportunities (Persons with Disability) Act |
| EPA | Enduring Power of Attorney |
| EU | European Union |
| FITA | Foundation for Information Technology Accesibility |
| HR | Human Resources |
| IBL | Inquiry-Based Learning |
| ICT | Information Communications Technology |
| IEN | Individual Educational Need |
| INCO | Inclusion Coordinator |
| ITS | Institute of Tourism Studies |
| LSE | Learning Support Educator |
| LSZ | Learning Support Zone |
| MCAST | Malta College of Arts, Science & Technology |
| MCH | Mount Carmel Hospital |
| MS | Multiple Sclerosis |
| NGO | Non-Governmental Organisation |
| PSD | Personal and Social Development |
| SEBD | Social, Emotional and Behavioural Difficulties |
| UN | United Nations |
| UNCRPD | United Nations Convention on the Rights of Persons with Disabilities |
| UoM | University of Malta |
| VR | Virtual Reality |

Disability Systematic Review

This is one of a series of research projects that attempted to converge in the form of a compendium the varied pieces of research that are relevant to disability policy. It is a much-needed study that helps contribute to the puzzle that we are constructing as a Faculty to map the research strengths and gaps we have in the sector. It is imperative that as a Faculty, now that we are closing up on our 10th Anniversary, have the necessary evidence that will help steer us into the next stage of our existence. A Faculty can only exist within a context and scholarship needs to be a tool that serves the community. Hence understanding where we are at is of the essence and this work led by the Department of Disability Studies gives evidence of this commitment. I would like to thank CRPD for their belief in this Faculty. The comfort of knowing that we have the support of this Commission is welcome.

Prof. Andrew Azzopardi

Dean

Faculty for Social Wellbeing

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INTRODUCTION

This systematic research review identifies and looks at dissertations relating to disability in Malta that were produced in fulfillment (partial or otherwise) of Masters' degrees and LL.D (Doctor of Laws) from 2000 to the beginning of 2018 at the University of Malta (UoM) and in foreign universities. Since most of these dissertations are unpublished, it is hoped that this review will be useful in bringing to the fore research findings on disability in Malta. The aim of this review is to provide a clearer picture of:

- how to better serve people with disability in Malta, through the identification of the challenges and support which different groups of disabled people in Malta encounter in their daily lives;
- which areas (on disability issues in Malta) have been more researched and those less so; and
- which areas, relevant to disabled people's lives in Malta, need to be further explored.

METHODOLOGY IDENTIFICATION OF DISSERTATIONS

The dissertations to be reviewed were identified through searching on the UoM Library portal HyDi, the UoM Library's online catalogue, and the UoM Institutional Repository, OAR@UM. The latter included searches from the following Faculties and Centres: Centre for Labour Studies, Centre for Entrepreneurship and Business Incubation, Centre for Environmental Education & Research, Centre for Resilience and Socio-Emotional Health, Centre for Liberal Arts & Sciences, Euro-Mediterranean Centre for Educational Research, European Centre for Gerontology, Faculty for Social Wellbeing, Faculty for the Built Environment, Faculty of Arts, Faculty of Education, Faculty of Health Sciences, Faculty of Laws, Faculty of Media and Knowledge Sciences, Faculty of Theology, Institute for European Studies, Institute for Tourism, Travel & Culture, Institute of Linguistics and Language Technology, and School of Performing Arts.

Searches were conducted using key search terms including 'masters' 'dissertations', 'disability', 'disabled people', 'people with disability' and 'special needs' (the latter was used in order to ensure the identification of older dissertations). Other dissertations, including ones carried out at foreign universities, were identified through the Wenzu Dalli Resource Centre at the Commission for the Rights of Persons with Disability (CRPD) premises; the online Disability Archive at the Centre for Disability Studies at the University of Leeds; the academic staff at the Department of Disability Studies at the UoM; internet searches; personal contacts; and references in dissertations reviewed.

SELECTION OF DISSERTATIONS

The dissertations reviewed were those which were submitted from the year 2000 onwards. This is the year the Equal Opportunities Act¹ came into force, since findings earlier than this date would not be as relevant to the aim of the present review. The end date was set to the start of 2018, since dissertations submitted during that period were already available at the start of this review.

The dissertations selected were those which are based on the social model of disability or related ones, such as the human rights model, the biopsychosocial model, and the affirmation model. For this reason, those dissertations which research the medical aspects of disability were not included. Furthermore, the dissertations reviewed deal with the topic of disability in Malta and are ones which deal with disability as a main topic, not as a by-product of the main topic of the dissertation.

REVIEW OF DISSERTATIONS

A total of 93 dissertations were reviewed. The method employed in reviewing the dissertations was the following. The abstract was read first, and the salient points of the dissertation were identified. Subsequently, those points were elaborated on through the relevant parts of the dissertation: in social science dissertations these parts are mainly the introduction, results, analysis and conclusions.

In other dissertations such as legal ones, which are not always divided thus, the most important chapters were looked at, or, where relevant, those parts which deal with the Maltese context. The review in the next chapter gives an indication of what each dissertation entails, giving as wholistic overview as possible. Some dissertations are delved into more than others due to various reasons, including: because they explore original topics (that is, topics which were not researched by other students) or because more detail is needed in order to explain the topic. Others were not explored in great detail due to reasons such as the fact that not all the dissertation would be on / relevant to the Maltese context / disability.

This review does not cover all the parts of each dissertation covered. In reviewing the dissertations, due consideration was given to the importance and relevance of the outcomes with regards to CRPD's work with disabled people in Malta. Furthermore, importance was given to the most significant findings of the dissertation, rather than to topics which are just touched upon. Emphasis was put on the recommendations put forward by authors, in order to bring out the more 1 Chapter 413 of the Laws of Malta: Equal Opportunities (Persons with disability) Act (2000). practical aspects of the dissertations and thus lay the basis for future research and action. Where the recommendations have since been implemented, this was noted in the review itself in the 'Reviewer's Note'. Where significant to the results of the dissertation, the methodology and sample size were also mentioned.

REVIEW OUTLINE

The review in the subsequent chapter is divided by theme, with a section for each theme (for example education, employment, etc.) which is covered by the dissertations reviewed. Where necessary, the section is then divided into sub-sections. Some of the sections, rather than by theme, relate to a specific impairment, due to the fact that there are dissertations wholly dedicated to that specific impairment.

Evidently, some dissertations cover more than one theme / impairment. Where this is the case, cross-references were utilised in order to refer the reader to the relevant section where the same theme / impairment is discussed. Nonetheless, each section and sub-section is a stand-alone one in the sense that it can be read and understood on its own. Where there is more than one author with the same surname who submitted a dissertation in the same year, the name initial was used in the text so as to differentiate between authors.

LIMITATIONS

While care was taken to identify all the relevant dissertations, it is possible that the UoM search engines mentioned above might not have shown all results. However, the use of both search engines and other sources helped to mitigate this possible limitation. Since dissertations submitted to foreign universities were partly identified through enquiries, however, some of these might have been missed.





REVIEW
Human Rights and Legal Aspects

DISABILITY MOVEMENT

The lack of a disability movement in Malta is explored by Cardona (2007) and Azzopardi (2000). Both authors identify the reasons for this absence and cite, among others, factors such as the large number of disability organisations controlled by non-disabled people, as well as the fragmentation amongst (and, as Azzopardi notes, sometimes within) disability groups into impairment-specific ones. Azzopardi also notes the fact that disabled people do not feel adequately prepared for proper activism, one of the reasons being the over-involvement of parents. Furthermore, both authors bring to the fore the charity-based model approach to disability in Malta which manifests itself in such events as campaigns to raise funds which often demean and humiliate disabled people. These perceptions, Cardona notes, remain largely unchallenged due to the lack of a disability movement.

Ultimately, Azzopardi concludes that the climate is ripe for the setting up of a coalition of organisations that can effectively combat the oppression of disabled people; while Cardona, writing seven years later, observes the emergence of the opposing of traditional views of disabled people, partly through his (no-longer existing) Maltese Council of Disabled Persons, the first Maltese crossimpairment organisation adopting the social model of disability. Unfortunately, the disability movement in Malta seems to be still non-existent at the time of writing this review in 2018, with some of the reasons cited by both authors still being in existence. Thus recommendations made by Azzopardi, such as the unionising by federating the existing organisations, still stand. As Azzopardi himself noted, while there is a Federation of Organisations Persons with Disability², there were respondents who did not understand its role or responsibility. Furthermore, Cardona notes the need for more empowering and transformative emancipatory research in order to move towards a society in which disabled people's quality of life is, in his own words, "just like anybody else's".

DISABILITY RIGHTS & NON-DISCRIMINATION

Pulis (2001) looks at the Equal Opportunities (Persons with Disability) Act of 2000 (EOA)³ and gives a historical overview and evaluation of the situation of disabled people prior to this Act, including key legislations and milestones relating to disability. The author emphasises that full inclusion and integration of disabled people would be beneficial to all: persons with disabilities would achieve their due rights, governments would be substantially relieved from the burden of social benefits, and the taxpayers would be alleviated from contributing for such purposes. Meanwhile, Borg (2011) and Cutajar (2006) – in attempting to establish whether the rights of persons with disabilities are effectively protected through the legal system in Malta as stated in the conventions and legislations of the United Nations (UN), the European Union (EU), the Council of Europe and national legislation – state that while the rights of persons with disabilities are being protected, adequate protection against discrimination towards disabled people should be provided in the Maltese constitution; and that had Malta adhered to the European Social Charter⁴ protocol⁵, Maltese citizens could benefit from the collective

2 <https://maltafederationoforganisationspersonswithdisability.wordpress.com>

3 Chapter 413 of the Laws of Malta: Equal Opportunities (Persons with Disability) Act (2000). Available at: <http://www.justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=8879&l=1>

4 Treaty No. 035 of the Council of Europe: European Social Charter (1961). Available at: <https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/035>

5 Treaty No. 158 of the Council of Europe: Additional Protocol to the European Social Charter Providing for a System of Collective Complaints. Available at: <https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/158>

complaints system available in this Charter. However, Pulis, Borg and Cutajar all suggest that legislation on its own is not enough. Pulis observes that formal equality, such as enacting laws which impose quotas on employers (which is discussed in depth in the 'Employment' section below) do not work: what is needed is rather positive action in order to do away with the ingrained mentality of discrimination and exclusion by society towards disabled people. Borg also states that most of the laws pertaining to persons with disabilities fail to take into account the diversity between disabled persons, who need different resources depending on their disability.

Furthermore, she argues that it would be better if the Commission for the Rights of Persons with Disabilities (CRPD)⁶ were entrusted solely with either the role of implementation (of policies) or that of monitoring (their implementation): in order to better safeguard rights, it would be best to have two different entities. Borg also suggests the implementation of other aspects outside the legal system, including:

- better awareness of these rights;
- the collection of data on persons with disability; and
- a network between various disability non-governmental organisations (NGOs) and committees that will ensure the better implementation of these rights.

Ultimately, rights are of little value if they are not accessible: as Borg and Cutajar both observe, persons with disability face barriers in access to courts, since they are at times precluded from personally appearing at court because of poverty and physical disability (an observation echoed in the 'Employment' section below). As Borg points out, the CRPD can only bring an action before the court once it has been concluded that no amicable settlement, for a particular complaint, has been achieved. At times courts fail to take into consideration the needs and impairments of the person with disability and the effect it has on his/her life, as was seen in the partial reversal, by the Court of Appeal, of the decision taken by the Court of First Instance on the Case *Il-Kummissjoni Nazzjonali Persuni b'Dizabilta' v. Michele Peresso Limited* (2007). Borg states that courts should strive to interpret and apply legislation in a manner that better protects the rights of disabled people (and not give rulings based on the medical model of disability); and that the general public is also persuaded of the worth of legislation protecting disabled people's rights.

While Pulis, Borg and Cutajar take a wide approach to the legislative frameworks protecting disabled people's rights, Grech (2017), Busuttill (2017) and Camilleri (2012) focus more specifically on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)⁷, the EU's and Malta's ratification – and lack of compliance with certain articles – of the Convention and its optional protocol⁸, and the subsequent amendments to the EOA. The authors provide a number of recommendations aimed at ensuring the full inclusion of disabled people in Maltese society, including:

- the early and full involvement of disabled people in policy making;
- reasonable accommodation to ensure disabled people's full participation in all areas of life;

6 <http://crpd.org.mt>. Formerly known as *Kummissjoni Nazzjonali Persuni b'Dizabilta'* (KNPD).

7 United Nations Convention on the Rights of Persons with Disabilities (2006). Available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

8 Optional Protocol to the United Nations Convention on the Rights of Persons with Disabilities. Available at: <https://www.ohchr.org/en/hrbodies/crpd/pages/optionalprotocolrightspersonswithdisabilities.aspx>

- the creation of a single National Human Rights Institution⁹;
- the enactment of the Bill¹⁰ which enables the provisions of the UNCRPD to be enforceable as part of the Laws of Malta;
- the inclusion of disability as an area where discrimination is unconstitutional;
- ensuring equal right to work for disabled persons;
- ensuring that when criminally charged persons with disability are to be informed in an accessible format;
- ensuring that when voting, persons with disability can be assisted by a trusted friend; and
- the development of more effective disability awareness raising campaigns.

Other recommendations specific to the EOA include:

- that the Board set up by the EOA with the aim of determining what is reasonable should have its current scope changed and focus on seeking accommodation rather than what hinders such accommodation;
- with regards to Article 19 of the Convention (on the right of persons with disability to live independently), it is recommended that this right within the EOA should be amended so that disabled persons are provided with a choice of living arrangements with the necessary support;
- that the obligations of guardians of persons with disability are subject to the rights present within the EOA, particularly the right present in article 3(8);
- the contribution that employers are asked to contribute when not complying with the employment quota are to be increased possibly up to the minimum wage, thus reducing the possibility that employers opt out from employing persons with disability (an issue discussed more in depth in the 'Employment' section); and
- that moral damages as envisaged in the EOA are increased.

Zooming further in, Bezzina (2015) looks at interagency collaboration and the National Policy on the Rights of Persons with Disability¹¹ of 2014, exploring its origins, drafting, which interests were addressed and which were the pressure groups lobbying for such a policy. After conducting interviews with representatives of different government departments as well as the CRPD and the Kumitat Azzjoni Lejn Soċjeta' Ġusta¹², the author reports that while most interviewees express similar ideas of what they understand by interagency collaboration –

9 In 2014, the government launched a scoping consultation to collect input from the civil society, trade unions, political parties, governmental institutions and the general public on the Human Rights Framework in Malta. A common recommendation in most of the feedback received referred to the setting up of an independent National Human Rights Institution (NHRI). More information can be found here: https://meae.gov.mt/en/Public_Consultations/MSDC/Pages/Consultations/HumanRights.aspx

10 Bill No. 104: United Nations Convention on the Rights of Persons with Disabilities Bill (2015). Available at: <https://parlament.mt/12th-leg/bills-12th/bill-no-104>

11 National Policy on the Rights of Persons with Disability (2014). Available at: <https://activeageing.gov.mt/en/Pages/National-Policy-on-the-Rights-of-Persons-with-Disability.aspx>

12 <https://activeageing.gov.mt/en/News/Pages/Jitwaqqaf-il-Kumitat-Azzjoni-Lejn-So%C4%8Bjeta'-%C4%A0usta.aspx>

and all of them agree on its advantages – few are convinced that this is actually happening in Malta. Furthermore, there seems to be an agreement that interagency collaboration should be a top-down process, starting at the top levels of the agencies involved and then flowing towards the lower levels. In contrast to this, not all interviewees agree at what stage in policymaking interagency collaboration should commence.

