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# **Studies in Social Wellbeing**

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Studies in Social Wellbeing (SSW) is an online, peer-reviewed, open access journal with an international focus on topics related to wellbeing from a social perspective. We look for contributions that engage with research that promotes wellbeing, inclusion, equity and equality. Contributions are welcome from scholars carrying out research in a broad range of areas related to wellbeing, including but not limited to counselling, criminology, disability studies, family studies, gender studies, gerontology, psychology, sociology, public health, social policy and social work, and youth and community studies. Our journal aims to promote original research which crosses disciplinary boundaries in an effort to stimulate knowledge-sharing in areas related to social wellbeing. The journal aims to have a broad scope, covering research from a wide range of academic disciplines, whilst also encouraging research papers with a niche focus on wellbeing. We encourage contributions from practitioners presenting their research or reflecting on their practice, as well as from post-graduate students. Co-authored interdisciplinary research articles are particularly welcome. The journal does not adhere to any single type of methodology; inviting qualitative and quantitative research studies that draw on various psycho-social approaches and philosophical orientations. The journal is owned and managed by the Faculty for Social Wellbeing, University of Malta. It only publishes manuscripts in English. The journal publishes one issue annually.

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# **Editorial**

Prof. Maureen Cole

Editor-in-chief

We are delighted to be launching *Studies* in *Social Wellbeing* (*SSW*), an online, peer-reviewed, open access journal of the Faculty for Social Wellbeing, University of Malta. The plan to publish a faculty journal took seed in the early days of the faculty's life and has come to fruition nine years later through the commitment and hard work of many.

The journal has a broad scope and will be publishing papers which focus on topics related to wellbeing from a social perspective. The journal's vision reflects that of the Faculty for Social Wellbeing which is outward-looking, engaged with various communities, and deeply committed to promoting wellbeing, inclusion, equity, equality and social justice.

We are confident that through your readership and support Studies in Social Wellbeing will serve as the forum for the publication of original research which crosses and intersects disciplinary boundaries around social wellbeing. Our vision is for the journal to serve as the space for scholars and for practitioners to share their research and reflections on practice and for post-graduate students to publish their research. We welcome contributions which shine a light on what Foucault (Gordon, 1980) describes as 'disqualified knowledges', popular knowledge, the knowledge of the people. In this light we look forward to the journal becoming the space for papers which are co-created with research

participants.

The papers in this edition truly reflect the broad focus of the journal. In a stimulating contribution, Dr Anne-Marie Callus and Dr Sue Vella critically engage in a consideration of the Independent Living Movement (ILM) and capitalism especially in its neoliberal form (pp. 12-25). They clearly articulate the parallelisms and contrasts between the two and argue in favour of a 'relational interdependent view of autonomy'. Dr Marian Muscat Azzopardi touches on the harshness of the stigma faced by children in alternative care in Malta (pp. 26-35). This paper is informed by qualitative research carried out with children in alternative care. The author proposes a way forward for policy and practice to help address the important issue.

Dr Andrew Camilleri and Professor
Andrew Azzopardi draw on two theoretical
models, the at-risk model and the protective
factors model, to embark on a useful analysis of
the literature to explore the causes and
correlations in relation to youth violence (pp. 3652). In their analysis they conclude that the
Maltese literature on the subject adopts the atrisk model which has less predictive results than
the protective factors model. The authors call for
more research to explore this further. Professor
Andrew Azzopardi, Ms Jamie Bonnici and
Professor Marilyn Clark write about a quantitative
study they carried out about the loneliness
experienced by people in Malta during the

COVID-19 pandemic (pp. 53-64) The study used a quantitative on-line survey with a sample of 906 adults in Malta. Interestingly the results show that the frequency of self-reported loneliness was linked to age group, nationality and occupational group. The study is of particular value as it compares with data about loneliness collected prior to the onset of COVID-19 and shows that rates of loneliness were markedly higher across the sample. The authors recommend interventions to ease loneliness based on their study.

This edition also features an interview with Dr Gauden Galea from the World Health Organization Office in China. Dr Galea, an expert in public health, kindly responded to questions about wellbeing and the COVID-19 pandemic (pp. 7-11).

Thanks are due to many as we launch Studies in Social Wellbeing. Firstly, to Professor Andrew Azzopardi, Dean of the Faculty for Social Wellbeing for believing in this project and for continuing to egg us on when energies were flagging. To the past and current chairs and members of the Research Publications and Scholarship Committee of the Faculty for Social Wellbeing for their unfailing support. To the members of the International Editorial Board for their consistent and constant support. To all the reviewers who offered their expertise and time so generously. To Ms Jamie Bonnici, assistant editor for her meticulous work and commitment. To the contributors, thank you for believing in the journal, there would be no publication without your contributions.

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# Interview: Reflections on Wellbeing

Dr Gauden Galea<sup>1</sup>

# What does 'wellbeing' mean to you?

The definition of health found in the Constitution of the World Health Organization (1948) has inspired my own ideas of wellbeing ever since I started my public health practice:

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. (2020, p. 1)

Adopted at a time of optimism in the recovery from World War II, this definition was inspired by a spirit of multilateralism, idealism, and solidarity, having been drafted by people who shared the resolve that the world should never again see such carnage as had just ended.

This definition has been praised for many reasons, among them:

- for being positive, eschewing the medical approach of "mere" prevention or control of diseases,
- for being holistic, encompassing multiple dimensions of wellbeing, and
- for being aspirational, setting a vision of health that is as idealistic and as relevant today as it was seven decades ago.

The definition could be improved. In one sense, it sets too high a standard. No-one has ever attained "a state of complete wellbeing". One can still enjoy some measure of wellbeing, even when https://www.um.edu.mt/ssw

suffering from disease or disability. Over time, our understanding has evolved to encompass the view that health and wellbeing sit on a continuum, and that people and societies should aim for the highest attainable level of health, rather than a state of "complete wellbeing".

Having agreed that health is a positive and multi-dimensional attribute, it still leaves the term "wellbeing" undefined. I will not attempt a canonical definition here, but I would point out three concepts that I regard as essential to wellbeing: balance, reserve, and resilience:

- Balance, or harmony, encompasses such ideas as peace and equity in society, sustainability in the environment, and homeostasis in physiology.
- Reserve, or redundancy in the engineering sense, refers to the additional physical, mental, and social resources or health assets that are needed to cope with surges in demand due to stress, disease, or disaster.
- Resilience is the ability of individuals and society to recover from such surges and to regain a state of balance after temporary departures from it. A person with a supportive social network will better recover from the loss of a loved one than a person who is isolated and lonely. A school child being bullied will

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<sup>&</sup>lt;sup>1</sup> Affiliation: World Health Organization Representative Office in China, Beijing 100600, China

better cope with the stress if they have a trusted adult to whom they can reach out for help. Much of the treatment of certain forms of depression depends on being able to talk about it with trusted family and friends and with mental health professionals.

# How pertinent is social wellbeing to your own professional work?

Public health and social wellbeing could not exist, one without the other. The two are inextricably intertwined. Indeed, in my discussion above, taking the lead from the WHO definition of health, I intentionally made no distinction between health and wellbeing.

In 1991, a few years into my public health

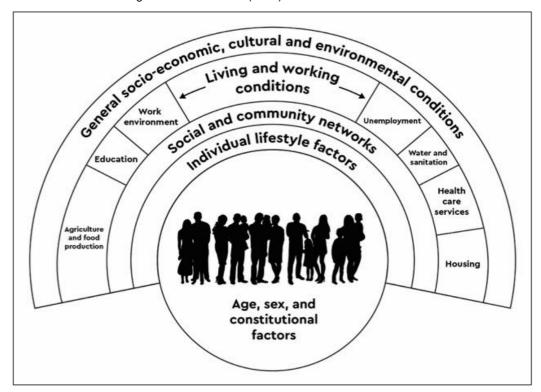
others like it grabbed the imagination of academics and practitioners like me who were at the time themselves working at the interface of health and social wellbeing, for instance on the "Health for All" movement.

At the core of the social model, on the inner circle, lie the more direct influences that define the biological limits of health: our age, sex, and genes. The next circle of influence is our behaviour, the choices that we make in life that amplify or diminish our health with risk factors such as tobacco or alcohol consumption on the one hand and protective factors such as healthy diet and physical activity on the other. Beyond the influence of genes or behaviour, all individuals are embedded within social and community networks, comprised of family, work, and social relationships that can help or hinder a person's health career.

Figure 1.

The main determinants of health.

Source: based on Dahlgren and Whitehead (1991)



practice, Dahlgren and Whitehead presented the social model of health in diagrammatic form as a series of concentric circles or arcs surrounding a group of individuals at the centre. Each of the circles from the centre outwards represents a more upstream influence on health. This model and

These social networks are, in turn, embedded in a larger set of socioeconomic, cultural, and environmental conditions, such as access to decent work and to health services, housing, water and sanitation, education, agriculture, and the physical environment itself.

These successive spheres of influence blur any artificial distinction between health and social wellbeing, between medical and social action, or between personal and population level determinants. The social and environmental determinants thus become targets for intervention, converting population health science into an instrument of social policy. Adopting a social model of health requires population health scientists to work on developing healthy public policy, collaborating across sectors of government, mobilising the whole of society, and constantly advocating for equity in health.

# How can we consider wellbeing in the context of the COVID-19 pandemic?

The fundamental concepts of balance, reserve, resilience, and the social model of health and wellbeing apply perfectly to the era of COVID-19 and the societal efforts to "build back better". A few examples will make this clear.

The accelerated development of effective vaccines has been a major scientific achievement. In the space of less than a year, humanity has developed an essential and coveted tool for protecting populations from hospitalisation and from severe forms of COVID-19. At the time of writing. over 1.2 billion vaccine doses had been administered worldwide. But the distribution has been unequal. According to OurWorldInData.org, (22 May 2021) just ten countries have used up 75% of these doses. While many countries are donating vaccine doses to the WHO COVAX facility, or providing vaccine donations on a bilateral basis, or even considering temporary waivers on vaccine patents, vaccine equity has become an urgent issue. It is an issue of balance and the fair distribution of health assets. It is an issue of reserve in vaccine production capacity. It is also an issue of resilience and recovery, since even countries that now enjoy high levels of vaccination remain vulnerable while transmission rages in other countries, and new strains of the virus arise from mutation. Wellbeing in this sense implies that noone is safe until everyone is safe.

Mask wearing, hand washing, and physical distancing have become established as important behaviours to protect self and others. Yet even these simple behaviours have shown up the

inequity within and between societies. Mask wearing has been readily accepted by many populations yet has become a bone of contention in many others. Hand washing is a luxury in populations with poor access to proper water and sanitation while running water in the home is commonplace in other societies. Physical distancing is an impossibility for certain occupational groups, while others enjoy jobs that enable them to work from the safety of their own home. Social wellbeing in the era of COVID-19 requires such basic inequities to also be addressed.

Beyond personal behaviour, the social model of health and wellbeing requires us to consider the broader living and environmental conditions. COVID-19 has given prominence to the idea of "One Health", the concept that human, animal, and environmental health are deeply interlinked. The One Health concept is central to our ability to prevent new pandemics. It calls for changes to the industrialised rearing of livestock and the use of antibiotics on animals raised under intense and stressful conditions, breeding grounds for new pathogens and for anti-microbial resistance. It calls for changes to the sanitary conditions in food markets that are, on the one hand, essential sources of food for many in the developing world, yet, on the other hand, may harbour illegal trade in wild animals. It calls for an end to deforestation which reduces the habitat for wild animals and increases encounters between them and humans, creating even more opportunities for animal-human spillover of new pathogens.

Resilience is another core concept. The health assets of societies need to be shored up. Universal health coverage needs to be guaranteed. Too many people worldwide lack access to a basic package of health services. Pandemic preparedness needs investment in surveillance and early warning systems, in reserves of protective equipment, and in improving society's ability to protect those who live and work under precarious conditions. During the lockdowns that have helped to "flatten the curve" in many countries, women have been exposed to a surge in domestic abuse, and many whose jobs cannot be conducted from the safety of their own homes have had their livelihoods threatened.