Interestingly, Bezzina finds that this type of collaboration was more present in the process of formulating the Initial Report submitted by Malta under article 35 of the UNCRPD¹³, than on the afore-mentioned policy and the consultative document that was issued prior to the publication of the policy itself.

Farrugia (2015) and Brincat (2014) too look at Malta's compliance with the UNCRPD, specifically with regards to its articles 12 (on equal recognition before the law) and 13 (on access to justice),

arguing that Malta is not in line with the Convention on these aspects as its laws are based on substitute decision-making, rather than supported decision-making as proposed by the UNCRPD. The Mental Health Act¹⁴ still permits interdiction and incapacitation, which revoke and limit the legal capacity of the person concerned, while the UNCRPD clearly argues that these should be abolished.

Guardianship legislation¹⁵, although a step in the right direction and an improvement on the previously existing legal tools – such as in providing for concrete measures to ensure the accountability of the guardians – is still a half measure and does not fully comply with the UNCRPD. Farrugia and Brincat thus argue for:

- supported decision-making legislation;
- more regular reviews of the guardianship orders,
- the assignments of monitors to guardianships; and
- the introduction of an Adult Protection Act.

Relatedly, Ellul (2015) analyses the Mental Health Act and the human rights and social inclusion of persons with mental health problems (which are further explored in the sub-section 'Persons with Mental Health Issues'). The author explores the discrimination and stigma that people with mental health problems face and analyses the various provisions found in the Mental Health Act in relation to the UNCRPD. She argues that such provisions as those regarding community based services, voluntary admission to a mental health facility and the setting up of the Office of the Commissioner for Mental Health¹⁶ are all measures which help to safeguard the human rights and dignity of people with mental health problems. However,

¹³ The report is available at: <https://www.gov.mt/en/Government/Press%20Releases/Documents/pr150271a.pdf>

¹⁴ Chapter 525 of the Laws of Malta: Mental Health Act. Available at: <http://www.justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=11962&l=1>

¹⁵ Act No. XXIV of 2012. Available at: <http://justiceservices.gov.mt/DownloadDocument.aspx?app=lp&itemid=24286&l=1>

¹⁶ <https://deputyprimeminister.gov.mt/en/CommMentalHealth/Pages/Commissioner-For-Mental-Health.aspx>

she also notes that the Mental Health Act does not do away with involuntary admissions, and suggests that it should be made explicitly clear throughout the provisions that in respect to admissions to mental health licenced facilities, voluntary admissions are the preferred alternatives to involuntary ones.

Human rights with regards people with mental health problems are also explored by Gatt (2016), who looks at the prohibition of inhuman and degrading treatment of prisoners under the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR)¹⁷, whose provisions are incorporated in Maltese law. Gatt looks at the treatment of prisoners with mental health problems at a European level and also in Malta, including court cases with regards to this issue. She concludes that in Malta, an infrastructural change for the accommodation of prisoners with mental health problems at the Mount Carmel Hospital (MCH)¹⁸ Forensic Unit needs to take place: the place is not large enough for the always-increasing number of prisoners. The author mentions that other states are trying to divert prisoners with mental health problems from the criminal justice system (an issue which is discussed further in the subsequent section) by providing prison diversion schemes, which have contributed towards reducing overcrowding in prisons. She also emphasises the importance of prison authorities and prisoners maintaining an active role in the development process of domestic mental health policy development. Furthermore, reintegrating a prisoner with a mental health problem back into society will cause exacerbated challenges if one's mental health needs are not addressed. In addition, there needs to be a continuation of the care from prison to the community setting, given that many persons with mental health problems already face difficulties in managing their basic needs without substantial distress.

Therefore, it is of utmost importance that offenders, after completing their sentence, are given guidance and support to maintain a healthy and crime-free lifestyle in the community.

'LEGAL INSANITY' AND LEGAL CAPACITY

Legal 'insanity' The four dissertations discussed in this sub-section look at 'legal insanity'¹⁹ and other grounds of exemption related to disability under the Maltese Criminal Code²⁰. Camilleri (2017), D'Amato (2009) and Zammit (2001) all explore the legal insanity plea, albeit from different aspects. The Maltese court can only condemn a person to have committed a crime if they have the intention to commit that act; hence if such action is committed by a person who is deemed as having legal insanity, the court cannot condemn that person. However, as Camilleri and Zammit observe, the Maltese Criminal Code does not define what legal insanity is and the Maltese Court often uses either that provided by Common Law or the definition provided by criminal theorists, primarily the definition given by the late Sir Anthony Mamo "as disease of the mind"²¹.

17 European Convention for the Protection of Human Rights and Fundamental Freedoms of the Council of Europe (1953). Available at: <https://www.echr.coe.int/Pages/home.aspx?p=basictexts&c>

18 <https://deputyprimeminister.gov.mt/en/mch/Pages/home.aspx>

19 The term 'legal insanity' is used with regards to exculpation due to mental health problems, where an individual is not held criminally liable if they 'unintentionally' commit a criminal act. This reasoning is the basis of defence of criminal insanity (Camilleri, 2017).

20 Chapter 9 of the Laws of Malta: Criminal Code. Available at: <http://www.justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=8574>

21 Sir Anthony Mamo, Mamo Notes 1954, vol 1, 84

Consequently, Malta has one of the most restrictive interpretation of this legal concept in Europe. Hence, both Camilleri and Zammit argue for the introduction of the concept of “diminished responsibility” to cater for persons with mental health problems or intellectual disability.

Meanwhile, D’Amato (2009) argues that it is not possible to holistically understand the issues relating to criminal insanity without any appreciation of the medical perspective of the subject, thus the law should make use of medicine to understand / explain such behaviour.

The author observes that generally three psychiatrists are appointed to examine the accused’s mental capacity. Other witnesses like his/ her relatives and people close to the accused are also examined. Ultimately, however, it is not the medical experts that decide the issue, but, as Camilleri (2017) states above, it is up to the court to define it. There were cases, like the Degiorgio one²², where it emerged that the accused, although he had a personality disorder, did not manifest any psychotic disorder. Thus although his mental capacities were diminished, it was not severe and therefore the lack of intent and volitional capacity was not complete: he understood his conduct and could have controlled and refrained himself from committing the acts.

Zammit (2001), on the other hand, discusses the issue of confinement of persons found “not guilty by reason of insanity” to a psychiatric hospital, and examines alternative approaches in foreign law. The main dilemma surrounding the treatment of offenders with mental disorders is whether they should be treated as “mad, bad, or both”, since they fall within the penal and psychiatric systems, two systems which often have differing aims and functions. Among various issues which Zammit explores, one argument is that those with severe forms of psychopathic personalities are unlikely to benefit from any kind of mental hospital treatment; and that in most countries they are cared for in special hospitals or special units in prisons.

Moreover, the Maltese Mental Health Act states that if the accused is found to be insane at the time of the offence, s/he is to be kept in custody in a hospital, “whether or not he is insane at the time of the criminal proceedings”. Zammit also explores the concerns arising from the fact that since a person is remanded to MCH by a court order, the Minister of Justice regulates certain aspects of his/her detention. The author thus recommends that while the test of insanity should remain as is, the chain of consequences which are produced by the verdict should be examined, arguing that there might be offenders who were really insane at the time of commission of the offence but who are deterred from pleading insanity because they prefer to be awarded a definite sentence than an indefinite stay at MCH. Other recommendations put forward by Zammit are that:

- the insanity defence is raised with other preliminary pleas (thus eliminating the possibility of pleading insanity at a very late stage in the trial);

²² Ir-Repubblika ta’ Malta v. Christopher Degiorgio (1997)

²³ The author of the dissertation recognises that sociologists say that the term is degrading. However, this is the term used in the Maltese Criminal Code (replacing the term “deaf and dumb”).

- the insanity plea be decided by the presiding judge (who will be aided by a psychiatric report on the accused), and not by a jury;
- the Court should have the option to order the person to do some kind of community service, and not necessarily admit the person to a psychiatric hospital.

Thus there needs to be a major rethinking of the whole system.

Depasquale (2005) explores a related concept to criminal insanity, that of “age and deaf mutism”²³, which are both grounds under which a person can be exempted from their criminal punishment, or else have their punishment reduced. In both categories, the Maltese Criminal Code treats persons as having a defect in their intellectual capacity and development; therefore minors under the age of nine are exempt from any criminal responsibility, whilst “deaf mutes” under the age of fourteen enjoy the same treatment. Even when the person who is “deaf mute” has attained the age of fourteen, they are still exempt, unless the necessary “mischievous discretion” (ħażen) is proved: therefore the law does not presume that a “deaf mute”, of any age, is capable of acting with mischievous discretion. Depasquale argues that the law should regulate society according to the present time and age, taking into account all the advances achieved which have substantially diminished the gap of intellectual development between a person who is deaf and a person who is not. Depasquale also argues that while imprisonment should never be imposed on juveniles and young offenders, it is of the utmost importance that such offenders are made aware of their wrongdoings and the damage they inflict on society. The author suggests various ways in which this can be done, including: the introduction of open centres which cater for young offenders (depending on the offence committed and their respective ages); and the wider application of, as Zammit (2001) argues above, community service orders (particularly through work that remedies the harm done both to society as a whole or to a particular person / group of persons). Depasquale argues that a healthy juvenile justice system does not necessarily mean the total elimination of offending by young persons, but rather having an efficient and effective system to tackle and rehabilitate such offenders.

LEGAL CAPACITY

This section looks at different aspects of legal capacity which can affect disabled people's lives, including the Enduring Power of Attorney (EPA), interdiction, and the special needs trust.

The EPA was introduced under Maltese law in 2012, offering vulnerable adults having mental difficulties because of old age and/or a disability, “an instrument of self-determined substituted decision-making which better safeguards the latter's autonomy and self-determination”. This is explained by J. Attard (2017), who delves into the legislative background before the

introduction of the EPA, the Civil Code²⁴ (which regulates the EPA) and various legal concepts such as substituted and supported decision-making (discussed in the ‘Disability Rights & Non-Discrimination’ sub-section) which are discussed with regards to the relevant provisions found in the UNCRPD. The study also includes a comparative study of this subject covered by various European jurisdictions, and international and regional instruments. J. Attard concludes that, under Maltese law, the EPA is governed by strict formalities. However, she proposes a number

²⁴ Chapter 16 of the Laws of Malta: Civil Code. Available at: <http://www.justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=8580>

of measures to improve such formalities so as to reduce as much as possible the chances of abuse against vulnerable people.

These recommendations include:

- the careful drafting of EPAs: when creating an EPA, care should be taken to ensure that the legal document reflects the mandator's (the person on whose behalf the EPA is created) wishes and expectations;
- stricter execution requirements that include a medical declaration procured within a stipulated time-frame;
- the appointment of joint mandatories: in the event that one mandatory (the person who is authorised to act on behalf of the mandator) is either unable to take up the role, resigns or dies, the EPA terminates automatically. This problem could be addressed if joint mandatories are nominated;
- private and public supervision mechanisms;
- the development of a Code of Practice which provides guidance and examples of best practice to both practitioners and carers working with vulnerable adults; and
- greater awareness of the benefits of EPAs.

Pace (2017) – looking at the administration of property of others under Maltese Law and the protection afforded to persons with disabilities – shows that this area contains fragmented legislation, since related provisions are to be found in different sections of Maltese laws; thus she recommends that these legal provisions are integrated. Furthermore, interdiction and incapacitation, for example, follow the substituted decision-making system, as mentioned earlier.

However, Pace argues that new methods, such as the EPA, can be followed. She also analyses forms of abuse and discusses the extent of protection that the Maltese legal system offers to vulnerable adults (namely the elderly and persons with mental or physical disabilities) in this area, including a detailed analysis (together with a number of recommendations to improve it) of the Draft Bill entitled the Protection of Vulnerable Older Persons and Adult Persons with Disability Act²⁵. Pace makes two main recommendations to reduce such abuse and to protect vulnerable individuals: the introduction of a new legislation regulating this area; and that legal provisions offering protective measures to these vulnerable adults should entail the least possible restriction to their legal capacity, thus being more in conformity with the UNCRPD.

Laferla (2009) notes that while most parents of a disabled child have undoubtedly thought of how they could provide for the needs of their child after their death, they would probably resort to the traditional solutions available under Maltese law, since they are still not familiar with the mechanism of a special needs trust. One example of a traditional solution that Laferla mentions is that during their lifetime, the parents of a disabled person can seek the interdiction of their child and demand that a curator be appointed to take care of him/her. The Court, after ascertaining the condition of the person to be interdicted, verifying the circumstances and being satisfied with the need to interdict, issues a Decree of Interdiction and nominates a curator (usually the parents themselves, siblings or close relatives) to take

²⁵ <https://activeageing.gov.mt/en/Pages/Protection-of-Vulnerable-Older-Persons.aspx>

care of the interdicted person. However, the curator is hedged with rules and restrictions, mainly those which bind them to have recourse to the court and obtain authorisation from the court to dispose of / deal with the property of the interdicted person.

Another option, that of an outright bequeath to a child, will most likely reduce or even disqualify them for social assistance. Parents are often faced with the possibility of having to disinherit a child in order to preserve the child's right to receive social assistance. Today this problem can be solved by creating an effective financial plan for a disabled child, and such plan must allow the providing of all that the disabled person needs without limiting the person's access to the available benefits. A special needs trust helps parents accomplish this goal. A trust is a legal mechanism set up by an individual (the settlor) creating a fiduciary relationship in which one person (the trustee) holds the title to the trust estate or trust property for the benefit of another (the beneficiary). There is thus the interaction of 3 persons: the person setting up the trust, the person who will manage the trust, and the person who will benefit from the trust. The property that is to be put in a trust can consist of any type of assets, including real estate, stocks, cash, bonds, mutual funds or insurance policies. This choice leaves complete freedom for the parents to manouver without the need for court intervention, and the trustee can act autonomously when s/he manages and administers / deals with the property held in trust.

BIOETHICS AND GENETICS

While the previous section looked at human rights in general, this section looks at a specific aspect of legal and moral issues related to disability: that of genetics and the related field of bioethics. This important issue has been placed in a section of its own due to its emerging and controversial nature which might be lost in the larger field of human rights and discrimination. While the the topics explored in these dissertations do not deal wholly with disability in Malta, the issues are still very important to this field.