On a global level, true wellbeing includes also multilateralism, the willingness to cooperate across borders to overcome health threats that do not respect national boundaries. These ideas are captured perfectly by Richard Horton as he concludes his book on "The COVID-19 Catastrophe" thus:

We are social beings. We are political beings. COVID-19 has taught us that we are mutual beings too. (2020, p. 127 of 134, e-book edition)

Maybe that is when humans will attain true wellbeing, when we recover that spirit of multilateralism, idealism, and solidarity, and when we come to act as though we are mutual beings too.

## **Disclaimer**

The author alone is responsible for the views expressed in this article and they do not necessarily represent the views, decisions, or policies of the institution with which he is affiliated.

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# The Independent Living Movement and Capitalism: Challenges and Contributions

Anne-Marie Callus1\*, Sue Vella2

#### **Abstract**

This article critically discusses how the Independent Living Movement (ILM) both reflects and challenges capitalism, especially its contemporary neoliberal variant. We first take a brief historical look at disability. Since time immemorial, physical and intellectual impairments have been viewed negatively, and these views - together with structural barriers - have served to disable people with impairments. The Enlightenment heralded social reform, yet the emerging scientific tradition medicalised and marginalised disabled persons who came to be seen as tragic and dependent. This was true of capitalist and state socialist societies, as both saw disabled persons as less productive and often in need of institutional care. Excluding disabled persons is not, therefore, solely a function of capitalism. Indeed, it was in capitalist societies that the Disabled People's Movement freely and successfully mobilised after the 2nd World War. This Movement developed the social model which, unlike the medical model, explains disability in terms of societal barriers which need to be removed. The spread of neoliberal philosophy from the late 20th century has had a paradoxical impact. On the one hand, its notions of choice, control and autonomy have provided a further impetus to independent living aspirations; on the other hand, austerity, welfare conditionality and a narrative of self-reliance have undermined effective independent living services. We argue in favour of a relational, interdependent view of autonomy, and for the political choices necessary to stamp out discrimination, ensure labour market integration and support the independent living aspirations of disabled persons.

**Keywords**: disability, independent living, capitalism, socialism, relational autonomy.

Both authors contributed equally to this article.

\*Corresponding author:

Anne-Marie Callus, Department of Disability Studies, University of Malta

Email: anne-marie.callus@um.edu.mt

<sup>&</sup>lt;sup>1</sup>Department of Disability Studies, University of Malta, ORCID iD: https://orcid.org/0000-0002-3505-3116 <sup>2</sup>Department of Social Policy and Social Work, University of Malta, ORCID iD: https://orcid.org/0000-0002-2808-1290

This article critically discusses the ways in which the Independent Living Movement (ILM) both reflects and challenges capitalism, especially its contemporary neoliberal variant (Mladenov, 2015). The ILM developed in the late twentieth century to assert the rights of disabled people to self-determination and equal opportunities. Three broad influences have shaped the development of the ILM. First, the social model of disability challenged the earlier medical model's view of disability as a condition to be fixed, and disabled people as being only in need of professional intervention and advice (Oliver, 2009). The social model proposed, instead, that the difficulties faced by disabled people do not arise solely from their impairments but from discriminatory social and economic structures. As Oliver (2009) argues, these structures present difficulties that cannot be dealt with only through medical and therapeutic interventions and welfare benefits.

Second, the ILM was also driven by a growing awareness of human rights. One of the landmarks to follow the devastation of the Second World War was the United Nations' Universal Declaration of Human Rights which, as stated in its Preamble, is based on the concept of a shared humanity with no exception and a focus on each person as a rights-bearing individual (United Nations 1948). This Declaration was followed by many international legislative instruments, the most recent and important of which is the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD) adopted in 2006. The UNCRPD followed decades of lobbying by disabled people for their rights and for recognition of the social model of disability. Indeed, the UNCRPD notes in its Preamble that "disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" (United Nations, 2006, p. 1).

Third, and possibly most significantly, the ILM knows its origins to the disabled people's movement which has focused its struggle on the removal of attitudinal and environmental barriers. This work has meant campaigning for legislative change, for the removal of structural barriers, and for increased awareness about the rights and dignity of disabled people. It has also entailed campaigning for services that enable disabled

people to be included, and to participate, in the life of their communities. These services are often referred to as independent living services (European Network on Independent Living, 2013).

The ILM grew at a time when many of its core tenets such as independence, choice and the personalisation of services were gaining political currency in the late 20th century. However, while the ILM shares some of the values of capitalism, the exclusionary effects of the latter have been criticised in the disability literature (Rosenthal, 2019; Ryan, 2019). In this article, we explore and critique the relationship between capitalism and the ILM, looking briefly at disability through history and within capitalism and communism, before turning to consider the ways in which the ILM not only draws upon, but also challenges and corrects the neoliberal outlook that is widely taken for granted today.

## **Impairment and Disability Over Time**

Impairment and disability have been conflated since time immemorial, yet the distinction is important. It allows for critical analysis of societies' response to impairments (Metzler, 2011) which are, in themselves, not necessarily disabling but are made so by socially constructed barriers. As Gardou (2015) puts it, disability "draws upon geological layers" (p. 14, authors' translation) of negative associations which over time became entrenched in the culture of different societies, regardless of historical period or socioeconomic arrangements.

The different - and negative - treatment of those with a physical or mental impairment can be dated back to at least Ancient Greece and Rome (Hughes, 2020). According to Garland (as cited in Draycott, 2015), such treatment was due to three factors: "first, that it was a means of bolstering group cohesion at the expense of the outsider; secondly, that it was a means of expiating fear and embarrassment; and thirdly, that it was an outlet for sublimated aggression" (Draycott, 2015, p. 202). Indeed, disability hate crime - though only recently coined as such - is certainly not new; while a rise in such crime has been registered in the past few years, there is evidence of it having occurred from antiquity (Ralph et al., 2016).

Kudlick (2003) highlights the significance of

the perfect body for classical Greek thinkers like Aristotle, and how any deviations from such perfection were described in the most demeaning ways that endure until today as terms of insult. This has contributed to "one of the most challenging aspects of disability...to convince non-disabled people that even when it involves pain and hardship, disability is not always a tragedy, hardship or lack, but in fact often provides much of value" (Kudlick, 2003, p. 769).

In the Middle Ages, speculation was rife about the origins of impairment. Wheatley (2010) and Metzler (2006) both refer to two such views: first, that impairment was a result of sin (one's own or one's parents'); and second, that it offered the opportunity for miraculous healing. Impairment was sometimes inflicted as a punishment for crime, a practice which Wheatley (2010) claims went on well into Renaissance Europe. The Middle Ages also saw the widespread giving of alms, encouraged among the faithful as a means of salvation (Wheatley, 2010). Even so, Metzler (2006) contends that there is very little evidence of persons with impairments being particularly reliant on aid, and they lived in a more or less integrated manner within their communities.

With the advent of the Renaissance from the late 15<sup>th</sup> century and its rediscovery of the classical world, reason began to displace religion as the foundation of social and political thought. This brought a new challenge to those with physical and mental impairments. "This remergence of the rational individual required the definition and particularization of ... reason's 'Other': the idiot, the blind and the disabled" (Stainton, 2004, p. 226). Reflecting on Bruegel's art, Stainton argued that representations of disabilities in the Renaissance became "metaphors for human misery, isolation and moral decrepitude" (p. 238).

By the early 18<sup>th</sup> century, scientific and intellectual progress had made the improvement of human and social conditions seem both possible and desirable. Superstition was challenged and authority criticised. The revolutions of the 17<sup>th</sup> and 18<sup>th</sup> centuries introduced principles of freedom, equality and democracy, and of government based on the consent of the governed. Influential Enlightenment scholars contributed to a growing body of liberal

philosophy, and were to leave an enduring influence on ethical, political and economic thought (Ferrone, 2017). In the German Enlightenment, Immanuel Kant called for respect for human dignity, for treating people as ends not means, and for the courage of critical intellect. For Kant, being autonomous meant being free to deliberate and choose, and that as moral agents. people had both rights and duties (Kant, 2009). In England, John Locke argued that humans had inalienable rights independent of any laws and that indeed, the scope of government should be limited to protecting these rights (Rosenblatt, 2018). In the Scottish Enlightenment, Adam Smith called for greater economic freedom and less government regulation of trade that had benefited only the few. Smith argued that leaving people alone to pursue their self-interests in a competitive market would result in a self-regulating and benign prosperity (Smith, 2012).

However, Enlightenment ideas have been criticised and are sometimes linked to the violence of the French Revolution and even to the genocide of the Holocaust (Peters, 2019; Baumann, 1989). While these links are controversial (Rasmussen, 2011; Healy, 1997) it seems fair to say that the universal humanity at the heart of Enlightenment thought was understood quite narrowly in male, European and ableist terms. Women's physiology was thought to diminish their capacity for reason (Bostic, 2012) while pejorative 'scientific' classifications of different races were used to justify slavery (Foutz, 2008). For persons with disability, the Enlightenment was a mixed blessing. Scientific knowledge expanded rapidly, impairments were no longer attributed to moral failure, and medical assistance became more sophisticated. At the same time, people with impairments became objects of diagnosis and treatment, and the line between those with and without a disability was firmly drawn (Russell & Malhotra, 2002). Many disabled persons who, under feudalism, had at least participated in life on the estates, were dispossessed in newly industrialised societies. According to Russell and Malhotra (2002), industrial capitalism created "a new class" (p. 213) of disabled persons whose body did not conform to that of the standard worker. As a result, they were excluded from paid work, were seen as a social problem and gradually marginalised in

institutions that "became the instruments for the facilitation of social death. Through a presumed scientific status, care for people with disability became depoliticised, technicalised and professionalised, predicated on notions of tragedy, burden and helpless dependency" (Clapton & Fitzgerald, n.d., para 12). This tragic notion of disability has been robustly challenged by disabled persons, who call for an affirmation model of disability that validates the positive identity and experiences of persons who live with impairments (Swain & French, 2000).

# The Emergence of Modern Capitalism

The exclusion of persons with impairments was further strengthened by modern capitalism. While merchants have bought and sold for profit since the earliest times (Fulcher, 2015), the onset of industrialisation allowed for the investment of private capital in new productive technologies that had a far wider effect on social and economic life than had the merchant trading that preceded it (Fulcher, 2015). The nineteenth century saw productivity rise in leaps and bounds, as industrial capitalism was enabled by the rise of political liberalism and free markets (McCloskey, 2019). Waged workers were essential to capitalism, as both producers and as consumers. However, working conditions were often very poor, giving rise to early social reform and the organisation of labour (Fraser, 2009). Early capitalism was blamed for causing much human misery, though not by all. Carver (1924), for instance, lamented that when referring to capitalism, too many pulled a "wry face [when] the masses of the people are better off under it than they have ever been under any other system" (p. 442).

The historical materialist view of capitalism, developed by Karl Marx in the nineteenth century, was less benign (Singer, 2018; George, 2012). His work articulated the forces of production and the relations between them, and how a legal and political superstructure comes to overlie, and prop up, the economic base on which it sits (Marx, 1992). For Marx, humans become free and fulfilled through their labour, as work allows them to master nature and meet their needs. It was the conditions of material life that shape consciousness, not vice versa. Under a capitalist system with its division of labour and appropriation of surplus value by owners, people

are estranged from what they produce and become alienated. The state was part of the problem, captured by the interests of the propertied class. And yet, capitalism was thought necessary to generate the class struggle necessary for its eventual overthrow. Marx' slogan "from each according to ability, to each according to need" became central to left-wing thought (Bovens & Lutz, 2019).

The economic turmoil of the early 20th century slowed down capitalist growth, and the Great Depression of the 1930s saw increased sympathy for socialism, which bifurcated into communism and social democracy (Sassoon, 2003). This "turn to the social" (Sassoon, 2003, p. 8) persisted after the Second World War, as capitalism was regulated and most political groupings supported universal suffrage, labour regulation and welfare provision. For three decades after WWII, it was a left-of-centre vision that characterised the *trentes glorieuses* of economic growth and the rapid development of welfare benefits and services (Pierson, 2006).

However, rising inflation and unemployment in the 1970s saw this vision of egalitarian capitalism give way to a neoliberal variant inspired, at least initially, by the classical liberal ideals of small government, free trade and private enterprise (Fulcher, 2015). The ascendance of neoliberalism coincided with, and was in part driven by, discontent with the welfare state on both the left and right of the spectrum (Offe, 1982). Critics on the left pointed out that welfare provisions did not adequately respond to need, and that they were usually delivered in a bureaucratic and paternalistic manner which failed to respect and empower service users (Beresford & Carr, 2018). On the right, the welfare state was accused of fostering a dependency culture, of reducing the efficiency of markets and of overextending the role and scale of the state to the detriment of initiative and personal responsibility (Fitzpatrick, 2011).

For Steger and Roy (2010), neoliberalism is something of an opaque catchphrase with three main manifestations. The first is an ideology of the primacy of individual choice, and the equation of rationality with the pursuit of wealth, which "puts the production and exchange of material goods at the heart of the human experience" (p. 12). The

second is a mode of governance based on enterprise, the self-regulating free market and the adoption of business practices from the commercial sector, also known as new public management. The third is a policy package of deregulation, liberalisation and privatisation, as well as tighter control of public expenditure and a move from 'welfare to workfare'. These authors assert that for many, neoliberalism is now a pejorative umbrella term, associated with unbridled selfishness, selective austerity and (mostly) American economic and cultural imperialism.

By the 1990s, neoliberal capitalism became global, aided by technology and by the financial liberalisation undertaken across the political spectrum (Stiglitz, 2019; Steger & Roy, 2010). Capitalism is now the predominant economic system around the globe. For some, this is good. McCloskey (2019), for instance, spoke of the "Great Enrichment" (p. 10) that has occurred since 1800, claiming that capitalism has brought about an increase of 3000 per cent in the real income of the poorest that would not otherwise have happened. Innovation, imitation and commercialisation have made an increasing number of commodities affordable even to those on lower incomes, to an extent that would not have been thought possible only decades ago. Others are less sanguine. Milanovic (2019) stressed the hegemonic nature of contemporary capitalism as legal and political institutions are geared to protect and foster a profit-driven economy, where making more money is widely deemed the principal way to better one's standard of living. While inequality between nations has gone down, within countries it has risen. Milanovic (2019) points to a number of explanatory factors. Financial assets have become concentrated not only among the owners of capital but also among a minority of highly skilled, highly paid workers while wages at the lower end of the spectrum remain stagnant. Assortative marriage between rich, educated men and women also serves to concentrate wealth and drive up inequality between households. In turn, the children of richer parents are more likely to access high-quality education, increasing inequality down the generations. The trend towards increasing inequality would seem inexorable, leading activists across the world, but also supranational

organisations that have championed neoliberal reforms, to call for inclusive growth (IMF [n.d.]; OECD [n.d.]). The disability movement was one of the earliest to take on unequal treatment, as discussed in the next section.

# Capitalism, Disability and the Disabled People's Movement

From the 1980s, prominent disability scholars adopted a materialist view to explain disability. Oliver (1999) and Russell and Malhotra (2002) argued that it was capitalism's 'productivist' exclusion of people with impairments that actually created disability, while at the same time creating a false consciousness among disabled people that their difficulties are due to their personal impairments. Efforts to normalise disabled people into an unequal society were not sufficient; only "[m]aterialist social theory [could] ... transform the society in which they live into one in which all roles are valued." (Oliver, 2009, p. 105).

Yet evidence from 20th century state socialist countries such as Russia and a number of Eastern European countries (Mladenov, 2015) suggests that the treatment of disabled people therein did not differ significantly from that of the West. Writing of Russia, Phillips (2009) noted how between the late 19th and early 20th centuries, care of the disabled by the Church and philanthropic élites gave way to a rise in medical treatment by experts. Institutional care was widespread, and it was in such settings that disability advocacy started in the USSR as early as the 1960s, though residents were often moved around to nip such advocacy in the bud (Phillips, 2009).

In the Soviet state, where work was glorified and citizens were, above all, to be useful (Dinu, 2019), persons with impairments were diagnosed and classified in terms of what they could not do. It was work, not need, upon which state socialism revolved. Under state socialism as under capitalism, those unable to work became poor and culturally devalued, and their disability was seen as a tragedy. While in the West, disability was tragic for the disabled person, under state socialism the tragedy lay in lost labour capacity (Mladenov, 2017).

It would thus seem that the commodification of persons with disability is not necessarily the

fruit of any one political economy. History has shown both capitalism and communism to embrace an ideology which, as Mladenov (2017) states, "reduces humans to resources utilizable for the enhancement of productive output" (p. 1110). Neoliberalism has entrenched this productivist philosophy, now evident also in welfare discourse and practice (Jordan, 2008). Particularly, there has been tighter conditionality applied to benefit systems, as "[p]eople are expected to practice personal responsibility by investing in their own human capital to make themselves less of a burden on society as a whole or face the consequences of a heightened disciplinary regime" (Schram, 2018, p. 308). In the case of disability, as with most other groups, the right to an adequate income has become increasingly conditional upon stringent work availability requirements, with tighter eligibility criteria intended to exclude those without a 'genuine' disability (Grover & Soldatic, 2013). This move to replace welfare with workfare for disabled people has been accompanied by an authoritarian and stigmatising discourse that is redolent of the distinction made in the 1834 English Poor Law Amendment Act between the deserving and undeserving poor (Grover & Soldatic, 2013).

Even if the productivist exclusion of disabled people is not peculiar to capitalism, we will now turn our focus to the relationship between the latter and the disabled people's movement. This relationship is especially important to consider, since the mobilisation of disabled campaigners into an organised movement first occurred in capitalist countries, especially in the US and the UK (Campbell & Oliver, 1996; Zames & Zames, 2011). The most significant achievement of the disabled people's movement has been its social model of disability, which distinguishes between biological impairment and socially created disability. This model has been a very powerful tool in campaigning for disabled people's rights, as it brought about a realisation amongst disabled people themselves that many of the difficulties they faced were the direct result not of their impairments but of societies that did not cater for their impairment-related needs (e.g.: Barnes & Mercer, 2010; Camilleri, 1999; Shakespeare, 1993). Oliver (2009), while not denying "the influence (some positive, some negative) of medicine, charity and welfare in the

lives of disabled people" (p. 43), regarded the social model and its focus on removing economic, cultural and environmental barriers as the best foundation for understanding and addressing disability.

The social model has not been without its critics. Thomas (2004) writes of her regret that the original relational conception of disability by early disabled pioneers Vic Finkelstein and Paul Hunt, in which impairments and barriers interact to cause disability, was eschewed in favour of a position that equates disability solely with socially created barriers. The relational nature of disability is acknowledged in the Preamble to the UNCRPD (2006). Barclay (2010), too, pointed out that impairments cannot be left out of any understanding of disability. Moreover, she contended that it is not really "plausible to suggest that failure to design a society equally favourable to all people, irrespective of their physical and mental traits, constitutes discriminatory treatment" (p. 161). Social institutions cannot be made to ensure the equal access and success of everyone, not least because the needs of one group may contradict those of another. In fact, anti-discrimination disability legislation includes the principle of reasonable accommodation which ensures that adjustments required to cater for impairment-related needs do not impose an unjustifiable burden on the persons or organisations required to make these adjustments. One of the first such laws was the Americans with Disability Act, promulgated in 1990 and followed by the enactment of similar anti-discrimination legislation in many other countries in the decades that followed (Breslin & Yee 2002), and by the UNCRPD (United Nations 2006).

While significant positive change has been registered in the quality of life of disabled people and in respect for their rights, decades of progress have still not brought about the levels of equality and inclusion that disabled people have campaigned for since the 1950s. In fact, the Concluding Observations on the by the Committee on the Rights of Persons with Disabilities (2020) on the State Reports submitted by countries that have ratified the CRPD highlight numerous shortcomings in each country. The limitations in the scope and extent of the progress achieved can be at least partially attributed to the

persistence of the logic of the individual 'tragic' model of disability which requires medical intervention, welfare and charity provision, or even the abortion of disabled foetuses and euthanasia (Prusak, 2005).

Challenging this logic means moving away from an exclusive focus on the negativity of living with an impairment, thus flying in the face of the age-old conflation of impairment and disability. As seen above, the negative associations of disability are entrenched in the culture of different societies, regardless of historical period or socioeconomic arrangements. While there may be differences in how disabled people were and are viewed and treated in, for example, Ancient Greece and Soviet Russia, what binds these different views together is not only their negativity but also the fact that they are based on non-disabled people's views of what it means to live with a disability. Adopting the social or social relational model of disability has meant questioning ideas that have become so deep-rooted as to be mistaken for objective facts.

In aiming to dismantle socially created barriers, these campaigners set their sights on the obstacles created by the socioeconomic systems that they themselves lived in. It is therefore not surprising that it was capitalism in its various forms that has come under fire from many of these activists (see for example Marta Russell's criticism of American capitalism in Rosenthal (2019) and Ryan's (2019) analysis on the effects of austerity on the lives of British disabled people in the past decade). At face value, the market logic of capitalism, and the retrenching of the state in its neoliberal version, run counter to the demands made by disabled people for equal rights and equal opportunities. In fact, the arguments made by Russell and Ryan, among others, are based on theories from the left of the political spectrum, since they argue that the social and economic disadvantages experienced by disabled people are structural problems, and that it is society that needs to carry responsibility for them, rather than disabled individuals themselves. From this perspective, the costs of services and measures in this area should be borne by the state on behalf of society.

Legislation, policies and related measures aimed at dismantling, or at least reducing,

disabling barriers are based on a political philosophy that challenges those who recognise only negative (or liberty) rights. For example, libertarian reasoning that welfare states restrict people's freedom is refuted by the argument that without state intervention, the rights of disabled people, as enshrined for example in the UNCRPD (2006) and in various national anti-discrimination disability laws, would only be hollow words. The funding of support services and measures to increase community access is essential for disabled people to live their lives in dignity and on an equal basis with others. In fact, article 19 of the UNCRPD (Living independently and being included in the community) obliges governments to take 'effective and appropriate measures' for disabled people in this regard (United Nations 2006, p. 13). Even if, as is often contended, negative rights enjoy primacy over positive ones (Cranston, 1983), the positive (social and economic) rights of disabled people must first be met if they are to enjoy their negative rights. After all, freedom of expression means little to a person who cannot communicate without adaptive technology, nor does freedom of association make sense to persons who lack the mobility aids they depend upon to meet and socialise with

# Independent Living and Individualised Services

Thus, for disabled people, liberty and autonomy mean having the necessary assistance to live life on their own terms in a society which has removed cultural and structural barriers (Morris, 1993). This means that disabled people need accessible environments in the mainstream of society, and varying degrees of assistance from others in their daily lives to cater for their impairment-related needs both at home and to participate in their community.

These are the foundational arguments of the independent living movement which, as Zames and Zames (2011) described, started with people with severe physical impairments working for deinstitutionalisation which in turn brought "a new population to the developing disability rights movement" (p. 33). The work of these activists involved not only campaigning for governments and other societal actors to dismantle barriers and to provide assistance for disabled people to lead

independent lives, but also disabled people getting organised and taking charge of these services, thus creating the changes they were calling for. Zames and Zames's (2011) account of the disability rights movement foregrounds the activism of Ed Roberts, one of the key figures in the US independent living movement in the 1960s and early 1970s. His work is testimony to what disabled people have managed to achieve through this approach. At age fourteen, Roberts became a tetraplegic in need of an iron lung after contracting polio. Against the odds, he graduated from Berkeley University with a Bachelor of Arts in 1964 and a Master of Arts in 1965 (Dawson, 2015). Roberts opened the way for other severely disabled people to enrol at Berkeley. Together, they formed the 'Rolling Quads' and "organized an agency in 1972 governed by and for people with disabilities, the Center for Independent Living (CIL) that eventually gained national and international prominence" (Zames & Zames 2011, p. 39, emphasis in the original).