Caruana (2017), Falzon (2014) and Piscopo (2014) explore the legal and ethical issues with regards to disability in light of new biotechnology advancements. Falzon's and Piscopo's dissertations deal with cases (in EU member states and the United States) of 'wrongful births' and 'wrongful lives', resulting from such advancements which help people not only plan their families, but also find out whether their unborn baby is disabled or not, have babies through artificial means, and select between embryos to discard those deemed less healthy. The two authors look at lawsuits brought by parents who claim that they parented a child (very often a disabled one) due to having been given the wrong advice or treatment before – or during – pregnancy, thus resulting in a 'wrongful birth'; or by disabled people themselves claiming damages arguing that their 'wrongful lives' were the result of negligence on the part of professionals and/or hospitals. Meanwhile, Caruana looks at human genetic engineering and explores the possibility that therapeutic human germline editing²⁶ can end up discriminating against the rights of persons with disabilities as declared in various international human rights legislation such as the UNCRPD. Caruana explores germline editing – which can modify the genome of future generations to produce 'designer babies', thus potentially eliminating

26 Germline gene therapy is when the DNA is transferred into reproductive cells. This allows for the correction of disease-causing genes that will be passed on from generation to generation. <https://www.yourgenome.org/debates/is-germline-gene-therapy-ethical>

disability – from the lenses of disability justice and ableism. She discusses the approach that this technology is undertaking, which is generally medical, abelist, and possibly eugenic.

Both Falzon (2014) and Caruana (2017) conclude that advancements in biotechnology can be discriminatory towards disabled people. Relatedly, Piscopo (2014) recommends that Malta signs the European Convention on Human Rights and Biomedicine (Oviedo Convention)²⁷ which offers the best recommendations on how to promote the protection of human rights in the biomedical field. Meanwhile, Falzon – analysing these issues from a Catholic moral perspective – argues that existence can never be considered an injury, thus such cases are seen as devaluing the lives of persons with disability, especially when courts award compensation because of ‘wrongful births’ and ‘wrongful lives’. According to Falzon, the way society views disability has to continue to evolve through time, justice and human nature so that society will truly start to promote a culture of life.

He notes that the absence of a clear regulatory framework in relation to prenatal testing in Malta may be damaging in several ways. Caruana, meanwhile, suggests that potential discrimination in human germline editing is not automatic and can be prevented if this practice is well regulated, utilising the legal concept of justifiable discrimination that allows differential treatment through the use of reasonable and objective criteria. The author also discusses the importance that the public becomes more aware of the valid contributions that persons with disability offer society. This can be best done by involving persons with disability in these discussions, particularly in the formulation of the regulations. The author recommends that these regulations:

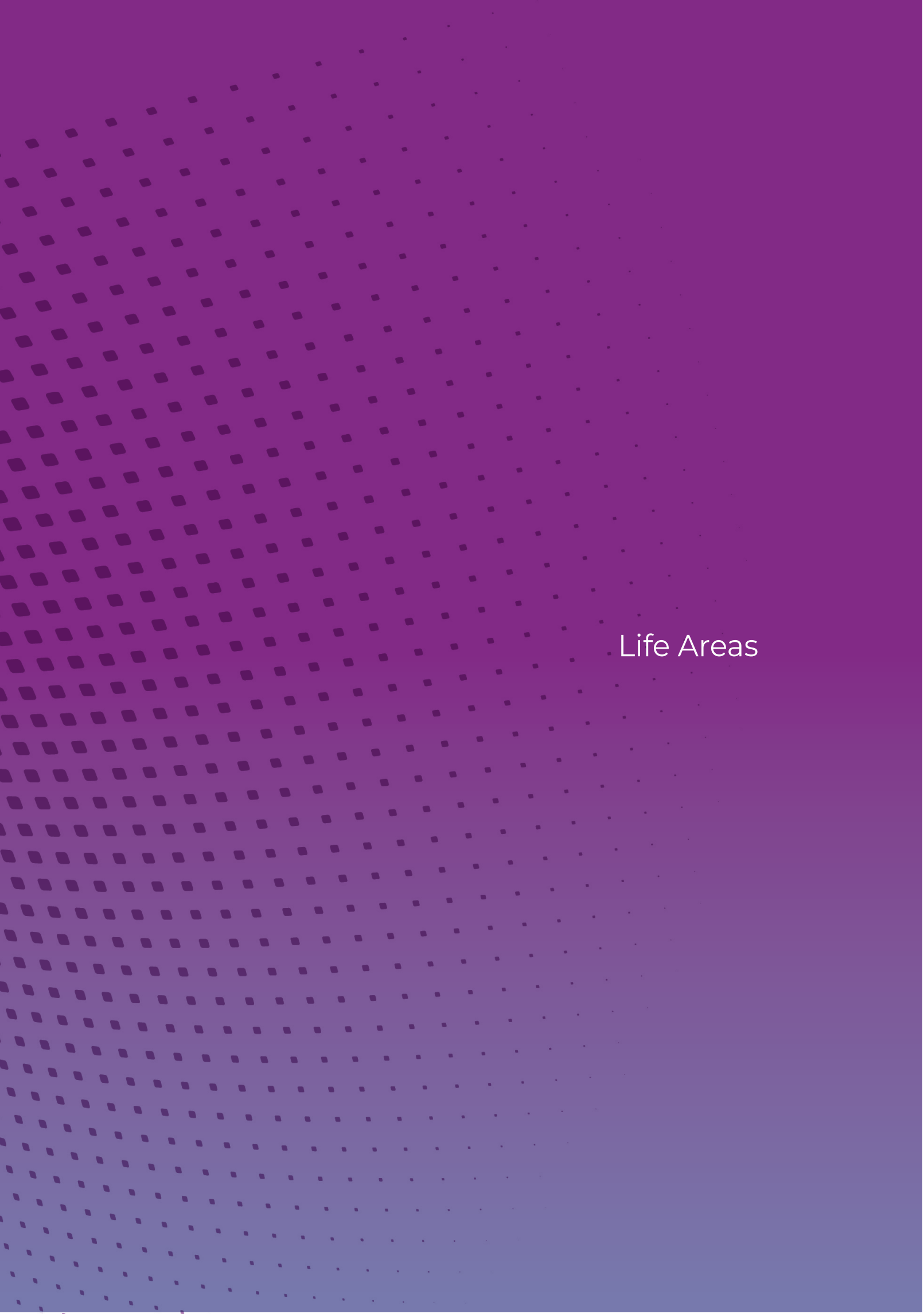
- include that these measures are to be undertaken initially only to prevent death;
- include the agreed definition of the ‘seriousness’ of conditions; and
- state that these practices follow the WHO International Classification of Functioning, Disability and Health.

Caruana’s recommendations would prove even more beneficial when taking into account Cremona Caruana’s (2016) study. Cremona Caruana (2016) looks at the various models of disability proposed over time, with the biopsychosocial model being the preferred one at the time of writing.

His dissertation discusses the stories of various disabled people found in literature and films, and goes on to discuss the relationship between the work of disability activists and bioethics (the study of ethical issues in the fields of biology and medicine), with special reference to transplants and euthanasia. He recommends that the two areas of bioethics and disability should compliment each other and that bioethics should support persons with disability to have the best quality of life possible. One way of doing this is by having bioethics focus on training professionals working in the disability field to change their approach when caring for and treating their clients with disability, and acknowledge that they have an active role to play rather than remaining passive recipients.

27 Treaty No. 164 of the Council of Europe: Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (1999). Available at: <https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/164>





Life Areas

EDUCATION

Education for disabled students is a subject researched from multiple aspects, as seen in this section. Research areas include inclusive practices; learning support zones; students with dyslexia, Attention Deficit Hyperactivity Disorder (ADHD), learning disabilities, Social, Emotional and Behavioural Difficulties (SEBD), challenging behaviour, and high abilities; Inclusion Coordinators' (INCOs) roles; primary, secondary and tertiary education; the transition from secondary and post-secondary education to the next stage; and sport in education²⁸. Students with Dyslexia Briffa (2015) investigates literacy skills in nine year-old students with dyslexia in state schools in Malta and Gozo. Interviewing also their parents and teachers, Briffa explores the various difficulties that are experienced by these students, both related to literacy as well as to other areas of learning and overall educational achievement. The research confirms that bilingualism increases the educational difficulties encountered by these students. Research participants also express the opinion that the curriculum is too heavy, and that too many changes within the curriculum are happening all at once. Examinations also increase the pressure on all stakeholders involved. Parents and teachers feel that they are not consulted enough. Training for both parents and teachers is also needed in order to help their dyslexic students / children. Teachers, for example, are not aware of relevant resources available from the Education Department. The importance of early diagnosis and intervention, collaboration between the various professionals (including the complimentary teachers), and parental involvement are also emphasised. It also emerges that the children with dyslexia themselves prefer active involvement in learning rather than passively receiving information, findings that are confirmed in studies with children with other types of difficulties, as seen in the rest of this section.

STUDENTS WITH ADHD

Camilleri (2015) investigates the experiences of six sixteen year-old male students with ADHD and their parents and finds that they experience school negatively. These students find it difficult to engage in the learning process, and feel that there is too much emphasis on academic subjects. They 28 Other dissertations dealing with education and students with disability explore educational interventions, rather than social and environmental factors. Thus, while being of the utmost importance, they are not directly in line with the scope of this review and were not included. also feel that their efforts are not recognised and appreciated enough by their teachers. Relations with school staff are generally reported to be difficult, although relations with the learning support educators (LSEs)²⁹ tend to be better and closer. However, some participants express the view that their LSE also hinders their social development. Thus Camilleri notes the importance of effective classroom management and a flexible curriculum that allows lessons to be more stimulating, similar to findings noted in the 'Dyslexia' and 'SEBD' sub-sections. The parents, too, complain of the rigidity of the education system which does not permit enough flexibility to let these students develop in their own way. Camilleri recommends:

- fostering a better understanding and collaboration between students, their parents and school staff;
- more awareness about ADHD;
- more training on teaching methods to address the learning styles of students with ADHD (findings which emerge in relation to other types of disabilities, as noted throughout this section); and
- the amendment of existing policies related to behaviour management, the curriculum and roles of school staff, in order to ensure that schools are truly inclusive to students with

ADHD.

STUDENTS WITH SEBD

Cefai (2009) analyses how SEBD students are included or excluded in the Maltese state mainstream primary classrooms. Her research shows that a nurturing and inclusive school ethos would help in supporting both the teachers as well as the students. Cefai puts forward the views of children with SEBD, who, among other suggestions, express the wish:

- of not being immediately blamed by their teachers when they misbehave in class;
- to be given extra help after school;
- to have more individual help in class;
- to have the teacher simplifying the lessons;
- to have more Personal and Social Development (PSD) lessons; and to move during the lessons, as it is impossible for them to stay concentrated on tasks all day long without moving (this links to Spiteri's 2012 findings – discussed further below – on the role that physical activity plays in improving children with SEBD's experience).

Both Cefai and Camilleri (2012) – who examines the relationship between teachers and students with SEBD in a secondary boys' state school – talk about the role of teachers with students with 29 Formerly known as LSAs (Learning Support Assistants).

SEBD. Camilleri reports that teachers' attitudes can be a factor in inducing misbehaviour and that the students with SEBD participating in her research feel that teachers prejudge them without taking the opportunity to first get to know them (recalling Cefai's findings discussed earlier). Both Camilleri and Cefai note that their research participants (teachers and students) feel that teachers lack the knowledge, confidence and motivation to deal effectively with these students and that the Faculty of Education³⁰ needs to adequately train its student-teachers on SEBD. Cefai also suggests that, with the ever-increasing number of SEBD students, local primary schools need to have specific plans of action on how to cope and deal with these students. Together with the plan of action, schools should also be equipped with a practical behaviour policy. Teachers should be given an active say in the development of this plan. Cefai also points out the need for:

- the development of adequate syllabi;
- an inclusive pedagogy;
- effective teaching resources;
- effective human resources; and
- a new approach to teaching and learning. This would include emotional literacy, an intervention strategy which centres upon raising the pupils' achievement as well as their personal and social development.

Camilleri also notes that students with SEBD argue for:

- more flexible classroom management;
- more positive provisions (such as private reprimands), rather than punishments;

³⁰ <https://www.um.edu.mt/educ>

- caring teacher-student relationships; and
- learning and mentoring groups.

Finally, Cefai also suggests the use of nurture groups.

The role of these nurture groups (temporary transitional settings – lasting from one to four semesters – that prepare pupils with SEBD to cope better with the demand of mainstream schooling) is explored by Fenech (2012) and Cutajar (2009). In her dissertation, Cutajar implements and evaluates a Nurture Group programme to support two students with SEBD who live in a residential home. The study reveals that both children improved in nearly all areas assessed, and were reintegrated back into mainstream school. Furthermore, the nurture group staff left a positive impact on mainstream staff, in terms of adopting more nurturing approaches in their classrooms.

However, the author notes that the group did not have all the characteristics of a nurture group, which reduced the effectiveness of the programme and did not allow the nurture group programme to reach its full potential. The author recommends that a nurture group should comprise ten to twelve students and be located within a mainstream school setting so as to facilitate the children's reintegration into that school. Additionally, Fenech reports that part of the success of nurture groups is due to the involvement of mainstream teachers, together with good communication between the nurture group staff and the mainstream teachers. However, the latter express their desire to have more time which they can dedicate to these groups. Through her study, Fenech also finds that the nurture groups help the whole school in being a more nurturing place for its students. Fenech makes a number of recommendations, including:

- better communication between stakeholders involved in order to ensure continuity of services provided and a smooth transition from mainstream class to the nurture group and vice versa;
- more support to mainstream class teachers who should all benefit from the services of a teaching assistant in their class, thus ensuring that the classroom teacher has more time that can be dedicated individually to their pupils;
- classes with a smaller number of pupils; and
- professional training of nurture group teachers.

Since parental involvement seems to be minimal in the schools that Fenech studies, she also suggests further research to see what is causing such barriers.

Camenzuli (2012), Grech (2012), Spiteri (2012) and Zahra Lehtonen (2012) explore other avenues of supporting children with SEBD. Learning Support Zones (LSZ) are regular weekly sessions, offered over one semester to students with SEBD, to provide them with an opportunity to improve their skills and engage more constructively in the classroom. Zahra Lehtonen investigates the reintegration of students from the LSZ back to their classroom. Taking an action research approach, the author, herself a coordinator of one of these zones, manages the reintegration of eight male students of a secondary school. She identifies eight main factors which contribute to the successful reintegration of these students:

- parental support;
- the relationship of the LSZ coordinator with their students;

- the continuation of support by other teachers;
- an effective LSZ programme;
- the preparation of students for transition into and out of LSZ;
- evaluation of students' progress and readiness;
- peer support and relationships; and
- full support from the School Management Team.