What was strikingly different about the services provided in these CILs was that, first of all, it was disabled people themselves who were in control. They were no longer simply passive recipients of care, dependent on decisions made by professionals and family members, but were running the services themselves. Furthermore, the services they developed were not based on the provision of daily care in a way that perpetuates dependence. Instead, what the CILs began to offer was a range of services that enabled their members to be active in their community. Zames and Zames (2011) explained that in these centres, the disabled person was no longer "the 'patient' or 'client', connoting dependence on authority ... [but the] 'consumer', suggesting control by the user of the service" (p. 46). The North Carolina Statewide Independent Living Council (NCSILC) reported that to this day, CILs are run mostly by disabled people and their goal is "to promote and support opportunities for people with disabilities to fully participate in an integrated community and search for the possibilities to live as they choose" (NCSILC 2020, para 2).

The changes in service provision brought about through the pioneering work of the CILs and of disabled activists and their allies in the US, the UK and elsewhere, would eventually be adopted to some extent by governments and service-

providers in the disability sector. By the 1990s, the independent living movement and the wider disability rights movement had come to the policy forefront. Service personalisation, as one of its lead proponents put it, had the potential to "overcome the limitations of both paternalism and consumerism" (Leadbeater, 2004, p. 11), as it gave choice and control over how support is delivered (Department of Health, UK, 2008).

In the UK, this policy provided for a direct payments system, where disabled people had the choice of either receiving support from an agency (often entailing mixed models of funding and provision among state, non-profit and private organisations) or being given funds by the state to directly pay for services by personal assistants that they choose themselves, thus becoming their own assistants' employers (Department of Health 2020). For Beresford (2009), receiving support from an array of user-controlled service providers was a collective and liberatory approach. The granting of budgets to individuals, on the other hand, reflects a 'managerialist/consumerist' philosophy dependent upon the market, where the cash allocated, and services available, may be less than optimal.

This individualising of disability services has been criticised by prominent disabled activists. Oliver (2009) pointed out how, in its individualised approach, the ILM placed the social model and its radical potential for collective action on the backburner. Duffy (2014), the founder of In Control - the social care reform organisation that led the individual budgets system in England for years - wrote that personalisation has failed to empower vulnerable citizens in three main ways: some recipients find individual budgets hard to manage; the monitoring of individual budgets is administratively complex; and individual budgets have been restricted in the context of cost-cutting policy. These criticisms lead Duffy to claim that personalisation has become "an excuse for abandonment... [and] to cut costs" (para. 5). Land and Himmelweit (2010) agreed that personalisation makes it easier to cut costs, because it is easier to contain cash payments than it is to reduce service costs (Land & Himmelweit, 2010). And yet, only adequate funding can ensure the success of good quality standards (Slasberg et al., 2012).

Kendall and Cameron's (2013) small scale study with service users and professionals bore out many of these concerns. While their participants expressed positive views of selfdirected support as offering them more choice and control, they also spoke of the complexity in navigating the system and a lack of transparency in resource allocation. Participants felt pressures to resort to the use of informal carers such as family members, which once again reduced them to gratitude rather than empower them through the ability to transact in the market. These data led Kendall and Cameron to identify "a retrenchment to paternalism [and] an acceleration of the neoliberal cost-cutting agenda" (p. 269). They further concluded that their contradictory findings reflected the ideological conflicts at the heart of personalisation:

If independence is conceptualised in terms of reduced dependence upon others, particularly the state, budgets will be generated to operate at the minimum possible level, reliance upon informal support will be entrenched, and direct payments will be promoted over managed services. By contrast, if independence is conceptualised as having access to the right level of support (Brisenden, 1989), there will be an emphasis upon service users' rights to access adequate and varied support, without the involvement of their family and friends if they so choose. (pp. 269-270)

# **How the ILM Challenges Capitalism**

The ILM casts disabled persons as consumers of independent living services and as employers of their own personal assistants, except that disabled people are not consumers or employers in quite the usual sense. Consumption in this case refers to the procurement of the most fundamental services to a person's life, a far cry from the consumerism to which many are accustomed. The employment of personal assistants is also quite different from the typical employment relationship. No capital is invested, as funds are generally provided by the state, and no profit is derived. The problem, as Russell (as cited in Rosenthal, 2019) implied, is that many disabled people are too poor to access the marketplace. She criticised the ILM for its unquestioning acceptance of capitalism:

On the one hand, it seeks to promote

autonomy and self-determination for disabled people. On the other, it implicitly accepts the foundations of free market ideology by framing the debate in terms of the right of disabled people as consumers to receive equal treatment from the marketplace. (p. 8)

However, the ILM (and the disability rights movement more generally) are not so much a rejection of capitalism as an adaptation of it. It is the existence of a social market, where the welfare state coexists with the freedom to contract, which makes the support for individual autonomy possible. Indeed, the ILM aims to bring about a society in which structures that curbed the individual freedom of disabled persons in the past (and to a considerable extent still do) are transformed into ones that provide them with the support and adjustments that are crucial for them to make meaningful choices and maximise their agency (Morris, 1993). In so doing, the ILM addresses the contrasting definitions of independence - reduced dependence versus appropriate support - identified by Kendall and Cameron (2013).

The two positions can be explained in terms of whether the emphasis is placed on societal structures or on personal agency. A person can attribute their success or failure purely to their own merits (and hence to the exercise of their personal agency), or to the favourable circumstances that the person finds themselves in (and hence to the societal structure to which they belong). A sole focus on personal agency risks solipsism, while a sole focus on societal structures risks losing sight of the individual altogether. These two positions can be seen as the extreme ends of a continuum along which most debates on structure and agency can be placed:

Sociologists who define social forces as though they are real things independent of the reflection and actions of human beings concoct the sociological fallacy of determinism and reification. If individuals believe and act as though they are autonomous and sovereign, then those individuals obscure the effects of structure... Yet the power of social forces does not determine individuals. As long as humans are alive and in possession of their consciousness, agency exists. (Musolf, 2017, p. 5)

Seeing disability as being only socially

created emphasises structural barriers and is based on an expectation that societal structures bear the responsibility of removing these barriers for disabled people to enjoy their rights to a life on an equal basis with others. The issue with this view is that it can be difficult to establish at what point the disabled person's autonomy and independence come into effect. Even if autonomy and independence are seen to be mediated through the support of others, namely from personal assistants on an individual level to macro-structures that enforce accessibility requirements in the community, there must be a point at which disabled persons are responsible for their own actions and lives, with the consequences of the decisions they have made. After all, the focus on disabled people's right to live life on their own terms, rather than it being determined by those whose support they depend on, is predicated on a view of disabled persons as active agents in their own lives (Morris, 1993).

The strength of the ILM is that it is based on a relational view of the individual and is thus less a rejection of the Kantian autonomous and rational being than a re-conceptualisation of personhood. The individual remains more important than the societal structures they inhabit (Musolf, 2017), even as all energies are directed towards changing these structures. The need to change these structures for disabled people to be able to exercise their individual agency is undeniable. Equally important is the need to emphasise this agency. In fact, apart from the social model of disability, the other crucial tenet of the independent living movement is encapsulated in the slogan Nothing About Us Without Us (Charlton, 1998), a slogan that reacts to millennia of disabled people's lives being entirely determined by other people, who are often not disabled themselves.

# **Concluding Reflections**

Ensuring the continuation of the positive changes ILM has achieved requires action on a number of fronts. The first is a matter of outlook. Appreciating our interdependence, and acknowledging how the progress of even - perhaps especially - the most successful, has depended upon the support and resources of others, may help to counter the view of care services as residual and pertaining only to the

vulnerable Other. It is also important to recognise that reducing the experience of disability - or of any diversity for that matter - to negative terms such as tragedy or dependence is simply not accurate. Disabled people share widely-held aspirations. Achieving them involves strength of character and ability – especially in the face of socially-created obstacles – as well as having the right support.

Attitudinal change is not enough. The ILM reminds us to challenge the subordination of values to economic growth, the profit motive and narrow cost-benefit analysis. Policies to strengthen the inclusion of disabled people, through choices such as accessible infrastructure and educational systems as well as good jobs are not simply "inefficiencies that impede the natural economy of self-interest" (Robinson, 2020, n.p.) but are fundamental to the exercise of disabled people's most basic rights. The choice to allocate sufficient resources that enable disabled people to exercise the rights and freedoms that most of us take for granted must be made and sustained. While containing public expenditure may be necessary, we must challenge a mindset of scarcity that would impose selective austerity upon those for whom such cuts have the most devastating effects.

To conclude, the ILM emerged from a long struggle to assert disabled people's rights to autonomy and social participation (Zames & Zames, 2011). As outlined, the movement has its own internal tensions but these do not arise from any problem inherent to the nature of the movement's claims, but from the complexity of the contexts that disability activists have had to grapple with. We contend that the ILM offers a good example of the way in which capitalism both creates, and defies, expectations of choice and self-determination, but also of how capitalism may be informed by the ILM and by the disabled people's movement more generally. The lessons that the ILM has brought into broader policy are invaluable. We grow up together and are interdependent. Our relations are, by their very nature, reciprocal and the social and economic contribution of everyone should be recognised and valued. The experience of CILs has shown us the value of cooperative enterprise and serviceuser involvement. More broadly, too, the ILM reminds us of the transformative force of collective action; of the fact that rights and freedoms must be universal and resourced if they are to have any meaning at all; and the fact that economic progress should be slave, not master, of those higher values that make society a better place for us all.

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# **Author Bios**

Anne-Marie Callus is Senior Lecturer in the Department of Disability Studies within the Faculty for Social Wellbeing at the University of Malta. She lectures and researches on disability rights, empowerment of persons with intellectual disability, inclusive education and cultural representations of persons with disability. She also has various publications on these subjects.

Sue Vella is currently Head of the Department of Social Policy and Social Work at the University of Malta, where she lectures on various aspects of social policy analysis and implementation. Her main research interests lie in the history of the Maltese welfare state; European social policy; housing, employment and social security; families and family policy; and the voluntary sector.

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# Raising the Profile of Children in Alternative Care: A Positive Approach

Marian Muscat Azzopardi1\*

## **Abstract**

This article focuses on the negative impact of stigma that can be experienced by some children in alternative care in Malta. The impetus to address this issue came from an instance of insensitive media coverage of alternative child care in Malta that unintentionally continues to feed and propagate the stigma. The concept of stigma is analysed in the light of research carried out with children in care and their caregivers, the recently enacted Minor Protection (Alternative Care) Act Cap 602 as well as the principles enshrined in the United Nations Convention on the rights of the child. The article draws on the rich qualitative data that informed a range of previous studies and submits this data to scrutiny under a narrower lens. The result raises sensitive questions and highlights policy and practice measures that can sensitively and comprehensively attempt to address this issue.

Keywords: Children in residential care, media exposure, social stigma, UNCRC, State Responsibility

<sup>1</sup>Faculty for Social Wellbeing, University of Malta, ORCID iD: https://orcid.org/0000-0003-0126-6399

\*Corresponding author:

Marian Muscat Azzopardi, Visiting Lecturer, Faculty for Social Wellbeing, University of Malta

Email: iktbuli@gmail.com

# Media Exposure and the Impetus to Address Stigma

Social stigma has been portrayed as an outcome of the fact that "society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these categories" (Goffman, 1963, p.5). Furthermore, this social stigma can adhere to other members of the family of the persons who are stigmatised in the form of associative or courtesy stigma. Goffman explains how social settings also "establish the categories of persons likely to be encountered there" (Goffman, 1963, p.5). Various and at times overlapping manifestations of stigma inform the understanding of stigma.

It is relevant at this point to mention what provided the impetus to address this issue at this moment in time. The impetus came from reading a recent article in a Maltese newspaper that, despite good intentions, was in my view potentially very damaging and stigmatising with respect to all the residents of one residential home that was mentioned by name in the article (May, 2020)1. Even though the main theme of the abovementioned article highlighted what were seen as positive developments and outcomes for these minors in residential care, some remarks were potentially very stigmatising. This article quoted a statement that was made by the professional who was being interviewed which asserted that all the minors in the home had a turbulent past and persistent challenging behaviour. This genre of media coverage unintentionally fuels the stigma. For example, being branded as having 'persistent challenging behaviour' contributes towards the stigma mentioned by some of the very residents of this home in 2008 when I was conducting research with these minors prior to the formulation of the 2009 standards of out-of- home child care:

Why should we all be here together? I came here because I was a victim. Other persons come here because they are troublemakers or very badly behaved. We should not be together because we have different needs. Why should I be lumped with them? I am not naughty. I do not have behavioral problems. (2008, unpublished)

Another resident made similar distinctions:

Do you know what happens when we are put together? This is what has just happened. There was a girl in here, her sister (pointing to another girl who was with us), who had been here for over a year and who was always well behaved. Another girl was brought here who was very naughty and troubled. She persuaded the quiet girls who had been here to escape with her. When they were caught, the quiet girl was sent to Mount Carmel Hospital<sup>2</sup> and the naughty girls were allowed to stay here. It is not fair. The guiet girl received the punishment and the naughty girl got away with it. We know that if we are naughty we are punished by being sent to Mount Carmel so we used to warn the quiet girl to be good. But she still escaped because the naughty one made her do it. (2008, unpublished)

This media typology purporting to depict persons in alternative care as being in an improved situation in contrast with their troubled past can unintentionally fuel stigma. The past that is being publicly described portrays the children as members of dysfunctional birth families.

Denigrating these birth parents not only hurts their children but fuels stigma. This paper is one of the reactions to the abovementioned typology of media coverage. Various other actions were taken

<sup>&</sup>lt;sup>1</sup> The article is not being identified for three main reasons. The first is that it is not in the interest of the residents of this home to be further exposed to stigmatising publicity. The second reason stems from the likelihood that the professional working in this home was quoted out of context; therefore, reading the article might expose this head to undeserved judgmental repercussions. The third reason is that it is

not this article in itself that is the subject under scrutiny, but the genre of media coverage of which this article is just an example.

<sup>&</sup>lt;sup>2</sup> Mount Carmel Hospital is a psychiatric hospital which includes in-patient treatment for children and adolescents with mental health difficulties.

behind the scenes to address the matter in confidence as it was feared that a public expression of outrage to a particular media article would draw more attention to the article and to the residents and increase the exposure to stigma. It is hoped that instead of publicly denouncing individual instances of stigma fuelling behaviour, a study on stigma as it is experienced by children in alternative care in Malta may contribute towards other efforts that are currently being made and proposed to address this sensitive issue.

# Methodology: Revisiting Child-centred Qualitative Research

Qualitative research that involves listening to children who have experienced alternative care can have a profound and long-lasting impact on the researcher. Such qualitative research produces a wealth of rich material that does not all find its way into published work or comprehensive analysis. This body of material sometimes exerts a lingering pressure on the researcher to fulfil a duty to tell the whole story. This is not to say that the researcher was negligent in leaving unsaid what should have been said. Every qualitative research study involves choices regarding what is most relevant to a particular research question and project. This claim regarding past choices about what to include in my research studies is just an admission that the data previously gathered can be subjected to 'supplementary analysis' Heaton (2004). In distinguishing between five types of secondary analysis of qualitative data, Heaton (2004) explains that:

'Supplementary analysis' involves a more in-depth investigation of an emergent issue or aspect of the data which was not considered or fully addressed in the primary study.... The foci of supplementary analysis are compatible with that of the primary work. (p.36)

Heaton (2004) further highlights that in the case of supplementary analysis, once the re-use of data by the researcher was 'not for purposes other than which it was collected ... this does not raise ethical issues.' (p. 73).

In this vein, this supplementary analysis adopted a methodology that involved ongoing reflection on the rich qualitative data that was obtained during the previous decade. As McLead

and Thompson (2009) succinctly maintain, "The richness and value of qualitative studies is not exhausted or fully captured in one reading or telling, or in one time" (p. 291). As McLeod and Thompson further claim, the research material can be further mined and subjected to a new focus.

Two different categories of sources provided the data that inform this work and were subjected to the supplementary analysis. One the one hand, published local studies were examined in the light of the present focus of interest. On the other hand, the rich source of qualitative material that had been gathered during my own research in the field over the past decade or so was revisited and subjected to secondary analysis. This material consists, inter alia, of transcripts of interviews and notes taken down during ethnographic immersion in the field. The studies that were revisited were subjected to a narrowly focussed view on the subject of stigma that was related to the children's alternative care status.

# Stigma and Child Alternative Care in Malta

Children in alternative care may often experience the negative effects of different categories of stigma associated with their status as children in alternative care. In fact, over the past decade, some children in residential and foster care have described stigma as a source of suffering and isolation; the stigma that they suffer has been highlighted in recent research that has given a voice to children in alternative care and their primary caregivers (Abela et al., 2012; Debono and Muscat Azzopardi, 2016; Grech, 2017). This phenomenon of social exclusion and stigma is manifested within different countries (Smith, 2011; Smith 2017; Kendrick, 2008; Kikadidi, 2017). Following Goffman's conceptual distinctions that are mentioned above, two kinds of stigma are being highlighted (Goffman, 1963). The first is the associative or courtesy stigma that attaches to being biological members of families whose children have been taken into care. The second is the stigma that could be attached to living in residential child care. However, as Deverell points out, even though in recent studies the concepts of stigma and disadvantage have been considered particularly relevant to children in alternative care and their families 'as a group', it is important to highlight that children in alternative

care and their biological families are a diverse group of individuals (Deverell, 2007). Measures suggested to address these stigma-related issues can form part of the current drive to improve outcomes for children in alternative care and the system of alternative residential care in Malta which is often viewed as in need of bettering (Abela et al., 2012; Grech, 2017).

# The Biological Family and Associative Stigma

Stigma is considered to result from a varied combination of factors. Burke (2007) examines the stigma that some may suffer as a result of being associated with persons who themselves are perceived as disadvantaged. This 'associative disadvantage and the stigma that is experienced' can be said to also pertain to the children in alternative care (Burke, 2007, p.12). The family circumstances that can lead to minors entering alternative care are various. These include a range of factors many of which can be said to share a stigmatising label of social dysfunction or malfunction (See Minor Protection (Alternative Care) Act 2019 (CAP 602)). Although the term stigma has wide applications, the focus here is on a narrow application. Reference is being made to the term stigma as it is used with respect to those attributes that are 'deeply discrediting' (Goffman, 1986). However, simply by being biological members of discredited members of society, the children in care may become the undeserving victims of stigma.

At this point, attention is now turned to the documented effects on the child in care of the transferability of this stigma to all members of the family. Children in care have repeatedly mentioned how much shame and isolation they suffer as a result of associative stigma resulting from belonging to a negative stereotypical biological family. It is not the intention of this paper to shed any doubts on the fact that all efforts to address the issues that led the child to being taken into care are being maintained to the extent that resources permit. Neither is it the remit of this commentary to find fault with how well the child's care plan is being thoroughly implemented. As mentioned above, the impetus that led to this paper sprung from various accounts given by children in care over the past decade that lamented the suffering that they experienced

because of stigma. The children's articulation of this lament did not emerge through any study about the subject but was the spontaneous response to more general discussion about care. It is hoped that in turning the spotlight on these first-hand accounts, targeted efforts that address this issue are given a fresh impetus in these fast-changing social conditions.

The reference to associative stigma emerged as an unforeseen outcome during indepth interviews and ethnographic research carried out with children in foster care (Debono & Muscat Azzopardi, 2016). A gender difference was noted in the responses. The few respondents who spoke about the potential shame and pain inflicted on them as a result of associative stigma were young adolescent and pre-adolescent girls. Even though these girls showed how happy and settled they were in their foster families, they still tried to hide the fact that they were fostered from their friends. They feared the stigma that they would suffer if their school friends found out that the family that they belonged to was not their birth family. As one eleven-year-old female respondent lamented:

In school four of us (girls) in my class are close friends and we always hang around together. I recently revealed my secret to one of the girls. Would you believe it?

She actually revealed what I told her to the other two girls! (2016, unpublished)

She told me that she was mortified by this. This same girl told me that she had been guarding her secret for a long time. She said that she had once confided with her foster mother that the girls in her class had often asked her who the lady who attended Parents' Day was. They thought that she looked too old to be her mother. The foster mother had told her she could say that she was her grandmother. However, this girl explained:

They told me several times in school that they had never seen my mother. And I am ashamed to say that I do not have a mother, really ashamed. Even when she (the foster carer) comes (to school), they all ask me 'who is she?' I do not quite know what to respond. She (name of foster carer) told me 'tell them that I am your grandmother.' But to me she is not a grandmother. I consider her to be my

mother. And I do not know what to tell them. (Debono & Muscat Azzopardi, 2016, p. 67)

Another young adolescent female respondent had explained that the mother of her best friend in school had visited the head of school to ask for the two girls to be separated. This parent had told the head of school that she did not want her daughter to be her friend:

She told the head of school that she did not want her daughter to have anything to do with me. She said that my birth family must have been up to no good. She said that for all she knew, my father may be in prison and my mother could have been a prostitute. (2016, unpublished).

Furthermore, one female participant "mentioned how she was taunted in school about the lifestyle of her birth family" (Debono & Muscat Azzopardi, 2016, p. 95). However, in stark contrast to the above young adolescent girls, a fostered boy of about the same age explained that he was not at all affected by his status as a fostered child. He said that, nowadays, most children have experienced family problems. He mentioned the frequency of family breakups and other social problems that seemed so common in Malta today. So he did not really feel different from anyone else. In fact, he said that he was very popular with his neighbours who are friends of his of about the same age. He explained that he was very much in demand in his circle of friends because he was also the only one to manage to mend their bicycles. This achievement was also made more feasible by the fact that his foster father had equipped a section of his garage with the tools and devices necessary for bicycle repair. This had helped him build up and maintain his confidence in his ability to repair bicycles which was held in high esteem by his friends. This boy exhibited resilience and self-confidence. This example will be revisited below when the way forward is discussed.

Specific reference to the negative consequences of associative stigma was mentioned by a young adolescent boy (Debono & Muscat Azzopardi, 2016). He was in residential care after his foster care placement had broken down. He explained that he really wished to be fostered but that being in residential care at his age was considered a sign of challenging

behaviour. He worried that no one would want to foster him because of the stigma attached to his status:

So, you see, here I am. I ended up in residential care. At my age no one would want to foster me because they would think 'at his age and in residential care, then he must be naughty'. They all prefer to foster younger children. (p.97).

Whether it is the case or not that persons may prefer to foster younger children is beside the point here. What is relevant is the painful fact that this young person felt stigmatised and that this stigma seemed impossible for him to overcome. He was also convinced that it blocked his chances of living in a family environment. Examples like this underscore the need to avoid stigmatising media coverage related to children in care:

A related aspect of the social stigma that was mentioned in the context of peers, also featured in a different context. A couple of participants mentioned that some potential foster carers might assume that older children are 'damaged' or 'troubled.' They mentioned that this made potential foster carers reluctant to foster older children. Some participants found this very painful. What they expressed underscored the importance of avoiding any social or media coverage of children in out-of-home care that may single them out as problematic or potentially problematic children. (Debono & Muscat Azzopardi, 2016, p. 97)

The need to counter this kind of stigma that can be attached to children in residential care has been convincingly documented more recently:

A few care workers in my study have pointed out, children in residential care face stigma. In order to honour children in residential care and their families, supporting McCall's (2011) argument, we need to rise above depicting residential homes as "terrible places for children" (p. 254). Wilson & Milne (2016) argued that the media in the UK had constructed negative imagery of these children and their families. An educational campaign on residential care (Gallagher & Green,

2012), and care leavers themselves (Happer et al. 2006), could reduce stigmatization by sharing stories of resilience and success of these children and their families. (Grech E., 2020, p. 318)

This recommendation echoes the views expressed by Andrew Azzopardi in his capacity as the director of Fondazzjoni Ejjew Ghandi3:

One of the things that irks me is the rhetoric about children in care – they are usually described as pitiful, sad and lonely in theatrical works, during electoral campaigns or by the media....Children in residential homes are also happy, enthusiastic and have aspirations and when we fail to show this other side, we fuel the stigma. (TOM, 13-11-2017).