The author recommends that the reintegration programme of these students:

- is given its due importance;
- be included in the LSZ Guidelines;
- and forms an integral part of the programme of each student attending these zones.

Another avenue which can be explored in order to support students with SEBD is the Circle of Friends, which Grech (2012) looks at in her dissertation. This programme also endeavours to create a safe environment wherein a group of people support a person experiencing exclusion (in this case, a student with SEBD). Grech, a PSD teacher, formed this Circle of Friends and found that the disabled student improved both his self-concept and his self-esteem. At the end of the programme, the student:

- managed his behaviour better;
- started to offer solutions to his difficulties;
- was able to build new relationships with some of his peers; and
- started to be included by his peers in their activities.

All the participants were able to better identify the positive qualities of the person they were supporting. A program like Circle of Friends, which is tailored made for students who experience neglect and exclusion, can be a useful tool to be used by the teacher.

Camenzuli (2012) specifically explores how the use of Inquiry-Based Learning (IBL) can help students with SEBD better learn Mathematics and reports how the research participants – boys in a Form 3 class of a church school – seem to enjoy and appreciate taking an active part in Maths lessons, and exhibit no deviant behaviour during these lessons. This study thus found that IBL can be of benefit when teaching Maths to students with SEBD: it seems to exploit, rather than inhibit, SEBD characteristics. Such benefits are more pronounced when IBL is utilised in a cooperative learning environment where students feel secure and work as a team. The author encourages Maths teachers to adopt IBL and recommends schools to include IBL in their School Development Plan and Training.

Spiteri (2012), on his part, looks at the effect that physical activity can have in improving the school experience of children with SEBD, which recalls Cefai's (2009) findings described in the beginning of this sub-section. Spiteri reports that his research participants (including the Sport Promotion Unit staff, Physical Education teachers, class teachers and heads of school of primary schools) believe that physical activity can have a positive effect on students with SEBD. The author writes about the importance of educational practitioners being able to develop flexible school policies and practices based on the desires and needs of their students. This means that if children with SEBD are responding positively to physical activities, such

activities should be maintained, if not increased. The research participants also emphasise that competitive physical activities very often are not suitable to these students as most of them find difficulty in coping with the negative emotions that competition creates. Physical activities have to be well planned to encourage effort by the students, good sportsmanship, and the possibility of improving their performance. The research finds that positive reinforcement, reward systems and activities with short term targets are suitable to be used with students with SEBD. These students also find that physical activity helps them to use their energy in a positive manner.

STUDENTS WITH SEVERE DISABILITY

Abela (2012) reflects upon the experiences of social inclusion or exclusion of boys with moderate to severe disability attending secondary school, and finds that severe communication difficulties are related to higher levels of exclusion by peers (a topic discussed in greater detail in the next subsection).

She suggests that children like the four boys she observes in her research should be taught how to interact, and that speech is not the only medium towards successful communication: there are gestures, signs, pictures and objects. Children need to be encouraged to explore alternative means of communication. Assistive Technology (AT) – which is explored more in the section ‘Information and Computer-Based Technology’ – is another area that needs to be taken into consideration: in the case of severe communication difficulties, AT can make it easier for children to make themselves understood.

STUDENTS WITH HIGH ABILITY

Since the concept of inclusive education is linked to individual educational needs, it also includes students with high ability (“gifted and talented students”). However, Maltese developments in this area are still very limited. This is the topic of Ghirxi’s (2012) dissertation, who investigates the social and educational experiences of students with high ability as perceived by themselves and their teachers. She notes that the most striking finding from her research is the high motivation of these students: they are inquisitive, strive for excellence, are aware of their strengths, are self-disciplined and show great persistence when faced with challenging tasks. Ghirxi notes that these students have high expectations for their future. She concludes that their educational and social needs require attention in mainstream classes and that if they have a facilitative environment (including support from parents and teachers), they do well both socially and academically. The author notes the need for:

- further research in this area;
- the provision of adequate mentoring and identification of underachievers;
- the provision of opportunities to talented students to work with peers of similar ability;
- parents and teachers to have realistic expectations and give talented students the opportunity to decide for themselves;
- training to teachers on good teaching techniques for talented students; and
- a national policy on talented students.

PERCEPTIONS AND ATTITUDES TOWARDS STUDENTS WITH DISABILITY

While perceptions of, and attitudes towards, people with disability emerges in multiple dissertations reviewed in other sections, two dissertations deal specifically with these aspects in education. Borg (2009) and Dimech (2007) explore these aspects with regards to primary and secondary school students respectively. Borg, taking a sample of 4 mainstream classes, finds that the student with physical disability but with age appropriate cognitive and social skills is highly accepted by peers. In contrast, pupils with disability who lack age appropriate social skills, social emotional and intellectual maturity – or have behaviour difficulties – are rejected or isolated, and have a lower social position than their peers (confirming Abela's 2012 findings discussed in the previous sub-section). The author also notes that the climate in the class of the child with physical disability is more inclusive and provides more opportunities for the child with Individual Educational Needs (IENs) to relate to her peers; while in the other classes there is evidence of prejudice against those who do not share the desirable characteristics of intellectual ability and sociability. Thus, Borg questions the benefits one expects from mainstreaming of children with IENs in regular schools, since the mainstreaming of the children in the study did not automatically improve their relationships. The findings of this dissertation also show that teachers are not always in favour of inclusion; and that teachers' viewpoints and attitudes are critical in guaranteeing the success of inclusive practices.

Dimech (2007), on the other hand, looks at a sample of boys in three secondary church schools, each of which has a different experience of inclusion: the first one was participating in an 'Inclusion Programme' with a special school³¹ for disabled students; the second one had students with disability in their classes; while the third one had no students with disability present in their classes. In-class inclusion is found to be more influential than an Inclusion Programme (at least in its then current form). The type of contact and the severity of the disability also play an important role in the formation of perceptions, attitudes and behaviour. In fact, the study finds that the interviewees see themselves more as helpers of their partners at the special school, rather than friends. Furthermore, the same students have reservations when it comes to introducing their peers with disability to their circle of friends. Similar findings emerge with the group which had no students with disability present in their classes. This implies that the visits to the special school did not have the desired positive effects on the students in the first group. Their contact cannot be described as realistic, since it only consisted of two visits during the scholastic year; while the contact that the second group experienced was an integral part of the school timetable, that is, both students with and without disability followed the same curricula (albeit with some slight modifications in certain cases). Thus, since they had more time and could become much more involved in purposeful activities, the second group's perceptions, attitudes and behaviours towards their peers with disability were improved and reinforced. Furthermore, the way the Inclusion Programme was being implemented brought disruption to the activities going on at the special school (which then also resulted in challenging behaviour from the special school students, rendering the visitors more lost and uncomfortable) and the participants did not always understand what was going on during the visits to the special school. The special school teachers suggest inviting the whole class of a student with a disability from the mainstream to join him during his special therapy sessions at their school (this was then being carried out to a small extent at primary level:

³¹ Special schools have now become Resource Centres. More information can be found here: https://education.gov.mt/en/education/student-services/Pages/Special_Education/Resource%20Centres/Resource-Centres.aspx

they suggest this should also be done at secondary level). The author suggests the implementation of a programme in Malta that was implemented in Ireland, where students with severe to profound disability participated in link programmes with their peers without disability for a whole scholastic year, once a week, for activities in arts, crafts and physical education. (Dimech notes that a similar programme was in fact already being used by a school in Gozo.) Finally, another idea proposed by one of the interviewees was to invite students with disability from the special school to his school.

These experiences would be beneficial if they become part of the regular timetable, thus laying the foundations for a framework which would improve inclusion and exclude segregation.

THE ROLE OF THE INCO

Inclusive education is further explored by Tanti Rigos (2012), who looks at the role of the INCO through tracing the path that led to the “birth” of this role and trying to identify in whose interests she, as an INCO, continues to carry out observations, judgements and assessments on students. She argues that the creation of the role of the INCO (just like the wider movement towards inclusion and inclusive education) was not triggered by caring sentiments and disinterested efforts to help disabled people and students: rather, it was born out of a much wider political project fueled by the needs of the economy. Evidence of this is the development of one syllabus for all students.

Nonetheless, the author argues that the INCO can serve a positive purpose, both within school and within society. While the role of the INCO might be “dangerous” because it pushes forward some agenda of an institution that has taken the lead discourse in the matter, it can still promote a just society, initially through practices of inclusion in schools which should later be disseminated to society at large.

THE TRANSITION TO SECONDARY EDUCATION

Borg (2012) explores the transition of boys with IENs from primary to secondary schools. Exploring the views of professionals, students and their respective parents / guardians, the author recommends:

- more individual attention to these students;
- listening to what they have to say;
- more training to teachers involved; and
- a whole-school approach.

She also proposes a sample of a conceptual socio-emotionally literate programme for students with IENs which would address such issues as:

- the peer pressure exerted on these students;
- the difficulties encountered by these students when relating with their parents, their teachers or their friends;
- the difficulties in learning;
- the importance of friendships; and
- how to tackle bullying, stress, anxiety and lack of self-esteem, and expressing themselves about their feelings.

THE TRANSITION TO POST-SECONDARY LIFE AND BEYOND

Galea (2015) and Mula Falzon (2012) explore the transition of students with learning disabilities from secondary and post-secondary school to the next stage of life. Galea researches this topic with regards to students who are eighteen years old and attend a Resource Centre, and finds that students' aspirations differ – being higher – to those of their parents and educators (a finding similar to ones discussed in the 'Children' section), indicating an element of overprotection (a theme which is recurrent throughout other dissertations). However, the students interviewed identify their parents as the main actors who will be supporting them in finding employment. Meanwhile, the Resource Centre offers these students vocational subjects such as 'Independent Living Skills' and 'Employability Skills'. The author makes a number of recommendations, including:

- training to parents regarding overprotection;
- more inclusive practices (such as peer mentoring system) in secondary schools;
- self-advocacy training to students with learning disabilities;
- long term policies to guarantee a steady flow of services to promote the activation of disabled persons into employment;
- more information to students with learning disabilities about the benefits they are entitled to when employed;
- more awareness and training to employers on these issues (which is, once again, a recurrent theme, further discussed in the 'Employment' section); and
- well planned transition programmes.

For transition programmes to be successful, Mula Falzon, who develops transition programmes for eight male government secondary school students and their families, states that they have to be student-centred, help the student to develop the necessary skills for self-determination and selfadvocacy, and should include training in daily living and social skills. Mula Falzon finds that – during the transition period from secondary school to post-secondary life – parents and students experience emotions such as fear, worry, a degree of overprotectiveness and a sense of helplessness. Parents demand more accessible information in order to be in a better position to make informed choices and support their offspring during this transition. Hence, the researcher recommends the development of a comprehensive booklet containing information on available services in this area, including post-secondary courses and training schemes. Cooperation between the different professionals involved (INCOs, guidance teachers, college career advisors, teachers and LSEs) is also emphasised. On a national level, the author calls for a national policy on the development of transition planning practices, thus empowering students and their families to own the transition process.

Pleven (2015) explores the experiences of eight people with intellectual disability in their post-secondary years attending the Malta College of Arts, Science & Technology (MCAST)³² Pathway to Independent Living Programme³³ and the Key Skills for Independent Living Course at the Institute of Tourism Studies (ITS)³⁴. She finds that more mainstream post-secondary options

³² <https://www.mcast.edu.mt>

³³ <https://www.mcast.edu.mt/154>

³⁴ <https://its.edu.mt>

are needed for people with intellectual disability, as well as more awareness on the available post-secondary options. While the research participants note their positive experiences at these two programmes, some of them encountered some challenges when they started more mainstream courses at MCAST, including bullying and difficulty of content. This indicates that more support is needed for students with intellectual disability in mainstream courses in order to bridge the transition to more mainstream courses at MCAST. Disability awareness training for students at MCAST and ITS as well as teaching basic skills such as using public transport and self-advocacy skills to people with intellectual disability are also very important. With regards to the outcome of mainstream postsecondary education, most participants remark that the courses that they followed at MCAST and ITS have further prepared them for employment.

THE UNIVERSITY EXPERIENCE

Spiteri (2015) delves into the experience of three university (undergraduate and postgraduate) students with physical and visual disability. Two of these three students drive but only one uses his own transport to go to university, because of parking problems. Barriers to inclusion experienced by all three students are various, including physical and attitudinal ones, together with lack of sufficient support services. This study also shows that these students have to be more resilient than their peers to be able follow through their studies, thus increasing their stress levels. Although experiencing a degree of isolation, they also have friends who very often serve to fill in the gaps and provide the support needed by these students. The participants are critical of the support they are given by the authorities as very often they are not individualised enough, especially when it comes to exams, timetabling and seating facilities in lecture rooms. The author strongly recommends:

- more disability awareness (a recurrent theme throughout dissertations discussed in various sections);
- the implementation of the principles of Universal Design³⁵ (a concept also recommended by dissertations discussed in the 'Leisure, Culture and Sport' and 'Children' sections);
- better support services; and
- more consultation with the students with disability themselves.

EMPLOYMENT

The seven dissertations explored in this section look at disabled people's employment in Malta, from disabled people's and employers' perspectives. Four of them look at employment from the legal aspect (other legal aspects related to disability are dealt with in the 'Human Rights and Legal Aspects' part of the review); while the other three look at the employment of people with physical and intellectual disability and the effectiveness or otherwise of the recently enforced quota legislation system: the 2% quota of disabled employees that an employer who employs 20 people or more has to employ. This measure, introduced through the 1969 Disabled Persons (Employment) Act³⁵ More information on the Universal Design Principles can be found here: <http://universaldesign.ie/What-is-Universal-Design/The-7-Principles-Act>³⁶, was only enforced in 2015³⁷ by introducing an annual contribution that employers have to pay if they fail to meet this quota.

36 Chapter 210 of the Laws of Malta: Persons with Disability (Employment) Act. Available at: <http://www.justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=8718&l=1>

37 Act No. XXII of 2015. Available at: <http://justiceservices.gov.mt/DownloadDocument.aspx?app=lp&itemid=26998&l=1>

In his dissertation, Axisa (2018) conducts interviews with ten Maltese employers – coming from different service industries in the private sector – who have disabled employees in their workforce. Axisa reports that the disability quota in employment is still a grey area amongst employers, with many unanswered questions, mixed feelings and misconceptions about persons with disability in employment: while all the research participants admit that their knowledge of the quota increased dramatically when the government decided to enforce it, most of them lack detailed knowledge of it. Most of them do not have a specific policy regarding persons with disability, with some even questioning its need. Many express their concern that they have disabled employees who are not registered and hence they do not count when it comes to establishing their quota. Participants also admit that they receive financial and other human support (mainly through job coaches) to recruit disabled employees, but very often the human support is of a short duration and thus not enough. Ultimately, most participants are sceptical about enforcement and some even argue that the contribution which employers have to pay if they do not satisfy the quota is simply another government tax. Among other recommendations, Axisa recommends that more research is carried out on this subject; while one of the employers suggests more awareness and education to employers on these issues.