# The Family – the Natural Environment for the Well-being of Children

The United Nations Convention on the Rights of the Child is undoubtedly the "most complete statement of children's rights ever produced and is the most widely-ratified international human rights treaty in history" (unicef.org.uk)4. Narrowing the focus of scrutiny of the Convention to the subject of discrimination, one sees that the Preamble recognises the fundamental principle of non-discrimination:

Recognizing that the United Nations has, in the Universal Declaration of Human Rights and in the International Covenants on Human Rights, proclaimed and agreed that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. (Preamble, United Nations Convention on the Rights of the Child)

The Preamble proceeds to draw attention to the special care and assistance that children are

entitled to in the abovementioned international legal texts. It then proceeds to recognise the role of the family in the life of the child:

Convinced that the family, as the fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community,

Recognizing that the child, for the full and harmonious development of his or her personality, should grow up in a family environment, in an atmosphere of happiness, love and understanding. (Preamble, United Nations Convention on the Rights of the Child)

The upholding of this fundamental principle is what reinforces the primary duty of the State to support family life. The State is thus obliged to take all measures possible with available resources to provide the full range of necessary support that is required to help the family fulfil its duties in the care and upbringing of children. However, in the case of children who cannot live with their family and are growing up in care, reading this statement can reinforce the feeling of loss, of being different and of rejection. In Malta, the central importance of the role of the family regarding social acceptance is widely recognised. As Aguis et al. claim, "The Family - the extended Family - is the most important influence on Maltese Individuals - in terms of its needs and the person's sense of belonging" (2016, p.75)

It is important to underscore that what is being claimed here is certainly not that the Convention should have been drafted differently. What is being suggested is that, to a child or young person growing up outside a family, reading the preamble may reinforce a feeling of loss. Failing to conform to the ideal as outlined in the Preamble or as valued in countries like Malta may indicate that one has failed to uphold this standard. However, it is worth repeating that this is not

<sup>&</sup>lt;sup>3</sup> (NGO) Community Organization, Child Protective Service

<sup>4</sup> https://www.unicef.org.uk/what-we-do/unconvention-child-rights/

intended as a criticism of the Convention. It is just a view from those living in ways which deviate from those established by the Convention. The intention here is to jolt us into increasing our endeavours to fully implement the principles of the Convention, for as Freeman warns us,

We should not mistake the words for the deeds... This is particularly significant now that we have begun to take children's rights seriously. The passing of laws, the implementation of conventions, is only a beginning: it is a signal that must be taken up by governments, institutions and individuals. (1992 p. 60)

Not mistaking the words for the deeds requires much more serious and sustained investment in alternative child care. The recent Minor Protection (Alternative Care) Act, Cap 602 is a milestone legislation that has been hailed as a significant development:

The new Minor Protection Act puts on a surer footing the standard of care to be provided to minors who need protection. The new setup provides for more autonomy, more professionalism and more checks and balances. (Vassallo, 2019, ESPN, p.2)

However, unless much more serious investment is made in residential child care, the provisions as laid out in the law cannot be fully implemented. The literature addressing residential care is unanimous in claiming that one of the most important factors affecting the wellbeing of the child is the specialised, individual daily care that a child receives from frontline workers and from their social workers (Smith, 2009; Kendrick, 2005; Gilligan, 1997, 2005; Daniel, 2008). These key workers are instrumental in helping the child develop resilience which is considered one of the key qualities that offsets the negative effects of stigma for children in alternative care (Kendrick, 2005; Gilligan, 1997, 2005; Daniel, 2008). Resilience is a concept that has been gaining increasing attention in child care discourse. Daniel (2008, p. 60) refers to Fonagy et al.'s key definition of resilience as 'normal development under difficult conditions' (Fonagy, 1994, p. 233). Daniel further supplements this definition with Gilligan's definition that mentions the qualities which 'help a child or young person to cope, survive and even thrive in

the face of great hurt and disadvantage" (Gilligan, 1997, p. 12). However, the child residential care sector is riddled with high child-to-staff ratios and frequent staff turnover. Carrying out research with care workers over the past decade has indicated a persistent trend of low staff morale, frustration with the system and a strong desire to be in an empowered position that would allow carers to carry out more productive work daily with the children in their care (Muscat Azzopardi M. 2009, 2012). Recent discussions with care workers from different homes indicated that no progress has been made (2019, 2020, personal communication). The care workers from one home opined that, despite the introduction of a regulatory system, their voices were not heard. They discussed the hardships and frustrations of working in a system that allowed such high staffto-child ratios. They described some of serious negative repercussions of the high staff turnover that resulted from such a system:

> I was on night duty in the child residential home that I work in. I was walking down a corridor. All of a sudden, a boy saw me and attacked me violently. He kicked me and scratched me and insulted me. (Muscat Azzopardi, 2020, Personal communication,)

This care worker explained that this boy had just been placed under her care. His previous care worker had resigned because he had found an opportunity for better employment. Nobody had explained to the boy why his previous care worker had been replaced and so he had blamed her for taking his place

Three care workers from another home regretted that the system did not allow for the possibility of meaningful implementation of child participation rights. They mentioned tokenism with respect to children's participation rights. They all regretted not being given enough time to listen to the children and to provide the kind of care that they knew the children would benefit the most from. One of the care workers opined:

Children require individual attention and the opportunity for some quiet, one-to-one time with a carer who they know and trust. However, on every shift there are two of us with a large number of children. We are also expected to do chores and

paperwork and answer emails during this time. So we cannot carry out the work with the children in our care as we know that we should. (Muscat Azzopardi, 2020, unpublished).

Children have categorically claimed that the relationship with carers and the time spent with caregivers was one of the most important factors that affects the wellbeing of children in residential care:

By far the most important factor that affects the way children feel is the relationship that they have with their caring staff. 34% placed this value at the top of their list. It was made clear that the interaction with caring staff within the residential home was what the children cared about the most. This was expressed in many different ways and along a broad range of situations and behaviours. (Muscat Azzopardi, 2010, p. 182)

#### **Need for more resources**

There has been general agreement over the past decades that more resources are needed for the sector to be in a position to offer the service required, give the children the opportunity to thrive and to acquire the resilience that can overcome the negative impact of stigma. The children themselves have explained graphically why this is so and why lower staff-to-child ratios are required:

Two of the older participants expressed that they realised that poor quality care did not only depend on the carers themselves. They understood that this quality also depended on having enough carers to deal with situations that may arise. It was pointed out that if children with demanding behaviour required more than one carer to concentrate on them, then that often meant that children who do not present problems feel that they are deprived of care. One of these participants put it graphically: 'The carers need to take good care of us and give us individual attention. This means that we need enough care workers to do the job well because, if for example a girl is having a serious problem, it is

understandable that she needs more than one care worker to look after her. When this happens, the rest of us do not get attention' (Muscat Azzopardi, 2010, p.183)

This fact has been known and documented for some time now. The ten-year strategic plan for the sector that was launched in 2009 stated that "The sector is suffering from a lack of financial resources and is unsustainable. There are serious gaps in the required continuum of services. More and better qualified staff is urgently required." (Ministry for Social Policy, 2009, p. 4). The writing has long been on the wall. Only a serious commitment to the sector can address the needs of the children who are in the care of the State.

# The way forward

The recently enacted Minor Protection (Alternative Care) Act Cap 602 and the 2020 Legal Notices establishing Social Regulatory Standards for Residential Services for Children in Alternative Care together form a corpus of welcome legislation. It is beyond the scope of this paper to give an overview of these legal texts. The major features of this legislation continue to receive justified consideration. However, attention is here drawn to a less frequently highlighted concept that is very relevant to the development of resilience and to the opportunity for the child to thrive and develop resilience-enhancing possibilities. For example, Standard 5 "Education, Enjoyment and Achievement" states that "Children shall have access to educational services and shall be given the opportunity to participate in social and recreational activities of their choice" (LN 33, 2020). The quality indicators to this standard state that the children "shall be empowered and supported to engage in educational programmes to maximise their potential.... and supported to participate in leisure activities of their choice." ('Guidelines Social Regulatory Standards, Residential Services for Children in Alternative Care', Social Care Standards Authority, 2020). If the resources are provided for the sector to fully comply with these quality indicators, the children in care could be given the opportunities to socialise with their peers and to acquire the qualities and strengths that can best counteract the negative effects of stigma (Kendrick, (2005); Gilligan, 2005)

This highlights one of the roles of the State

in addressing real or potential social exclusion and stigma by empowering those most at risk. Mark Smith (2009) highlights the relevance of this development in social policy to an advancement in the residential child care policy:

Thus, the focus of social policy has shifted from poverty and structural inequality towards raising individual opportunities and emphasising individual responsibilities. Policies such as those to improve the education of children in care need to be understood in this context. (p. 66)

Reference to media coverage is also made in the Minor Protection Act. Article 77 (1) makes it an offence to publicly identify a minor in alternative care through any means set out in the law. The intention of the legislator in regard to the protection of these service users from publicity is clear. The spirit of the law is to protect identifiable children in alternative care from harm through media publicity.

Seen together, the above-mentioned legal and policy developments are beneficial because they focus both on protection and also improving outcomes for children in need of care. But, as Mark Smith pertinently warns, we must ensure the timely provision of the resources and policies that are required for improving outcomes for children and 'meaningful change' (Smith, 2009).

It is sincerely hoped that a holistic approach to the issue will lead to a reduction of this specific stigma which affects so many children. Appropriate legislation, enforcement of standards, focussed education and policy decisions as well as responsible media coverage all play a fundamental role towards this end. The State has the obligation to provide the necessary resources to ensure that all these factors are in place.

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## **Author Bio**

**Dr Marian Muscat Azzopardi** Ph.D. is a Visiting Lecturer at the University of Malta. She has carried out extensive research in the area of out-of-home child care and has publications on different aspects in this area. She has contributed

# **Loneliness in Malta During the Covid-19 Pandemic**

Andrew Azzopardi<sup>1\*</sup>, Jamie Bonnici<sup>2</sup> and Marilyn Clark<sup>3</sup>

# **Abstract**

The reduced social contact which became necessary during the outbreak of coronavirus disease 2019 (Covid-19) occurred against a backdrop of elevated levels of loneliness, both in Malta and abroad. The present study used a quantitative online survey to assess levels of loneliness vis-à-vis intensity and frequency amongst a sample of Maltese adults (N = 906), as well as exploring any relationships between loneliness and sociodemographic variables. Results showed that frequency of self-reported loneliness was associated with age group, nationality, and occupational group. Younger participants and non-Maltese persons residing in Malta reported more frequent loneliness compared to older age groups and Maltese persons, respectively. Occupation type was significantly associated with both loneliness frequency and loneliness intensity, with participants working in entry-level positions or not in employment reporting more frequent loneliness and being more likely to be severely or very severely lonely. Rates of loneliness intensity were markedly higher across the sample, when compared to findings from the previous year, before the pandemic. These findings highlight the need for loneliness interventions which target specific sociodemographic groups in order to alleviate loneliness during the enforced social distancing measures of a pandemic.

Keywords: Loneliness, Malta, Covid-19, prevalence

<sup>1</sup>Faculty for Social Wellbeing, University of Malta, ORCID iD: https://orcid.org/0000-0002-5294-9803

<sup>2</sup>Faculty for Social Wellbeing, University of Malta, ORCID iD: https://orcid.org/0000-0003-4209-1740

<sup>3</sup>Faculty for Social Wellbeing, University of Malta, ORCID iD: https://orcid.org/0000-0003-0459-761X

\*Corresponding author:

Andrew Azzopardi, Faculty for Social Wellbeing, University of Malta

Email: andrew.azzopardi@um.edu.mt

revealed that 43.5% of Maltese people experience some form of loneliness (Clark et al., 2019) - a figure which highlighted the extent of the phenomenon in the Maltese Islands. The study by Clark et al. (2019) used the 11-item De Jong Gierveld Loneliness Scale, which indirectly measures the intensity of loneliness experienced by respondents (De Jong Gierveld & Kamphuis, 1985). The present study used the same research tool as that adopted by Clark et al. (2019) to gauge the prevalence of loneliness in the midst of the Covid-19 pandemic, during a period wherein social distancing directives were issued by the Maltese Government (Caruana, 2020).