While Axisa looks at the employment of people with disability from the point of view of employers, I.M. Zammit (2017) conducts interviews with both people with physical disability and also with Human Resources managers. Among other findings, Zammit reports on:

- the stigma and discrimination experienced by disabled job seekers;
- the lack of disability awareness of recruiters; and
- the generally positive effect that the quota enforcement system has on the recruiters.

His study also shows the lack of accessibility in Malta (a theme which emerges in other dissertation discussed throughout this review), together with other barriers, and concludes that Maltese jobseekers with a physical disability have less chances of being employed when compared to their non-disabled peers. Career progression is also quite rare. The author recommends that:

- job agencies and rehabilitation centres provide education about this area;
- various media be utilised to raise disability awareness;
- young people with disability continue to be educated in mainstream settings;
- employment centres ensure that persons with disability are well informed regarding policies and services available in this area;
- employers be held liable if interview venues are not accessible;
- legal assistance be provided to employees with disability who feel that they do not advance

in their career due to their disability;

- more consultation by authorities regarding the employment quota system is held;
- there is better enforcement with regards to reasonable accommodation; and
- adverts related to the job interviews are accessible to all.

A. Attard (2017) focuses her research on a young man with intellectual disability employed with a local company, while also interviewing his parents, supervisor, colleagues, job coach

and staff from an employment agency. The author likens the journey of employment to the experience of riding a bicycle, where one removes any obstacles that may come in the learner's way and continues to support the individual until they are confident enough to let go and ride independently. The author states that the way forward should focus more on incentivising employers to offer job opportunities to persons with disability rather than penalising them for not conforming to legislation. Findings from this study were passed on to the Lino Spiteri Foundation³⁸ in the belief that, although the story of the participant with intellectual disability in this dissertation is unique, its narrative can help other persons with intellectual disability to find and maintain employment. Bonello (2015), Camilleri (2010), Zammit (2010) and Bezzina (2005) look at the legal frameworks encompassing employment and persons with disability in Malta (with Camilleri taking a wider approach and looking at how the EU, including Malta, tackles discrimination in the area of employment). National and international legal precursors, and legislation subsequent to, the EU Council Directive 2000/78/EC³⁹ – considered as the most important instrument the EU has adopted in the disability field – are explored, as well as the directive itself, with both its positive aspects and limitations. Malta adopted this Directive regarding the disability sector mainly through the EOA.

Camilleri and Bezzina both discuss, among other aspects, direct and indirect discrimination; and Camilleri also looks at relevant cases at the European Court of Justice⁴⁰. Camilleri and Zammit also discuss the proposal for a new horizontal anti-discrimination directive which has not yet materialised. Through interviews, Zammit, corroborating J. Attard's (2017) findings discussed earlier in this section, finds that enacting legislation is not sufficient in ensuring that disabled persons achieve their right for equal treatment. Despite writing ten years apart, both Bonello and Bezzina conclude – through interviews and analysis of data – that Maltese persons with disability are still finding various barriers to access the Maltese labour market. Bonello reports that these problems are further accentuated in the case of persons with intellectual disability, mental health problems and older persons with disability. Reasons include:

- low level of education;
- lack of physical accessibility (especially transport) – corroborating I.M. Zammit's (2017) findings mentioned earlier in this section; and
- employers' negative attitudes.

The three studies result in various recommendations, which include:

- the development of an EU disability-specific directive, protecting disabled people in all walks of life;
- local legislation to be continuously updated to be fully compliant with European and international legislation;
- that the definition of disability be the same in different local legislations;
- reinforcement of the access of disabled people to justice or conciliation procedures

38 <http://linospiterifoundation.org>

39 Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation. Available at: <https://eurlex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32000L0078:en:HTML>

40 https://europa.eu/european-union/about-eu/institutions-bodies/court-justice_en

regarding employment (recalling the general access to justice discussed in the 'Disability Rights & Non-Discrimination' sub-section);

- support to disabled persons so that more disabled persons can speak out for their rights (confirmed also by the findings in the 'Disability Movement' sub-section);
- more and better vocational training and professional training of vocational trainers;
- further support to employers in providing equal treatment (including reasonable accommodation and physical accessibility at the workplace) to disabled persons;
- a mixture of law enforcement of existing legislation and soft law initiatives to be observed on a voluntary basis;
- government-funded schemes to encourage persons with disability to move from sheltered employment into open employment, or to become self-employed;
- more state funding of NGOs working in the disability sector;
- more consultation between all stakeholders (government, employers, unions and persons with disabilities);
- more accessible public transport;
- statistical data on this sector to be gathered and analysed properly; and
- more awareness raising in all sectors of society.

INFORMATION AND COMPUTER-BASED TECHNOLOGY

Debono (2006) brings to the fore the importance of making effective use of Information Communications Technology (ICT) in order to support disabled people in bridging the digital divide.

The author argues that the digital divide between disabled and non-disabled people arises because disabled individuals and those whose decisions bear on disabled people's lifestyles, fail to perceive the enabling qualities of ICT. Despite the fact that his dissertation was written more than a decade ago, many of Debono's observations are still valid today, such as the oft-cited fragmentation of services (see the 'Families' section). In order to combat this, the author recommends that a coordinating body should be set up. The author also recommends that government and private enterprises cooperate in developing better policy and service delivery: a 'joined up' approach has already proven to reduce the fragmentation that can create barriers to community participation (examples include the initiative by Foundation for Information Technology Accessibility (FITA)⁴¹ together with (the then) Maltese Council of Arts and Technology, the Education Division, the Ministry responsible for information technology and local commercial enterprises). Debono also notes that removing the digital divide is a cross-cutting issue and will require leadership, funding, and the involvement of major business companies. He also recommends that policy makers must allow plans and projects to evolve organically from the people they aim to help, and provide support mechanisms to truly enable the development of sustainable projects. Furthermore, aggressive awareness initiatives are needed to educate disabled persons who could benefit from assistive technology, their families and friends, service providers, and the public about assistive technology available today. Finally, Debono recommends future research to substantiate the effectiveness of these

⁴¹ <https://fitamalta.eu>

recommendations in ensuring that Maltese disabled persons can participate as full members of society, and to evaluate the perspectives of other stakeholders like service providers, employers and organisations whose role is to support disabled persons.

De Martino (2017) and Gatt (2007) both look at the role technology in the school experience (which is discussed in detail in the 'Education' section). Gatt explores communication through technology of children with learning disability and complex communication difficulties. She analyses the barriers which prevent the provision of Augmentative and Alternative Communication (AAC) systems to these children. Through interviews with professionals – including speech and occupational therapists and special education teachers – and family members, it emerges that, at the time of reporting, AAC in Malta was still emerging and was surrounded by lack of awareness, inequality of opportunity and provision, negative attitudes and lack of training and funding. Similar to what Debono (2006) notes, Gatt also observes that territorialism prevails between different government and non-government organisations, wherein teams function in a multidisciplinary setup which lacks sound support services for AAC users and their families. Gatt notes that there also seems to be remnants of the medical model, with funding opportunities for communication aids being mainly charity based. Respondents in this study call for more collaboration between major stakeholders and a person-centred approach towards service delivery. The author recommends, among others, that:

- legislative measures are put in place in order to ensure that the EOA and the Education Act⁴² are in line with the UNCRPD;
- a national AAC policy be developed to provide equality of opportunity;
- AAC users have access to AAC in the classroom;
- manual signing and other means of communication are introduced at National Curricular level; and
- more research is carried out to analyse the barriers to active participation.

Gatt suggests that by successfully overcoming these barriers, the benefits of AAC will be experienced by more Maltese students with complex communication difficulties.

Technology for the classroom is also explored by De Martino (2017), who notes that while teachers need to be able to understand and empathise with students with autism, they are often unprepared for including an autistic student in their class because they cannot fully visualise the experience that the student goes through. De Martino creates a tool (an app that combines with a Virtual Reality (VR) headset) in order to enable teachers to experience the student with autism's experience. Using narratives from parents of autistic children as well as experts in the field of autism and learning with autism, her project focuses on re-creating the classroom experience as perceived from the autistic learner's perceptions that include sights, sounds, actions and interactions.

Diacono (2015), meanwhile, looks more specifically at internet access for people with visual impairments. Conducting his research with adults – the majority of whom identify as totally blind or having severe visual impairment and use computers regularly – Diacono observes

42 Chapter 327 of the Laws of Malta: Education Act. Available at: <http://www.justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=8801>

43 <http://openingdoors.org.mt>

that Braille's standing as the principal means of reading for people with visual impairments has been in steady decline, while text-to-speech technology has the potential of being a learning curve-free source of the published word. The author recommends, among others:

- a one-size-fits-all web page structure for news portals;
- diffusion of government information and commercial website; and
- further research on related issues.

LEISURE, CULTURE AND SPORT

This section looks at the often neglected (in research as in services) leisure and sport aspects of disabled people's lives in Malta. A recurrent theme emerging from most of the dissertations discussed in this section is the importance of sport and activities such as performing arts in challenging the medical model, which – as has been established from previous sections – is still the predominant view of disabled people in Malta. The dissertations also look at barriers that disabled people encounter in accessing leisure, cultural and sport activities, not only in people's attitudes, but also in terms of physical accessibility.

LEISURE AND CULTURE

L. Attard (2017) explores physical accessibility as a key barrier to disabled people in Malta. While she looks mainly at accessibility in places of entertainment as experienced by six young adults using a wheelchair, her findings and recommendations can be generalised to many different places in the Maltese islands (as seen in the 'Families' section below). Her study confirms that wheelchair users experience many obstacles with regards to accessing entertainment and leisure activities, and thus their opportunities to entertain themselves are substantially reduced, to the detriment of their overall quality of life. Such restrictions end up influencing negatively their opportunities for socialising with other (disabled and non-disabled) people, fostering new and possible significant relationships, and improving their general well-being. This means that inaccessibility is one major issue where the wheelchair user population is not enjoying the same rights as those enjoyed by the rest of the Maltese population. This issue thus needs to be addressed more aggressively, and here the author recommends that society implements the principles of Universal Design – which would benefit both disabled and non-disabled people – and a disability awareness campaign to help society grasp a better understanding of disability issues.

A cultural activity explored by Baldacchino (2016) is dancing. She looks at the dance devising process of ten young dancers with learning disability at the Opening Doors Association⁴³. Besides learning to dance, these adults are also able to express themselves through movement with music, emphasizing their role in this creative process. Such an approach challenges various misconceptions about intellectual disabilities which are based on the medical model of disability. These performers are very eager to learn, share, be involved and express their own personality, emphasizing that they need more than just therapeutic services that address their physical needs.

Cini (2017) looks at how three boys with sensory processing difficulties view and participate in play and leisure activities. The main leisure activities of these boys are football, karate and judo, with other activities including the use of computers and other technological equipment. Similar to Psaila's (2015) findings – discussed in the 'Children' section – Cini finds variances in children's and adults' perceptions: while therapists view participation in these leisure

activities as ideal for the children's sensory processing needs, children participate in play and leisure purely for enjoyment and learning purposes. Families also tend to limit engagement in unstructured play such as in playgrounds, one of the reasons being the importance that Maltese society gives to schooling and advancements in career. Another barrier to this participation are the attitudes (a recurring theme throughout the majority of dissertations reviewed here) that these children face in these environments. Cini recommends that children are listened to more, and that more awareness is raised about the needs of these children amongst coaches, teachers responsible for leisure activities and other parents. The author translated these findings into two leaflets, one addressed to parents and therapists, and the other to leisure entities.

SPORT

As noted by one of the authors whose dissertation is discussed in this section, very often the issue of sport and persons with disability is not given its due importance (Mamo, 2017); and despite the physical, social and psychological health benefits that sport provides, Maltese persons with disability's participation in sport is extremely low (Cachia, 2017). The two dissertations discussed here explore both the benefits of sport in disabled people's lives, but also the barriers encountered as well as issues relating to the identities of the disabled athletes.

Cachia (2017) delves into the experiences of two swimmers with a physical disability and two wheelchair basket players, together with those of their non-disabled coaches, and finds that these disabled athletes face a number of barriers, mostly due to the negative disability discourse used within the personal tragedy and medical model of disability still prevalent in Maltese society, as confirmed by various other dissertations explored in this review. Other barriers are inaccessible transport, poor planning of sporting activities, and limited financial resources. Interestingly, the research participants have conflicting perceptions of disability: on one hand, sport activities help these athletes develop a positive image of themselves – an aspect also noted by Mamo (2017) - enabling them to become role models (not only in sport but also in other spheres of life) and disability advocates. On the other hand, success in sport activities brings about the feeling of being 'normal'. Indeed, the concept of 'normalcy' is still dominant, especially in the coaches' attitudes who see their athletes as 'normal' persons. Mamo, who looks at the story of a twelve-year old female with intellectual disability participating in sporting activities both in Special Olympics and also in nondisabled mainstream competitive sport, also notes that the athlete questions her identity as a disabled person. Mamo, too, notes the attitudes of coaches and other non-disabled persons in power, who take on the attitude of "we know what is best"; while society's negative attitudes implies that the athlete can only succeed with other disabled athletes. The author ultimately concludes that although hard work, commitment and resilience are essential for a disabled person to succeed in competitive sport, this could not materialise without the support of the parents and the coaches. Meanwhile, Cachia recommends that sport programmes should be developed in consultation with disabled athletes and their coaches; and that more promotion of these programmes and sport awareness is carried out.

INTIMATE RELATIONSHIPS AND SEXUALITY

As noted by the research participants of one of the dissertations discussed in this section, being in an intimate relationship helps people with disability satisfy other human needs, such as the need to belong and the need to feel emotionally close to others (Debattista, 2015).

Intimate relationships and sexuality are the themes explored by both Debattista, mentioned above, and E. Zammit (2017). While the latter looks at the experiences of adults with mild to moderate intellectual disability, the former extends his research to people with physical, visual, hearing, intellectual and learning impairments. Both studies find that people with disability face obstacles in sexuality and intimate relationships (including sexual expression). These obstacles are due to societal stigma and stereotypes and internalised ideas regarding disability and sexuality, especially when it comes to people with intellectual disability. Both authors cite cultural and religious beliefs, including stereotypical ideas of family life and marriage, as well as the tragedy model of disability, as some of the barriers that disabled people face in this area. This is further compounded by inaccessible (or lack of) information and sexual education, as well as lack of preparation from parents and caregivers towards expressing sexuality and developing safe sociosexual relationships. Other factors cited by the authors include physical inaccessibility, lack of privacy and lack of opportunities for social interaction. Zammit and Debattista recommend:

- better awareness raising activities involving the active participation of people with disability;
- education, easily accessible information (on sexuality and reproduction) and professional support for young adults with disability; and
- training and education for parents and professional caregivers so that they are well equipped not only in supporting disabled people in expressing their sexuality, but also in promoting sexual health and autonomy and eliminating overprotection (a theme which comes out in many dissertations, such as those found in the 'Education and 'Persons with Intellectual Disability' sections).

Debattista also proposes the reviewing of sexual education guidelines to ensure that persons with disability are not shown negatively, together with a revision of legislation discriminating against persons with disabilities in the area of marriage.





Services

COMMUNITY SERVICES

An evaluation of the community services available to persons with disabilities in Malta is carried out by Vella (2017). In her dissertation, Vella investigates whether the services offered by the CommCare Assessment Unit⁴⁴ of the Active Ageing and Community Care Directorate⁴⁵ are truly catering for disabled service users' needs. Using both qualitative and quantitative methods, the author finds that service users are on the whole satisfied with the overall care and the standards of service provision.

However, two important shortcomings emerge: the frequency of service provided (e.g. in the case of physiotherapy, occupational therapy and home help service); and the timing of certain services such as nursing and care. Other issues noted by this study include the communication both between professionals and service users (an aspect which also comes in the 'Residential Settings' section), as well as interdisciplinary communication; various misconceptions about these services; and, above all, the need of continuity of care. The findings of Vella's study thus show that there is room for improvement in the delivery of these services, both at policy and the practical levels: specific needs of the persons with disability are not always being met. The author recommends that a re-evaluation of these services is undertaken. The improvements that the study suggests do not only include changes in the service provision itself, but also structural changes to eliminate external barriers which are hindering people with disability from fully participating in their community. These recommendations include the introduction of 'age-adapted living' – meaning community residential houses which also cater for older people with disability – and deinstitutionalisation, meaning that services should not be provided in institutions but be community-based.

RESIDENTIAL SETTINGS

Darmanin (2014) explores the experiences of adults with intellectual disability in residential settings in Malta, where the participants express appreciation that they have contact with members of their families, with some saying they miss their families. Furthermore, since most of the participants do not have friends outside the residential homes, they form strong friendships with other residents and carers (while some of those who are employed also say they have friends at their place of work).

Indeed, few participants have contact with the outside world and most are confined to participation in activities organised for disabled persons. Darmanin highlights that some participants feel that they are not listened to when they complain or make suggestions, and that they have difficulty communicating with foreign carers. Furthermore, only a few participants say that they are encouraged to participate in the day-to-day running of the home, or in the administration of their finances. The author thus recommends that:

- an evaluation of the practices used in these group homes in order to ensure that the needs and concerns of residents are met is carried out;
- guidelines for group homes to eliminate disabling practices are drawn up;
- residents participate in community activities; and
- a consultative committee for each group home is set up, to be chaired by an independent person and formed by residents and staff.

⁴⁴ <https://activeageing.gov.mt/en/Pages/CommCare-Unit/CommCare-Unit.aspx>

⁴⁵ <https://activeageing.gov.mt/en/Pages/Welcome-Active-Ageing.aspx>

[Reviewer's Note: While standards for residential services for persons with disability were published⁴⁶ in 2015 (after the writing of Darmanin's dissertation) and included the setting up of a consultative committee for group homes, there is no legal mechanism to ensure that they are adhered to.]

Dalli (2017), meanwhile, looks at the experiences of people whose spouses with dementia are admitted into a care home. The majority of the research participants did not choose to admit their spouses – it was rather a decision taken by professionals – thus most of them were not prepared for such a move and experienced feelings such as loneliness, emptiness, and helplessness.

At the same time, however, they also experience relief from the stress caused by their spouses' disabilities. The research participants also report their efforts to maintain a connection with their institutionalised loved ones through continued spousal caring, despite the challenges posed by the dementia itself, physical separation and healthcare provision. With regards to the residential setting, albeit a different one than that explored by Darmanin (2014), Dalli reports some similar findings and thus proposes some recommendations which cut across both types of residential settings. Indeed, Dalli reports that participants have mixed opinions on the facility's capacity to involve them in the care of their beloved ones, with some complaining about the lack of communication between participants and staff, and the high turnover of staff. Others talk highly of the staff's attentiveness and diligence and also praise the facility's commitment to provide them with various opportunities to relate with their spouses. The author ends with a number of recommendations, which include:

- better preparation of the spouse on the decisions to be taken;
- better communication between staff and relatives;
- more emotional support and counselling;
- person-centred and relational-centred care for the elderly; and
- ongoing evaluation of care homes' regulations and policies.

PSYCHOLOGICAL AND COUNSELLING SERVICES

Camilleri Zahra (2014) notes the need of counselling in disabled people's lives and the fact that disabled people as a client group are often avoided by counsellors. This section looks at the counselling profession in relation to disability from various aspects, including in education settings (while education in general is explored in the section 'Education').

Camilleri Zahra (2014) finds that the social construction of disability among counsellors is influenced by mainly three factors: international and national politics of disability; counsellors' professional training; and cultures of practice. These result in contradictory disability discourse in the counselling profession, termed by the author as looking at disabled people as "all the same but different." The counsellors participating in her study find difficulty in explaining their understanding of disability, on the one hand claiming that disability is not inherent to the individual whilst at the same time claiming that it is the disabled person's responsibility to overcome their impairments.

⁴⁶ These can be found here: <https://family.gov.mt/en/DSWS/Pages/Disability/National-Standards-for-Residential-Services-for-Persons-with-Disabilities.aspx>

Despite their good intentions, they lack a grasp of the nuances of disability. On a positive note, they are ready to receive further training in this area. The author concludes that their training does not match the developments that took place in disability politics, and thus recommends that Maltese counsellors receive training in disability issues.

Similarly, Portelli (2016), who explores the experiences of – and specifically the psychosocial effects of dyslexia on – young adults with dyslexia and counsellors working with secondary school students, reports that his participants recommend that counsellors' training should include preparation on dyslexia. His findings reveal frustrations due to the environment that living / working with dyslexia provokes in both students and professionals. Research participants emphasise that dyslexia cannot be addressed in a vacuum: the person's context and personality are important; as well as the fact that the counsellor's role is not only related to the counselling room: advocacy, education and a proactive approach are required. Participants also recommend that counsellors are active at policy and advocacy levels with other stakeholders.

The importance of psychologists in education settings with children with disability is also shown by Cortis (2014), who finds that the majority of primary school teachers participating in her study and teaching students with ADHD in state, church and independent schools feel the need to consult the psychologist when working with these students. However, very few of them report that such consultations actually occur. Cortis' findings show that the majority of participating teachers feel the need for more psychological services within their school. In tandem with Portelli's (2016) recommendations, Cortis concludes that the psychological profession needs to be more proactive, and recommends that psychologists promote more their roles and put more emphasis on collaborative practices with teachers.

Perera Vega (2014) confirms another of Camilleri Zahra's (2014) observations: that counsellors tend to avoid people with disability. She looks at counselling services for children with autism and finds that they tend to prefer creative and nonverbal modalities in therapy. The study highlights the importance of communication for effective therapy and the need to increase counselling services for both children and their family members (emphasising the the parents' need for emotional support, as discussed in the 'Parents' sub-section). Group therapy is found to be of benefit to both children with autism and to their parents, helping them to realise that they are not facing these challenges alone. (Similar findings are found with regards to siblings of children with disability, as discussed in the 'Siblings' sub-section.) Like Camilleri Zahra's study, this study notes the need for more awareness on autism amongst counsellors and therapists. Bugeja (2014) too finds that counselling with people with autism would be more beneficial if it takes an individual approach that values difference, rather than the traditional arrangement. Meanwhile, she reports that the professionals whom she interviews and who work with autistic clients view counselling autistic clients more as a form of coaching / mentoring.

Counselling is also explored in relation to persons with physical disability by C. Farrugia (2016). Acquired physical disability is discussed from various aspects in different sections (see the 'Families' and 'Youth' sections), but Farrugia explores the experience of an amputation and its impact on the self-identity of the person concerned. The author looks at various related issues including:

- amputation as an emotionally-charged experience;
- issues with control;

- the traumatic nature of the experience;
- re-negotiation of identity;
- the ups and downs of adjusting; and
- the role of professionals.

The role of resilience (which is discussed further in the 'Families' section) and the fact that the experiences, while having commonalities, are also very individual (another recurring theme), emerge from Farrugia's study. With regards the process of adjustment, the author confirms findings by other authors discussed in this review, that is, that it is not helped by attitudinal and physical barriers. The author recommends:

- more social awareness on disability;
- that health is included as an area of specialisation in the training of counsellors; and
- that counsellors are employed within the health care setting.





Stages of Life



CHILDREN

Children with disability are the topic of the two dissertations dealt with in this section (however, the topic is also explored from other aspects in other sections, such as the ones on education and leisure, culture and sport). While children with disability are also the topic of disability studies in general, there are specific issues which pertain solely to children and which merit much-needed research in this regard. Studies like that of Bartoli (2017) and Psaila (2015) enable children's voices and narratives to emerge through their research.

Bartoli (2017) writes about the stories of three boys with high functioning ADHD and autism and identifies the meaning of successful participation for them, which comprises:

- a feeling of belonging amongst friends;
- being able to perform a task to a satisfactory level; and
- having a degree of autonomy in different activities.

All three children have positive experiences of inclusion; however, while social acceptance is the main aspect that makes them feel included, it is the same attitudes (albeit negative ones) that are considered by these children as the main barrier to inclusion. Ultimately, Bartoli, highlighting the individuality of each child and the fact that “there is no single ‘most effective’ method for the inclusion of all children, even those having similar impairments” argues for a needs-based approach which targets a child's specific requirements and learning styles, whilst complimenting a Universal

Design framework. The author also recommends:

- collaborative group-based learning at school;
- disability equality training by organisations of disabled people; and
- the inclusion of children with specific impairments in local support groups.

Psaila (2015) narrates the story of a boy with spina bifida who uses a wheelchair, and observes that the child's outlook of life is more positive than that of the adults in his life. His priorities differ from those of these adults and are very often overlooked: for him, the most important things are physical accessibility; the freedom to identify himself as equal to his school peers; and to assume the role of the eldest brother in the family. On the other hand, the priorities of the adults in his life are that he walks, attends his physiotherapy sessions and does well at school in order to compensate for his impairment. The information generated through this study was used to enable the child to create a booklet depicting the boy's life which can be disseminated to schools, NGOs and other institutions. In this booklet, the child emphasises the frustration he feels when he encounters physical inaccessibility.

YOUTH

Three dissertations deal specifically with young persons with disability, albeit from different perspectives. Garland (2015) looks at the impact of the family, the church and the state in Malta on young disabled people's aspirations. Through interviews with four young adults with physical and hearing impairments, parents, a politician and a member of the clergy, the study shows that the formation of the identity of these young people with disability are the result of their experiences in education, their family life and society at large. All of them strive to achieve a non-disabled identity – which depends heavily on a positive educational experience

– without refusing their disabled one.

The parents, whose expectations for their children are high, report that they had to be assertive (especially with medical professionals, who were rather negative about the future of their children). The participants also associate the church with the prevalent societal attitude towards persons with disability, that is, the charitable approach; while viewing the state as being instrumental in providing the necessary support services to achieve independence, to enforce relevant legislation and to achieve accessibility that enables them to fully participate in society. The author therefore concludes that Maltese society, influenced by the family, the church and the state, influences the aspirations held by young adults with disability. Finally, Garland makes a number of recommendations that include:

- more awareness of services available;
- the development of a Church Disability Policy to move away from the charitable approach to disability; [Reviewer's Note: It is to be noted that the church has a disability policy⁴⁷ which is currently being updated].
- consultation with disabled people by their representatives on the various Government boards [Reviewer's Note: This concern has since begun to be addressed through Act No. VII of 2015⁴⁸];
- better accessibility to cultural venues; and
- incentives for developers to build new housing units that are physically accessible to all.

Given the influential role that the church plays in young disabled people's lives in Malta, Darmanin Carbonaro's (2015) dissertation is relevant in that it studies the ways in which people with disability can be fully integrated within parishes in Malta. Following the Maltese Diocesan Synod, *Id-Dar tal-Providenza*⁴⁹ introduced the Special Religious Development (SPRED)⁵⁰ method for its residents but this did not reach disabled people in the parishes. The author recommends the setting up of an Adaptive Catechetical Ministry within the Secretariat for Catechesis in the Maltese Dioceses to support parishes to better include persons with disabilities and to better prepare them for the Sacraments.

The relationship between people with disability, or their relatives, and professionals mentioned by Garland (2015) is a theme which also comes out in deBono's 2015 dissertation on the lived experiences of youth who acquire a physical impairment and have to adapt to a new way of life. One of the themes that emerge is the fact that the participants feel that they are the expert on their experiences, rather than the professionals, and here they (especially those who had also received health treatment abroad) also criticise local health services. deBono explores the changes that were brought about in the participants' lives: while they all worked towards becoming as independent as possible and to establish a sense of 'normality' in their lives, an emerging theme is the great changes brought about in different aspects of their lives,

47 *Arċidjoċesi ta' Malta* (2006) *Lejn Knisja dejjem aktar inklużiva: is-sehem tal-persuni b'diżabilità fil-ħajja u l-ħidma tal-Knisja*. Floriana, Malta: *Arċidjoċesi ta' Malta*.

48 Act No. VII of 2015. Available at: <https://parlament.mt/media/37392/act-vii-various-laws-personswithdisability-membership-in-various-entities-act-2015.pdf>

49 <https://www.dartalprovidenza.org>

50 <https://www.dartalprovidenza.org/?p=6665>

including at home, in employment, and in day-to-day activities. However, they felt that life had to go on, with their relationships, their interests and their dreams. Among other themes the author explores, once again, the issue of the negative views of disability by the public (discussed in various sections throughout this review) comes out, although some express the view that these attitudes are improving with time. Based on these emerging themes, the author recommends:

- disability awareness campaigns highlighting the lived reality of disabled persons;
- lifeworld-led⁵¹ services in the health sector and other areas; and
- better statistical data about disability in Malta.

FAMILIES

The dissertations explored in the 'Residential Settings' section (and in others) touch upon the role of relatives in disabled people's lives. This section brings out more in detail the experiences of families, parents and siblings of persons with disabilities.

FAMILIES AND COUPLES

The three dissertations discussed in this sub-section explore the resilience of families and couples who have members with various disabilities. However, the experiences of families of people with disability are also discussed in other sections, notably the 'Persons with Mental Health Issues' section.

Xerri (2017), exploring the experiences of a family with two disabled children (one with physical and one with intellectual disability), cites two main important themes emanating from his study: that of the lack of physical accessibility (especially in housing), which often results in lack of inclusion; and the lack of cooperation between service providers (both governmental and nongovernmental ones), which often leads to fragmented and inaccessible services. A recurrent theme which emerges throughout different dissertations discussed in this report (see, for example, the 'Disability Movement' sub-section and 'Intimate Relationships and Sexuality' section) is the concept of pity towards these families and at the same time the lack of sensitivity towards the needs and feelings of the different family members.