During the Covid-19 pandemic, residents in Malta - as well as populations across the globe - were advised to limit their social interactions in order to minimise the spread of the disease. This involved reducing social activities, avoiding any non-essential travel or visits to friends and family, and remaining at home as much as possible (Brooks et al., 2020). The economic impacts of the pandemic also meant that people faced uncertainty about their employment and housing situations, which could potentially increase the risk of a deterioration in health and wellbeing (Brooks et al., 2020).

Loneliness and social isolation have been identified as some of the adverse consequences of the Covid-19 pandemic (Sanders, 2020). Social isolation is a related but distinct concept from loneliness; the former referring to a lack of "social interaction, social support structures and engagement with wider community activities or structures" (Public Health England, 2003, p. 6). On the other hand, loneliness is a more subjective evaluation of one's desired versus actual social connections (Sanders, 2020). Nonetheless, experiencing social isolation can be a significant predictor of experiencing loneliness, and both have been shown to have detrimental effects on physical and psychological wellbeing (Golden et al., 2009). Across the globe, governments advised individuals to limit non-essential activities and practice social distancing in an effort to reduce further infection rates of the virus (Dehning et al., 2020). Moreover, this pandemic occurred in the midst of an international 'epidemic of loneliness' (Sharma et al., 2020, p. 31). Thus, there have been increasing concerns that the rates of loneliness could worsen due to Covid-19 lockdowns (Bu et al., 2020).

Social connectedness plays a crucial role in an individual's overall wellbeing, wherein studies identifying loneliness as being as damaging to one's health similar to smoking 15 cigarettes per day (Holt-Lunstad et al., 2015). This places loneliness as a higher predictor of mortality than obesity, with an estimated impact which could shorten a person's life by a total of 15 years (Holt-Lunstad et al., 2015), highlighting the importance of addressing this social issue. There is also increasing body of evidence linking loneliness and social isolation to cardiovascular disease, even more so mental health outcomes (Leigh-Hunt et al., 2017), and an increased risk for dementia (Boss et al., 2015; Kuiper et al., 2015), among other negative effects.

Further exacerbating the negative effects of loneliness are the findings that a person who feels lonely is more likely to engage in harmful health behaviours. A systematic review of 25 studies revealed that half of the studies found a statistically significant link between smoking and loneliness, with loneliness increasing the chances of smoking amongst adolescents (Seo & Huang, 2012; Barbosa Filho et al., 2012) and adults (Dyal & Valente, 2015). Moreover, persons experiencing loneliness are also less likely to reach out to strengthen their social connections, paving way to a vicious cycle of reduced social interaction (Arpin & Mohr, 2019).

# Loneliness Across the Lifespan

The nationally representative study by Clark et al. (2019) which measured loneliness in Malta revealed an association between loneliness and age. Rates of moderate loneliness were found to follow a U-shaped distribution; 33.3% of Maltese individuals aged 11-19 were moderately lonely, followed by lower rates of 24.7% among those aged 20-34, after which rates steadily increased for subsequent age groups. These findings were similar to those found in countries such as the United Kingdom (Victor & Yang, 2012) and Australia (Franklin & Tranter, 2008), where loneliness appears to peak in adolescence, decrease into young and middle adulthood, and increase again in later life (Victor & Yang, 2012).

The higher rates of loneliness in adolescence and later life have been proposed to occur due to the substantial life changes that occur at such times. In adolescence, there are

critical challenges to navigate regarding personal and social development (Laursen & Hartl, 2013). These challenges present a conflict between the adolescent's need to develop a self-concept and their opposing desire for building intimate relationships, which together increase the chances of loneliness (Sippola & Bukowski, 1999). On the other hand, the high prevalence of loneliness in individuals over the age of 55 may occur due to life changes - such as limitations in mobility or the loss of a loved one - that typically happen in later life (Dykstra et al., 2005). Likewise, Luhmann and Hawkley used a three-item version of the UCLA Loneliness Scale (Russell, 1996) to analyse loneliness rates across the life span in a nationally representative sample of German adults. Their findings also suggest that "the late-life increase in loneliness could be explained by lower income levels, higher prevalence of functional limitations, and higher proportion of singles in this age group" (2016, p. 3).

## **Loneliness and Culture**

Loneliness together with forced social isolation during the Covid-19 pandemic may also have been particularly harmful for foreign nationals residing in Malta, who make up 14% of the population (Eurostat, 2019). Depending on the length of time which non-Maltese residents had been living in the country prior to the pandemic, such individuals may not have had time to form adequate social networks in Malta, potentially worsening their loneliness levels.

# Occupational Status and Loneliness

Several studies have reported a link between employment and loneliness. Pyle and Evans (2018) analysed the results of the United Kingdom's 'Community Life Survey 2016-2017', which asked respondents how often they felt lonely. They found that unemployed individuals who were seeking work reported significantly higher rates of loneliness frequency, compared to those in employment.

Another study which used the University of California, Los Angeles (UCLA) Loneliness Scale to determine loneliness amongst primary care patients in the United States (N = 1,235) revealed that unemployed individuals experienced significantly higher rates of loneliness (Mullen et al., 2019). Moreover, research investigating social loneliness amongst youth (N = 148) also revealed that

unemployed participants without access to paid work experienced the greatest level of loneliness (Creed & Reynolds, 2001).

# Effects of Social Isolation and Social Distancing Measures

Past pandemics and outbreaks of infectious diseases provide evidence of the damaging effects of social isolation on mental health (Hawryluck et al., 2004; Jeong et al., 2016; Brooks et al., 2020). For instance, during the 2009 influenza A (H1N1) pandemic in the United States, the incidence of post-traumatic stress among children who were quarantined was four times as high as those children who had not been quarantined. During the same pandemic, parents in quarantine reported more symptoms of traumarelated mental health disorders (28%) than parents who were not quarantined (6%) (Sprang & Silman, 2013).

Although the prevalence of loneliness was considered to be a public health issue of epidemic proportions prior to Covid-19 (Sharma et al., 2020), the resulting increase in social isolation imposed by the virus is likely to compound matters (Buecker et al., 2020). This is because loneliness has been linked to a series of other phenomena related to wellbeing, including mental health issues, substance use, problems with interpersonal relationships, and physical health issues such as an increased risk of mortality and cognitive decline (Ingram et al., 2020).

Research to date on the effects of physical distancing directives during Covid-19 have been inconclusive. Some studies reported that loneliness levels increased (e.g. Elmer et al., 2020; Killgore et al., 2020; Sweeny et al., 2020), whilst others found that loneliness levels remained stable (Fancourt & Steptoe, 2020; Folk et al., 2020). The differing sample sizes and sociodemographic variables across these studies may account for contradictory results (Buecker et al., 2020). Nonetheless, the fact that a number of studies' findings show that previously established risk factors for loneliness are different during the pandemic than pre-pandemic point towards a need for the re-evaluation of such risk factors (Buecker et al., 2020).

A recent study in the United States including 1,013 adults identified that the self-

isolation measures adopted in response to Covid-19 led to a significant increase in rates of loneliness, which was also associated with a higher risk of depression and suicidal ideation. Participants who reported that they were lonely were also more likely to fulfil the clinical criteria for depression (54.7%) than non-lonely participants (15.3%). Loneliness was also linked to higher rates of suicidal ideation, with lonely participants being more likely to experience some form of suicidal ideation (34.9%) compared to non-lonely participants (4.5%). Findings from this study were consistent with the notion that a severe rise in social disconnection and loneliness are attributed to the prolonged duration of directives to stay at home (Killgore et al., 2020).

Another recent study in the United Kingdom compared data on the sociodemographic risk factors associated with loneliness, before and after the pandemic. The authors revealed that those risk factors associated with loneliness prior to Covid-19 were "near identical" during the pandemic (Bu et al., 2020, p. 1). Specifically, loneliness was more common amongst women, young adults, individuals with lower incomes or education levels, economically inactive persons, as well as those living alone or in urban areas.

Results from other studies have, however, contradicted the findings by Bu et al. (2020). Repeated cross-sectional data, collected daily in the United Kingdom since the 21st March, 2020, indicate that different groups of people were at risk during the pandemic than pre-pandemic. Results revealed that, in addition to young adults, people who lived with children, in overcrowded housing, or in cities were more lonely than other groups (Fancourt & Steptoe, 2020).

# Managing the Psychological Impact of the Covid-19 Pandemic

Razai et al. (2020) noted that primary care physicians may be uniquely placed to identify patients who experience negative psychological effects due to the social isolation imposed during the Covid-19 pandemic. They suggested that patients' social and psychological wellbeing could be improved through social prescribing, which refers to using non-medical interventions in order to improve wellbeing with existing community-based assets and resources. For example, a physician may suspect that their patient is at a particularly

high risk for loneliness and confirm this through validated screening tools, such as a short scale for measuring loneliness. If this screening confirms that a high degree of loneliness is present, then the physician could prescribe social activities such as joining a choir, painting classes, or similar activities (Drinkwater et al., 2019).

More importantly, the World Health Organisation reported that multiple studies found evidence that engaging with the arts, or other forms of social prescribing, offer a cost-effective solution to improve physical and mental health (2019). Although the nature of Covid-19 limits people's ability to physically attend communitybased activities, a number of these activities have also become available in digital forms (Razai et al., 2020). Nonetheless, some older adults who may not have access to attend such activities online could be contacted by telephone and given advice about maintaining their health and alternative means of support (Beaney et al., 2020). For example, the provision of emotional support over the telephone have been implemented both locally and abroad (The Malta Independent, 2020; Razai et al., 2020).

# Method

## Sample

Participants were recruited through a voluntary sampling method (Setia, 2016), also known as a self-selection sample, whereby an invitation to take part in the study was disseminated through a sponsored post via the Facebook page belonging to the Faculty for Social Wellbeing, University of Malta. The decision to use this form of non-probability sampling was based on the time-sensitive nature of the research topic, whilst considering the cost effectiveness of such a sampling technique.

The invitation to participate in the online survey explained that this was open to any resident of Malta over the age of 18 years. Data collection took place between the 29th April 2020 to the 11th May 2020. The final sample consisted of 906 individuals, aged between 18 and 83 years. The study obtained ethical approval from the University of Malta's Faculty for Social Wellbeing Research Ethics Committee. Participants were provided with written information about the purpose of the study as well as the voluntary

nature of their participation and their right to quit the study at any time.

# Research instrument

An online survey using SurveyMonkey was designed to assess loneliness. The 11-item De Jong Gierveld Loneliness Scale (DJGLS; De Jong Gierveld & Kamphuis, 1985) was employed to determine the intensity of loneliness experienced by participants, as well as to enable comparison of results with those reported by Clark et al. (2019). The DJGLS has shown to be a valid and reliable tool to measure loneliness (De Jong Gierveld & Van Tilburg, 2006; Masi et al., 2011; Penning et al., 2014), with adequate construct and structural validity demonstrated in existing studies (lecovich, 2013; Uysal-Bozkir et al., 2017). It includes questions which indirectly measure loneliness, by asking participants to rate their agreement with a number of statements using a 3-point Likert scale (e.g. 'There are plenty of people I can rely on when I have problems' Yes, More or less, or No). Responses to the DJGLS were calculated according to the guidelines provided by the original authors (De Jong Gierveld & Van Tilburg, 1999), resulting in each participant being assigned a total loneliness score of between 0 to 11, with a higher score indicating a greater degree of loneliness. Participants scoring between 0 to 2 were classified as 'not lonely', those scoring between 3 to 8 were classified as 'moderately lonely', and a score of 9 to 11 was classified as 'severely or very severely lonely'.