Schembri Lia (2016; 2012), on the other hand, explores the resilience of several families (2012) and heterosexual couples of whom one member (in the case of couples, the female partner) has acquired a physical disability (2016). In her first study, the author looks at the experiences of different members of the families who go through processes similar to bereavement (a concept also noted by Bugeja (2014) who, as discussed in the 'Psychological and Counselling Services' section, looks at autism), sometimes being optimistic and finding the necessary strength, while sometimes finding their resilience withering. She reports that although there are similarities of experiences, each family and each member develop different methods to cope as best as they can. With regards to couples, Schembri Lia (2016) reports that coping post-disability is brought about by mutual and reciprocal patterns of interaction initiated and maintained within the couple relationship but influenced by the socio-cultural context. These processes, over time, limit the difficulties experienced by both parties (The issue of dealing with acquired physical disability is also dealt with in the 'Youth' section and the 'Parents' sub-section, albeit mainly from the person with disability's perspective.)

51 As deBono (2015) explains, the "lifeworld is composed of being a body in space, a self in time and living with others." Through various related studies, the author explores individuals' lifeworlds before and after the onset of impairment.

Both Schembri Lia (2016; 2012) and Xerri (2017) make a number of recommendations to be taken into account when providing services for families of people with disability. The former emphasises the need for more services (including psychological ones) that are not only personalised but also family-inclusive, in order to further the health and growth of the family as a whole.

Meanwhile Xerri makes a number of practical recommendations such as:

- the establishing of a keyworker as a point of reference to the family with children with disability to coordinate and access the required services;
- the possibility of getting services from different organisations according to the needs of the disabled child, rather than being forced with a 'bundle' of services from the same service provider;
- better training of personnel working with disabled children and their families; and
- a study to ensure better coordination between the different service providers.

PARENTS

As noted in the previous sub-section and also by the author (Mifsud, 2017) of one of the dissertations discussed here, when a child is disabled, the whole family tends to be disabled through social barriers, negative attitudes and the way the needed services are delivered. This sub-section links to the previous one in that it looks at specific members of families which include persons with disability, that is, parents. While one dissertation looks at parents who are themselves disabled, the other three dissertations look at the experiences of parents (sometimes having a disability themselves) of children and adolescents with disability.

Gauci's (2017) research explores the lived experiences of Maltese parents with Multiple Sclerosis (MS), and explores such themes as:

- the experience of living with MS;
- parenting roles;
- children as a blessing;
- concerns around the children's wellbeing; and
- the availability of support.

Although some of the lived experiences of these parents are comparable, each experience – as discussed by Schembri Lia (2012) in the previous sub-section – is unique in its own way. The research participants themselves – like many research participants in other dissertations – recommend:

- better public awareness campaigns both with regards to MS specifically and to disability in general, in order to improve attitudes towards disabled persons;
- addressing the realities of living with MS;
- developing the necessary policies; and
- ensuring that the specific services needed by these persons are available.

Mifsud (2017), looking at the experiences of parents (some of them having hearing impairment themselves) of children with hearing impairments, finds that while services do exist, the

parents emphasise that it is difficult to access them without proper information. Furthermore, these parents recognise the importance of meeting other parents to discuss these issues and to feel that they are not alone, hence an online parent-to-parent group was set up to provide informal support to these parents. In addition, parents put forward other recommendations:

- that children are diagnosed as early as possible in order to help children's language and social development (the importance of the diagnosis and its role in helping parents find "a sense of closure" is also noted by Bugeja (2014), whose dissertation is discussed in the 'Psychological and Counselling Services' section);
- that hearing screening is introduced to all newborn children in Malta and Gozo;
- that professional counselling be made available to parents of children who are diagnosed as having an impairment;
- that service coordinators are engaged to provide parents with unbiased information about the various options available, thus helping parents feel more in control and empowered to make informed choices; and
- that a national strategy is developed for this sector in order to ensure the best quality of life to these children and their families.

Finally, to meet information needs, parents recommend the publication of a leaflet containing all the necessary unbiased information which could facilitate this process. A draft leaflet was drawn up as part of this dissertation and the participants were asked to evaluate it. [Reviewer's Note: The leaflet with necessary information for parents of newly diagnosed children with a hearing impairment found in this study was published in 2018.]

Dimech (2014) and Cassar (2014) both look at mothers of children with disability. While Dimech compares mothers' narratives following the birth of their disabled child across different countries, including Malta, Cassar looks specifically at mothers' constructions of their children's autism.

Dimech (2014) discusses different themes that emerge from the mothers' narratives, including the upheaval that the birth brought about in their lives, and how they dealt with this sudden change. Other themes include the relationship these mothers experience with the different medical professionals (see other sections discussing this aspect, such as the 'Youth', 'Persons with Mental Health Issues', 'Residential Settings' and 'Community Services' sections), with other members of their families, with members of society at large, with the various educational institutions, and with their offspring. Dimech's study also brings out the way that specific norms (such as 'perfection' and 'normality') very often end up marginalising people with disability and their family members (recalling also the concept of 'normality' discussed in the 'Sport' sub-section). These findings are related to Cassar's (2014), who reports that the mothers' first contact (related to their children with autism) is with medical professionals. At first, the mothers perceived their children as different from the 'norm', and looked to the medical profession to give a name and solution to their children's autism. Thus diagnosis was followed by attempts to medically remove their sons' difference, mainly through rehabilitation therapies (a process which is confirmed by Bugeja (2014) in her dissertation on autism, discussed in the 'Psychological and Counselling Services' section).

Eventually, the mothers started embracing the social model of disability, acknowledging their children's personhood beyond their autism traits, and the fact that society discriminates

against them because of their disability. They challenge the concept of 'normality' whilst working to ensure that their children's rights, especially for the required services, are met.

SIBLINGS

The often unheard voices and stories of siblings of people with disability are explored in the three dissertations discussed in this sub-section. While two dissertations look at adults siblings, another one explores children's experiences as siblings.

Vella Gera (2017) – who looks at children whose siblings have cerebral palsy, visual and hearing impairments, Down Syndrome, autism and ADHD – notes the unique concerns and sibling relationships of these children. Exploring the siblings' variety of experiences and emotions (both negative and positive, such as resentment, pride, protection), the author emphasises the need for siblings to share their experiences and to have access to information and support. Indeed, Vella Gera writes about the siblings' need:

- for more knowledge about their sibling's impairment;
- to share their experiences with others in a similar situation; and
- to have more communication with, and attention from, their parents.

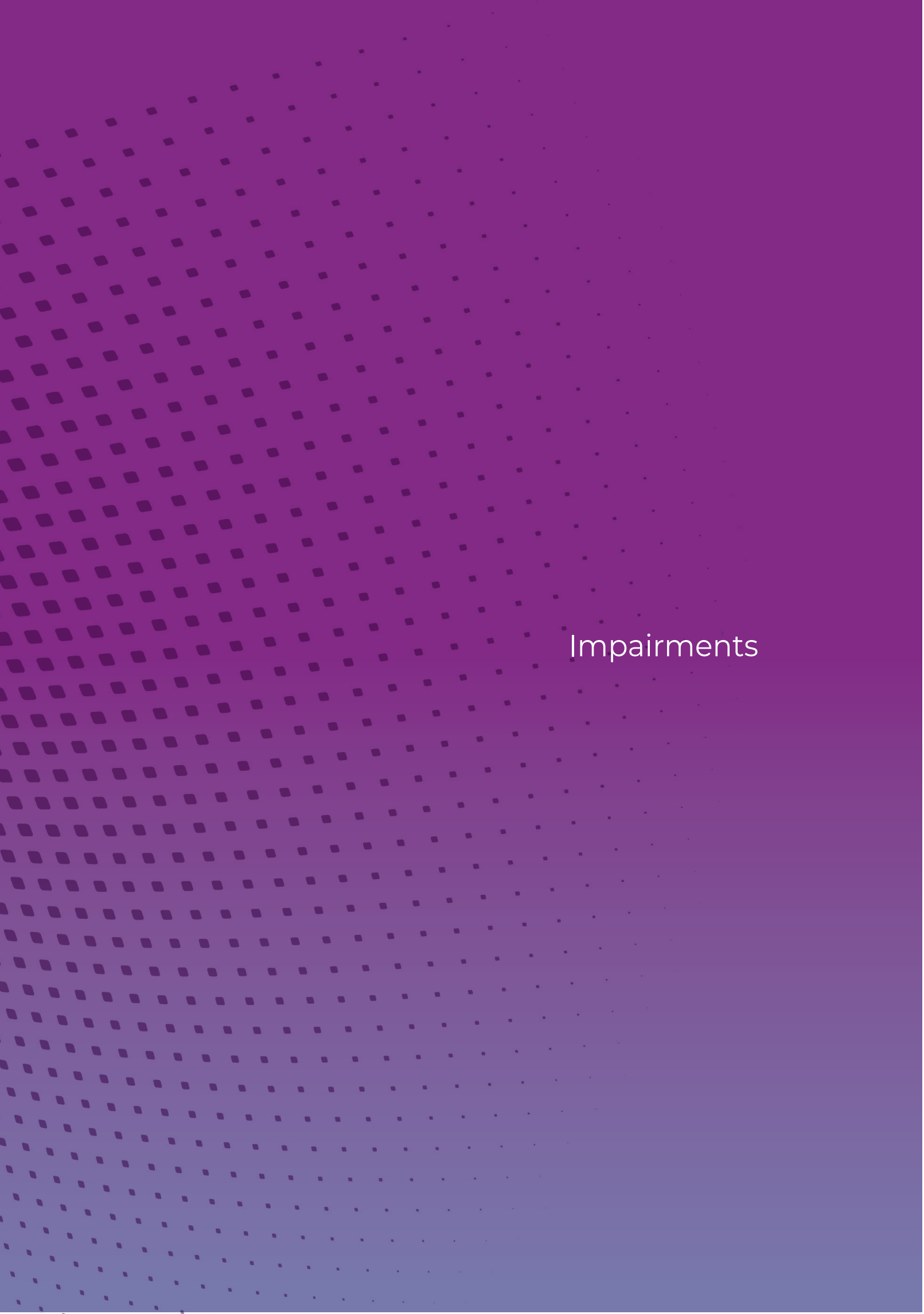
The author recommends that siblings support groups be put in place. [Reviewer's note: While Aġenzija Sapport⁵² provides sibling support groups for adult siblings; and Equal Partners Foundation⁵³ intermittently organises sibshops (a type of children's sibling support group), there still seems to be a need for more support.]

The need for support, as well as the need for attention, from parents, also come out in Cortis' 2017 dissertation which looks at adults siblings of people with complex dependency needs and Maidani's 2013 one which also looks at adults siblings of people with disability. The participants in Cortis' study talk about finding alternative means of communication with their disabled sibling, as well as – while recognising the need for their parents to dedicate more time to their disabled sibling – more attention from their parents. As adults, they feel comfortable about the fact that they have a disabled sibling, but this was not so when they were young and longed for 'normality'. Similar to the findings in Vella Gera's (2017) dissertation discussed above, the siblings also feel that they developed a number of positive attitudes (such as being caring, responsible, independent and self-sufficient) due to their experiences. Both Cortis and Maidani find that the experience of having a sibling with disability – while having common aspects (such as pride and embarrassment) – also differs according to the individual (for example in terms of their involvement with the care of their disabled sibling). Maidani emphasises the individuality of experiences both of siblings and other family members, recalling Schembri Lia's (2012) findings as described in the 'Families and Couples' sub-section and Gauci's (2017) in the 'Parents' sub-section. Significantly, both Cortis and Maidani report that participants feel a certain amount of responsibility and fear about the future of their disabled sibling after their parents' death, an issue which they do not feel much involved in decisionwise, and one they find difficult to discuss with their parents. Finally, the participants express their need for services, especially psychological ones (which is emphasised by both Schembri Lia's (2012), as well as Mifsud's (2017) dissertation discussed in the 'Parents' sub-section), which they feel are lacking. This confirms Vella Gera's observations that support services for siblings – who ultimately also support their disabled siblings – are lacking in Malta.

52 <https://sapport.gov.mt>

53 <http://www.equalpartners.org.mt>





Impairments

THE DEAF COMMUNITY

The experiences and needs of parents of children with hearing impairments were discussed in the 'Parents' sub-section earlier. The present section explores the general experiences of people with hearing impairments. In her 2017 dissertation, Portelli explores the participation in community life of Maltese Deaf adults who use Maltese Sign Language as a main mode of communication and form a Deaf micro-community within Maltese society. Portelli studies the participants' aspirations for their future in Malta, both on an individual level and also as a cultural and linguistic minority group, and concludes that Deaf people in Malta are marginalised individuals facing various barriers to full participation in their communities: such barriers are not only to information and communication but also include attitudinal ones. Portelli examines issues which Deaf adults encounter within their family, among their peers, with their colleagues and within other social situations, as well as Deaf people's involvement in areas like education, employment and service provision. The author also delves into policies that impact on the involvement of Deaf people and argues that in order to ensure that Deaf people are fully included, every member of society needs to do his or her part. The author's recommendations include:

- the use of Deaf adults as role models for language learning and Deaf identity;
- professional support to parents of Deaf children;
- more qualified sign language interpreters; and
- more accessible TV programmes through sub-titles and/or sign language interpretation.

PERSONS WITH INTELLECTUAL DISABILITY

While intellectual disability is looked at from different perspectives in other sections (see 'Leisure, Culture and Sport' section), one dissertation (Bezzina, 2013) deals with people with (mild to moderate) intellectual disability in general, while another (Darmanin, 2014) explores people with intellectual disability's lives specifically in residential services. Due to the importance of this theme, the latter dissertation has been placed in a separate section (see the 'Residential Settings' section).

However, some common sub-themes are found in both dissertations, including the rejection of, or non-identification with, the label of intellectual disability by some of the research participants; as well as difficulties in accessing and using public transport.

The aim of Bezzina's (2013) dissertation is two-fold: it explores the use of participatory methods with people with intellectual disability, and seeks to investigate the impediments in the lives of people with intellectual disability with regards to living independently. The topic, identified by the research participants – who are members of a self-advocacy group – themselves, comprises three main aspects:

- control from family members (a theme which also comes out in Mamo's 2017 dissertation explored in the 'Sport' sub-section);
- inaccessibility of public transport (which emerges as a recurrent theme throughout various dissertations explored in this review); and
- engaging in romantic relationships, marriage and parenting (a theme explored in E. Zammit's (2017) dissertation reviewed in the 'Intimate Relationships and Sexuality' section).

Solutions to these barriers, brainstormed with the participants themselves, include:

- the self-advocacy group holding a meeting with the family members;
- teaching each other in a practical manner how to make use of public transport;
- communicating more with their parents about their romantic relationships; and
- making other people more aware of their issues as disabled people.

Communication is the theme common to all these solutions. The dissertation also affirms the fact that the method used, participatory diagramming, is one favoured by the participants over interviews (since they can express themselves more freely and collectively), as well as being accessible also to non-literate participants.

PERSONS WITH MENTAL HEALTH ISSUES

This section explores mental health issues from different perspectives. While two dissertations look at mental health and hospitalisation; another three look at various mental health aspects: antenatal depression; mental health difficulties experienced by caregivers of those with dementia (which also links to the 'Families' section); and at mindfulness skills for people with anxiety.

Through her dissertation, Zammit Said (2014) explores the experiences of six couples who went through antenatal depression. The research participants talk of the perinatal period which includes:

- feelings of joy and sadness;
- differences between the experiences and coping strategies of men and women;
- mothers' feelings of being misunderstood;
- feelings of shame and of being inadequate mothers;
- inability to cope;
- feelings of being judged; and
- fear that depression might harm the unborn child and other siblings.

The author reports that the couples tend to move toward co-parenting, although the marital relationships very often are put aside and result in couple strain, loneliness, marital discord and a sense of guilty complex. The situation tends to change after the birth of the child, with this period often described by the participants as one of adjustment and stress. Interestingly, the experience with professionals is described as sometimes being facilitative and at other times as hindering the couples. Furthermore, the fathers feel that they are not supported enough during the perinatal period. Thus, participants express the need for more awareness on the emotional and cognitive aspects of pregnancy, and the need for consistency in the support offered during the postnatal period.

Muscat (2015), meanwhile, attempts to discover whether caregivers of people with dementia living in the community are more prone to develop mental health problems. The larger part of the sixty caregivers participating in this study are female, married and unemployed; and while nearly half of them are the spouses of the persons with dementia, a little more than 25% of them are the daughters. The author reports that more than half of the caregivers have moderate to severe anxiety, while 25% have moderate to severe depression. The findings

demonstrate that caregivers' depression and anxiety differs among individuals, with the prevailing cause of stress being the ongoing burden that the caregivers perceive when caring for a relative with dementia. The role of professionals (and the importance of their listening to the service users and their carers) is once again mentioned here (confirming findings such as Zammit Said's (2014) described earlier in this section, as well as those in the 'Residential Settings' and 'Community Services' sections). The author emphasises that it is essential for community professionals and care providers to be aware of the adversities experienced by both the caregiver and the care-recipient in order to support them and facilitate accessibility to services that aid in easing psychological distress. Indeed, Muscat recommends:

- that caregivers should be partners in care planning;
- that caregivers should be entitled for an assessment of their needs;
- more information and training to be available to caregivers;
- more support from employers of caregivers
- better financial support to caregivers;
- the availability of caregiver support groups; and
- more respite services for people with dementia.

While counselling with people with disability is dealt with in a section of its own, one dissertation (Zammit Cutajar, 2013) looks specifically at using mindfulness skills in counselling persons who have anxiety. Her study is based on the lived experience of a forty-year old woman who has anxiety and is a mother of a young adult with Asperger's Syndrome. Her anxiety is the result of both having a disabled child and various other reasons (including issues from childhood). She equates anxiety with a fear over which she has no control. By incorporating mindfulness into her life, the participant was able to take a step back from her internal narrative and her negative experiences, resulting in the possibility of seeing and doing things in a new way, possibly a whole new way of being. This counselling also helps her to find her voice without undue fear of displeasing or angering others (which had previously been sources of fear for her).

MENTAL HEALTH AND HOSPITALISATION

L. Farrugia's (2016) dissertation outlines the evolving development in the psychiatric field during the period spanning from the 1920s to the 1960s. While the greatest single factor that influenced this area was the opening of Mount Carmel Hospital in 1861 when people with mental health problems started being hospitalised; during the period that Farrugia investigates, decentralisation characterised the mental health care in Malta: patients were no longer institutionalised but were treated by trained personnel in psychiatry. However, MCH was criticised as being outdated and overcrowded, and the government tried, without success, to improve and broaden the services provided at the General Hospital. Notwithstanding, this hospital underwent constant progress in the services it provided to persons with mental health problems. Treatments slowly moved away from the traditional ones, introducing new psychiatric therapies in all areas including diagnosis, categorisation and treatment. As diagnosis became more specialised, the categorisation of psychiatric conditions started to be more complex and detailed. The treatments were based upon surgical procedures, physical methods, restraints, pharmacology and psychology. Often, MCH lacked the necessary staff and equipment to offer all the required services, such as occupation therapy and electroconvulsive therapy. After the war, other services started to evolve such as the Kennedy Memorial Clinic,

the Child Guidance Clinic, the Diagnostic Clinic and the Speech Therapy Clinic. Special schools, day centres and residential homes were also developed. Although many of these services were underresourced, they promoted various advances in the care of people with mental health problems in Malta. The voluntary sector also helped in this area, emphasising the importance of having a caring, albeit segregated, environment for people with mental health problems. It also tried to raise awareness on these issues and lobbied the government for more resources and the introduction of legislation to safeguard the rights of these patients. Farrugia concludes that one of the most evident results of all these advances in the field of mental health in Malta during this period was the decrease of stigma attached to mental illness. However, Galea (2017) states that while nowadays people with mental health problems are more accepted in society, their problems are still considered as a taboo and they are often faced with stigma. Stigma affects negatively the quality of life of the persons concerned and leads to decreased employment opportunities, diminishes the quality of health care and limits interaction between the persons and society. Their family members, meanwhile, indicate that, rather than experiencing barriers themselves, they are more affected by how others treat their relative with mental health issues. The author suggests that persons with mental health problems should be included more in the workforce, an issue which is discussed further in the 'Employment' section. Additionally, further emancipatory research needs to be carried out regarding services for the family members. Finally, she explores possibilities of reducing the stigma attached to mental health problems, an issue which has been discussed by multiple dissertations throughout this review and which affects people with all types of disability.

Galea's findings show that the transition of services from MCH to Mater Dei Hospital⁵⁴ might be one possibility that might decrease the stigmatising manner in which the public views mental health problems; while the media can also be used to provide awareness and education about mental health issues.

54 <https://deputyprimeminister.gov.mt/en/MDH/Pages/Home.aspx>





CONCLUSION

While this review comprises dissertations which cover a wide range of topics related to disability and disabled people's lives in Malta, several recurrent themes, as noted in the text, emerge. These themes are highlighted here in order to bring to the fore some of the most pressing issues affecting the lived experiences of people with disability and their families.

Foremost in multiple findings is the fact that the charity-based model is still present in different aspects of people with disability's lives in Malta. This is seen through fundraising campaigns, court decisions and public attitudes. Related to this, is the stigma and discrimination which people with disability in Malta still face, another recurrent theme emerging throughout the review in various aspects of people's lives, including in employment, sport, and intimate and sexual relationships. As expected, inaccessibility comes out as a barrier continuously faced by disabled people in terms of physical accessibility, access to justice, access to information, and barriers posed by the above-mentioned negative attitudes. As most authors thus recommend, there is a great need for awareness raising as well as training to different segments of society including the general public, parents (including in over-protection, especially of their children with intellectual disability), employers, teachers (especially in dealing with students with different types of difficulties), staff in residential settings, and counsellors. With regards to the education system, many authors also point out the rigidity of the education system and the need for a flexible curriculum and less emphasis on examinations. Meanwhile, with regards to staff of residential settings as well as other professionals such as medical ones, the need for better communication between them and disabled people and their relatives is strongly apparent.

With regards to services, the great need for support, including psychological support to both individuals with disability and their families, is emphasised. There is also a persistent observation by several authors regarding the fragmentation of services available to people with disability, and thus a call for cooperation between different entities. Authors also note the need for further legal protection against discrimination, including in Malta's Constitution and with regards to bringing national legislation fully in line with the UNCRPD on issues such as supported decision-making.

Relatedly, the need for involving disabled people in policy making and decision-taking is evident. Ultimately, the issues that disabled people encounter in their daily lives point towards the need for a strong disability movement led by disabled people in Malta, the topic dealt with in the beginning of this review. Without detracting any importance from the emphasis on the individuality of experiences of people with disability – an observation made by numerous authors in emphasising the heterogeneity of the 'group' of disabled people – the need for a collective identity is evident in combating the discrimination faced by people with disability in Malta.

List of Dissertations

- Abela, M. (2012) The Social Inclusion of Students with Moderate to Severe Disabilities in a Boys' Comprehensive Secondary School: A Qualitative Study (M.Ed Inclusion and Individual Educational Needs)
- Attard, A. (2017) Perspectives on the Employment of Persons with Intellectual Disabilities (M.A. Disability Studies)
- Attard, J. (2017) The Introduction of the Enduring Power of Attorney Under Maltese Law – A Critical and Comparative Analysis (LL.D.)
- Attard, L. (2017) Experiences of wheelchair users accessing buildings of entertainment frequented by young adults in Malta (M.A. Disability Studies)
- Axisa, T. (2018) The Effectiveness of Disability Quotas when Employing Persons with Disabilities: An Exploratory Study among Maltese Employers (M.A. Youth and Community Development Studies, De Montfort University)
- Azzopardi, A. (2000) Understanding Disability Politics in Malta: New Directions Explored (M.Ed. Inclusive Education, University of Sheffield)
- Baldacchino, I. (2016) Devising Dance Performance with Adults with Learning Dis/abilities: An exploration of dis/ability, dance and artistry, with special reference to Opening Doors dance group (M.A. Performance Studies (Dance))
- Bartoli, S.A. (2017) Living an Inclusive Life: Perceptions of Children with Neurodevelopmental Disorders (M.A. Disability Studies)
- Bezzina, L. (2005) Persons with Disabilities and Employment: Equal Treatment under Council Directive 2000/78/EC (M.A. Human Rights and Democratization)
- Bezzina, L. (2013) Taking down the Walls: Participatory Diagramming with People with Intellectual Disabilities (M.A. Research Methods (Human Geography), University of Durham)
- Bezzina, R. (2015) Interagency Collaboration? A Case Study on the National Policy on the Rights of Persons with Disability (M.A. Public Policy)
- Bonello, A.M. (2015) The Human Rights of Persons with Disability to Non-Discrimination in the Maltese Employment Sector: A Legal Perspective (M.A. Human Rights and Democratization of Governance)
- Borg, D. (2012) The Transition to Secondary Education for Boys with Individual Educational Needs (M.Ed. Inclusion and Individual Educational Needs)
- Borg, E. (2011) The Protection and Promotion of the Rights of Persons with Disabilities (LL.D.) Where the University is not specified, this means that the dissertation was submitted to the University of Malta.
- Borg, M. (2009) How do Mainstream Primary School Children without Disabilities perceive the Inclusion of Peers with Disabilities? (M.Ed Inclusion and Individual Educational Needs)
- Briffa, A. (2015) Investigating Literacy Skills in Students with Dyslexia in Malta: Models of Intervention, Implications for Teaching and Inclusion (M.A. Disability Studies)
- Brincat, M. (2014) A Study of the Guardianship Legislation with Emphasis on Intellectual Disability (LL.D.)
- Bugeja, R.M. (2014) Autism: Disorder or Difference? A local study on the perceptions of professionals working in the Autism Field (M.A. Transcultural Counselling)
- Busuttil, B.A. (2017) Combatting Discrimination Based on Disability from a Substantive and Institutional Point of View (LL.D.)
- Cachia, D. (2017) Disability and Sport: The Experiences of Athletes and their Coaches (M.A. Disability Studies)
- Camenzuli, J. (2012) Inquiry-Based Learning in Mathematics: The Case of Students with SEBD (M.Ed in Social, Emotional, Behavioural Difficulties)
- Camilleri, C. (2010) A Critical Analysis of the various ground of discrimination, the regulation thereof and ECJ Judgements (Magister Juris (European and Comparative Law))
- Camilleri, C. (2012) An Analysis of the United Nations Convention on the Rights of Persons with Disabilities and its influence on the European Union and Malta (M.A. Human Rights and Democratization)
- Camilleri, M. (2015) Must I Sit Down? A Study of the Experiences of Secondary School Male ADHD

- Students with regards to their Inclusion within the Inclusive Education System in Malta (M.A. Disability Studies)
- Camilleri, R. (2012) Bridging the Gap: Skills to Enhance Positive Relationships between Teachers and Students with Challenging Behaviour (Masters in Counselling)
- Camilleri, R. (2017) Redefining Insanity: Bringing the Insanity Plea into the 21st Century (LL.D.)
- Camilleri Zahra, A.J. (2014) Enabling Counsellors: An Exploration of the Social Construction of Disability among Maltese Counsellors (M.A. Disability Studies, University of Leeds)
- Cardona, G.C. (2007) Just like Anybody Else?: An investigation into the outlook of young empowered disabled people living in Malta on how they view themselves, society and how they may interpret disability (M.A. Disability Studies, University of Leeds)
- Caruana, D. (2017) Does therapeutic human germline editing discriminate against persons with disability? (LL.D.)
- Cassar, N. (2014) Maltese Mothers' Construction of their Sons' Autism Spectrum Condition (M.Psy.)
- Cefai, B. (2009) Factors Leading to Socio-Emotional and Behavioural Problems within the First Year in the Primary Classroom (M.Ed in Social, Emotional, Behavioural Difficulties)
- Cini, M. (2017) Play and leisure environments as seen through the eyes of a child with sensory processing difficulties and of significant others: Reflections on needs and proposals for change (M.A. Disability Studies)
- Cortis, A. (2017) The Lived Experience of Adult Siblings of Persons with Complex Dependency Needs (M.A. Disability Studies)
- Cortis, L. (2014) Walking the Talk or Acting as Gatekeepers? Classroom Teachers' Perceptions of the Role of Psychologists in Supporting Primary School Children with ADHD (M.Psy.)
- Cremona Caruana, K. (2016) Disability: An Agenda for Bioethics (M.A. Bioethics)
- Cutajar, K. (2006) An Analysis of the Disability Concept as Taken from the Legal Perspective (LL.D.)
- Cutajar, T. (2009) Breaking the Link Between a Poor Start in Life and a Dismal Future - Helping Children with SEBD in Malta through Nurture Groups: An Action Research Study (M.Ed in Social, Emotional, Behavioural Difficulties)
- D'Amato, A. (2009) The Interrelation Between Legal and Clinical Insanity in Criminal Law (LL.D.)
- Dalli, M.G. (2017) The Impact of Admission of a Spouse with Dementia in a Care Home on Spousal Relationships (M.A. Gerontology and Geriatrics)
- Darmanin, E. (2014) The Narratives of Men and Women Labelled with Intellectual Disability, who Have to Live in Residential Settings in Malta: A Thematic Analysis (M.Sc. Applied Psychology of Intellectual Disabilities, University of Portsmouth)
- Darmanin Carbonaro (2015) People with Disabilities and Catechesis: The Way Forward! (M.A. Youth Ministry)
- De Martino, S. (2017) Living Autism – An Immersive Learning Experience (M.F.A. in Digital Arts)
- Debattista, M. (2015) Persons with Disability and Intimate Relationships: Realities in the Maltese Context (M.A. Disability Studies)
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