In addition to measuring the intensity of loneliness with this standardised tool, another question was included in the survey to assess participants' self-reported loneliness frequency (i.e. 'How often do you feel lonely?' Often/always, Some of the time, Occasionally, Hardly ever, or Never). This measure of loneliness frequency was not included in the 2019 study by Clark et al. Sociodemographic details were also gathered, relating to participants' age, gender, occupation, and nationality.

# Data Analysis

Responses for some sociodemographic variables were grouped for purposes of statistical analysis. The ages of participants were grouped as: 18-19, 20-24, 25-34, 35-44, 45-54, 55-64, and 65+. Participants' occupation type were grouped into the

following categories: Professionals (Managers, Professionals, and Technicians and associate professionals): Entry-level (Clerical support workers, Service and sales workers, Craft and related trades workers, Plant and machine operators and assemblers, Elementary occupations, Armed Forces) and; Not working (Unemployed, Student, Retired, Cannot work due to illness and/or disability, and Taking care of the house and/or family). Participants with a country of birth other than Malta, with the most common birth countries being Britain, Sweden, Denmark, and Italy, were categorised as 'Non-Maltese'. Data analysis consisted of performing chi-square tests of association, using the Statistical Package for the Social Sciences (SPSS version 27), to explore any significant associations between measures of loneliness and sociodemographic variables.

## Results

Descriptive statistics of the sample, in addition to loneliness rates are presented in Table 1. A total of 94% were classified as lonely according to the DJGLS measure of loneliness intensity, of which 59% were moderately lonely and 35% were severely or very severely lonely. The relationship between loneliness and age followed a U-shaped distribution, with the highest rates of moderate loneliness found among participants aged 65 years and over, and the highest rates of severe or very severe loneliness amongst the 20-24-year olds. However, the 20-24 age group also had the lowest levels of moderate loneliness compared to other age groups. The lowest levels of severe or very severe loneliness were found amongst those aged 65 years and above.

Self-reported loneliness frequency revealed that 13.5% of participants felt lonely often or always during the Covid-19 pandemic. The largest proportion of participants (37%) reported feeling lonely occasionally, whilst 21% reported feeling lonely hardly ever or never.

# Variables Associated with Loneliness

Significant associations were found between loneliness frequency and age group, nationality, and occupation type. Loneliness intensity, characterised by the DJGLS score, was also significantly associated with participants' occupational type, as well as with loneliness

frequency. No associations were evident for gender and loneliness frequency or intensity. Each of the significantly associated variables will be further outlined below.

# Loneliness Frequency and Age Group

Participants' self-reported loneliness frequency was significantly associated with age group ( $X^2$  (20, N = 904) = 45.3, p = .001). Reports of feeling lonely most frequently decreased with age, with 28% of 18-19-year olds feeling lonely 'often' or 'always', compared to 8% of those aged 65 years and above. Similarly, feeling lonely 'some of the time' was reported by 36% of the 18-19 and 20-24 age groups, steadily decreasing with age to 24% of 65+ year olds.

or very severely lonely', was associated with occupation type ( $X^2$  (4, N = 904) = 12.6, p = .013). Participants working in entry-level occupations had the highest rates of severe or very severe loneliness at 44%, followed by participants who were not working (36%). Rates of moderate loneliness were identical for professionals and individuals not in work, with 60% of each occupation type being classified as moderately lonely.

# Loneliness Frequency and Nationality

An association was found between participants' self-reported loneliness frequency and whether they were of Maltese nationality or non-Maltese ( $X^2$  (4, N = 906) = 12, p = .018). Non-Maltese respondents were more likely to report frequent feelings of loneliness, with 22% feeling lonely 'often or always' and 36% feeling lonely 'some of the time'. In comparison, 13% of Maltese respondents felt lonely 'often or always' and 28% felt lonely 'some of the time'.

# Loneliness Frequency and Occupation Type

Self-reported loneliness frequency was also significantly associated with participants' occupation  $(X^2 (8, N = 904) = 15.7, p = .047)$ . Of those individuals falling under the 'not working' category, 17% reported feeling lonely 'often or always', compared to 11% of the 'professionals' occupation category. Feeling lonely 'some of the time' was most common for those working in the 'entry level' occupational group (36%), followed by participants who were not working (28%). Professionals were most likely to report feeling lonely 'occasionally' (39%), compared to those not working (34%) and those working in entry-level positions (33%).

# Loneliness Intensity and Occupation Type

Participants' loneliness intensity, categorised as either 'not lonely', 'moderately lonely' or 'severely

# Azzopardi et al. Table 1

Sociodemographic Characteristics and Loneliness Rates of the Sample

Variable	Loneliness frequency n = 900			Loneliness intensity			
	Ofte n / alwa ys	Some of the time / Occas ion-ally	Hardly ever / Never	Moderately lonely		Severely or very severely lonely	
				2020	2019	2020	2019
Gender							
Female	13%	67%	20%	60%	41%	34%	2%
Male	15%	58%	27%	54%	41%	37%	2%
Other	33%	67%	0%	44%	35%	56%	0%
Total	14%	66%	21%	58%	41%	35%	2%
Nationality <sup>1</sup>							
Maltese	13%	65%	22%	59%	42%	34%	2%
Non- Maltese	22%	64%	15%	50%	38%	43%	0%
Age Group							
19 and under <sup>2</sup>	28%	60%	12%	56%	33%	40%	1%
20-24	25%	59%	16%	53%	24%	43%	0%
25-34	14%	70%	16%	59%	27%	37%	1%
35-44	11%	68%	22%	56%	38%	36%	1%
45-54	13%	64%	24%	56%	42%	36%	4%
55-64	10%	68%	22%	64%	49%	31%	3%
65+	8%	59%	33%	70%	58%	20%	2%
Total	13%	65%	21%	59%	41%	35%	2%

<sup>&</sup>lt;sup>1</sup> The 2019 data for nationality is based on participants' country of birth

<sup>&</sup>lt;sup>2</sup> The 2019 data includes individuals aged 11-19; 2020 data includes individuals aged 18-19

# Comparison of Loneliness Intensity Between 2019 and 2020

Compared with the results obtained by Clark et al. in 2019, the present study showed a substantial increase in overall loneliness rates as a result of the Covid-19 pandemic. On average, moderate loneliness increased by 18%, whilst severe loneliness increased by 40%. However, the use of a non-probability sampling method precluded the present study's data on loneliness intensity from being statistically analysed in comparison to those from 2019. Furthermore, it was not possible to compare frequency of loneliness found in the present study with findings from Clark et al. (2019), since the latter only measures loneliness intensity.

# **Discussion**

This study revealed that participants experienced substantial increases in rates of Ioneliness intensity in the midst of the Covid-19 pandemic, when compared to the rates of loneliness reported in the year prior to the pandemic (Clark et al., 2019). The data presented in this study highlights that particular sociodemographic characteristics might play a role in people's vulnerability to experiencing loneliness during the Covid-19 pandemic. Increased loneliness levels in specific sub-groups may cause additional threats to physical and social health in the future: It is therefore crucial to identify those groups who are at particular risk from social distancing measures, so that policy can target interventions to such groups (Buecker et al., 2020), as well as informing clinicians who may encounter individuals at increased risk of loneliness. The increase in rates of loneliness compared to those found in 2019 (Clark et al., 2019) are of particular concern, given other research findings showing that elevated loneliness during the pandemic were associated with significantly higher levels of depression and suicidal ideation (Killgore et al., 2020). Furthermore, the present findings highlight the importance of adequate measures being put in place to address loneliness, particularly to improve preparedness for the eventuality of a second wave of the Covid-19 pandemic (Xu & Li, 2020).

Similar to the findings by Clark et al. (2019), the present study found loneliness frequency to be

associated with participants' age group. The relationship between age and loneliness was also akin to that from the 2019 study, with a complex Ushaped distribution and higher percentages of younger participants feeling lonely 'often' or 'always'. Whilst no significant associations were evident for age group and loneliness intensity, voung people between the ages of 18-24 had the highest rates of severe or very severe loneliness compared to other age groups. Taken together, these results point to a potentially higher risk of loneliness amongst younger populations, which may have been worsened due to limited access to socialising during the pandemic. The identification of young adults as particularly vulnerable to loneliness during the pandemic has also been reported in studies from the United Kingdom (Fancourt & Steptoe, 2020; Bu et al., 2020). However, young people had already been identified as demonstrating higher rates of loneliness prior to the pandemic (Bu et al., 2020) and these recent findings therefore serve to confirm existing literature.

Loneliness frequency also demonstrated significant associations with nationality, with non-Maltese participants feeling lonely more frequently than Maltese nationals. Whilst further research is needed in order to explore this finding further, researchers have noted that foreign nationals may be particularly vulnerable during a pandemic, since they might not be aware of how they can access the necessary resources to cope with a deterioration in their mental or physical health (Wickramage et al., 2018).

Participants' occupation type was associated with both loneliness intensity and frequency, again echoing findings by Clark et al. (2019) who found that loneliness was more likely among Maltese people who were not working. The increased rates of loneliness amongst participants who were not working also confirm those by Bu et al. (2020) which reported that loneliness was more common for economically inactive persons. If one assumes that the occupational groups in the present study are indicative of participants' education and income levels, then the present findings may also provide support for Clark et al. (2019)'s results, whereby individuals were more likely to experience loneliness if they had lower levels of education or lower perceptions of their household income. Our results also demonstrate

similarities with international studies which found that people who are economically inactive (Pinquart & Sörensen, 2003) or have a lower household income are at increased risk of loneliness during Covid-19 (Bu et al., 2020). The protective function of education in loneliness has been proposed to happen due to an enhanced sense of competence (Hensley et al., 2012) or increased opportunities for socialising (Hawkley et al., 2008).

#### Limitations

Due to the use of a non-probability sampling method, the findings from the present study are not necessarily generalisable to the entire population of adults residing in Malta. The selfselection of participants who volunteered to complete the online survey could also have resulted in an over-representation of those individuals who have strong opinions about the topic (Setia, 2016). The final sample also suffered from an under-representation of male participants, who made up 17% of the sample. In spite of the self-selection bias and possibility of generating findings that are not necessarily representative of the population, the self-selection sampling method offers advantages in that data collection can be completed in a short time period; participating individuals could also have been more willing to provide insight into their experience of loneliness (Lund Research Ltd, 2012).

# **Conclusion and Recommendations**

The present study's findings contribute to the growing corpus of data regarding the social and psychological effects of lockdowns and social distancing measures due to the Covid-19 pandemic. The rates of moderate and severe or very severe loneliness show that a substantial increase in loneliness occurred during the first wave of the pandemic in Malta, indicating the need for public health measures to combat feelings of loneliness. For example, further governmental support for local mental health services may be needed to address individuals' increased need for psychological support. The setting up and implementation of screening tools and social prescribing measures by professionals, such as healthcare professionals, is also warranted. This would enable the identification of individuals experiencing significant levels of loneliness and the provision of advice and assistance on how to

improve their situation.

This study was also the first attempt to measure how often people in Malta self-report feelings of loneliness, in contrast to previous studies which used indirect measures of assessing loneliness. Associations between loneliness frequency and age, nationality, and occupation highlight the importance of implementing targeted interventions that address the specific needs of particular 'at-risk' groups. Further research is needed to assess long-term outcomes for individuals who experienced heightened levels of loneliness during the pandemic, as well as to investigate the efficacy of any interventions undertaken to reduce loneliness.

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Development.

Jamie Bonnici is a Researcher and Casual Lecturer within the Faculty for Social Wellbeing at the University of Malta. Her research has focussed on addiction studies, cyberpsychology, social psychology, quantitative methods and gender issues.

Marilyn Clark is an Associate Professor within the Department of Psychology, within the Faculty for Social Wellbeing at the University of Malta. Her research interests relate to Addiction, crime, victimisation and youth.

# **Author Bios**

Andrew Azzopardi is Associate

Professor in Community Development and Disability Studies. He is currently Dean of the Faculty for Social Wellbeing and member of the Department of Youth and Community Studies at the University of Malta. His research interests are disability politics, youth activism and community development. He was a pioneer in starting the first Master degree in Malta on Community Action and