L-Università ta' Malta
Faculty for Social Wellbeing

The Impact of Covid-19 on Persons with Disability

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The pandemic
that changed the World for many

The Covid-19 pandemic remains a phenomenon which is leaving an impact on a number of sectors in our Society. The effects of this pandemic have left minorities in dire need of support and comfort due to the impact it had on them. The Faculty for Social Wellbeing has teamed up with the *Commission for the Rights of Persons with Disability – CRPD* to investigate how this pandemic has impacted this minority. What is innovative, but has also become characteristic of our Faculty research, is that we draw our data from the grassroots and ensure that we use an emancipatory model to guarantee representation and voice of the minority in our studies. In any case, the truth of the matter is that this pandemic has damaged our communities and has left the greatest impact on the 'populations' in our communities which have been side-lined for so long. We hope that this study will nudge the authorities in taking on the recommendations listed in it.

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Executive Summary

INTRODUCTION

On March 11, 2020, the World Health Organisation (WHO) declared a global health pandemic, due to the spread of a novel coronavirus, later named "Covid-19". Dr Tedros Adhanom Ghebreyesus, WHO Director-General, declared a "Public Health Emergency of International Concern" as cases of Covid-19 had been found in five WHO regions. In Malta, the first cases of Covid-19 were identified on March 7, 2020. No lockdown was announced in Malta, yet within a few days from the first cases, the Government of Malta announced that schools were to close down, major events and mass gatherings cancelled and that persons travelling from a number of European countries were to undertake obligatory quarantine. This report highlights the ways through which the disability sector is being impacted by the Covid-19 pandemic, reflecting on underlying experiences of individuals with disability, their caregivers and service providers and provides actionable recommendations.

LITERATURE REVIEW

Despite the additional challenges faced by persons with disability and their caregivers throughout Covid-19, they were overlooked and marginalised in public discourse (Karagianni, 2020; Pilson, 2020; Schippers, 2020). From the initial stages of the pandemic, authorities have consistently focused on the high risk of vulnerable people, including elderly and persons with chronic illnesses, excluding persons with disability.

The pandemic brought light towards scarcity of resources, leading to higher consciousness on their efficient and effective use (Liddard, 2020). This led to concerns about the current biopolitical (Ktenidis, 2020) and necropolitical (Lee, 2020; Tsakiri &; Mavrou, 2020) scenario, whereby both terms relate to the extent of which lives should be saved, usually resulting in disabled lives being deprioritized (Mbembe, 2008; Saltes, 2013). Persons with disability were not included in financial support measures given to other specific social groups to compensate for the economic implications of the crisis. Covid-19 may have also exacerbated discrimination in employer-employee relationships, particularly when employers were put under financial strains.

The provision of services within the disability sector was also influenced. Residential services for persons with disability were closed and individuals living in institutional and group residential settings were not allowed visitation from their loved ones (Schippers, 2020), including Malta (European Social Network, 2020).

Exclusion from decision-making processes, absence of understanding at governmental level of the barriers faced by persons with disability (Pilson, 2020), and limited visibility in the media (Van Hove, 2020) including during the Covid-19 pandemic, results in further lack of understanding of the complexities and complications experienced by persons with disability (Adams Lyngbäck et al., 2020).

METHODOLOGY

The scope of this study was to identify the impact that the Covid-19 pandemic has on the lives of persons with a disability and their families. To address this scope, clear objectives and research questions were developed.

The objectives included:

- identifying the key aspects in the lives of persons with disability which have been impacted by the Covid-19 pandemic, either in a positive or negative manner; and
- developing practical and policy recommendations to address needs arising from the Covid-19 pandemic.

Data collection was based on a purposive sample. Semi-structured interviews were conducted with five (5) persons with disability, three (3) informal carers, one (1) individual representing a non- governmental organisation (NGO) and three (3) entities in the disability sector. As to be able to document the different experiences of persons with different disabilities, participants engaged in the study represented a diversity of disabilities, including cerebral palsy, autism, visual impairment, intellectual disability and mental health challenges. Caregivers involved were all parents of persons with disability, two (2) of which had children with autism, and another (1) with delayed development. Furthermore, entities involved in this phase included: the Commission for the Rights of Persons with Disability (CRPD); Aġenzija Sapport; and the Social Care Standards Authority (SCSA). Thematic analysis was used, hence common themes arising from the interviews were brought together to better understand similarities and differences highlighted by participants in that respective area.

RESULTS

- Impact on education: Schools and educational services reacted in different manners to the closing of educational facilities. Some schools took some time to offer online platforms but did not offer tailored teaching for persons with disability. When the online adaptations made by educational institutions were not sufficient, this was a cause of additional stress on the parents. Parents responded in the ways that were possible, some opting for homeschooling at great personal cost.
- Impact of restrictive measures: One of the most strongly felt impacts that was experienced by persons with disability was the increased sense of isolation (Person on the autism spectrum). The sense of isolation was not unique to persons with disability but particularly for persons with disability that struggled with social contact, the sense of isolation had a double effect, on the one hand it meant an increase in loneliness and more time spent alone (Person with an intellectual disability) but also the deteriorating of certain social skills that were hard acquired (Person on the autism spectrum).
- An additional impact that restrictive measures had on persons with disability, especially those using or staying within hospital premises was the fact they might go into lockdown or enter quarantine and would not be able to leave hospital (Person with a physical disability). This shifted their aims from completing their treatments well to completing their treatments quickly.
- Psychological Impact of restrictive measures: The introduction of restrictive measures, which included the immediate stopping of a number of services provided to persons with disabilities resulted first and foremost in panic (CRPD). Persons with disabilities would phone CRPD in large volumes querying about various services that were stopped

immediately and without being informed of what alternative arrangements were going to be made. Such a disruption caused immediate reactions from persons who could not communicate (Carer for person with an intellectual disability). People with psychosocial problems struggled tremendously and acted out these situations with challenging behaviour (CRPD).

- Impact on the Family: The impact of the restrictive measures did not stop with persons with disability, but left a huge impact on their families, particularly parents or guardians. Family members were not necessarily experts when trying to support persons with disabilities, particularly those who communicate their frustration and boredom through challenging behaviour (CRPD, Aġenzija Sapport). Parents in fact phoned in desperation when dealing with challenging behaviours that they were either not accustomed to dealing with or did not have the expertise to manage this behaviour (Aġenzija Sapport). Parents were also impacted in their work life due to the additional care responsibilities that were thrust upon them (Parent 1). Family members also felt that at times they were abandoned and that their needs were not met (Aġenzija Sapport, Parent 1).

Secondary and unforeseen effects of restrictive measures: Persons on the autism spectrum and other disabilities found the mandatory wearing of masks particularly onerous. On occasions, the need for masks was not always easily explained and when this was imposed nonetheless, this resulted in the persons having a meltdown (CRPD, Parent 1, Parent 3, Aġenzija Sapport). Persons with auditory impairment were also particularly disadvantaged since the mask would impede lip reading which was an essential part of their communication process (CRPD).

Policies relating to persons with disability: The Covid-19 response within Malta throughout the first few months after the first few cases was rapid. However the consensus amongst the interviewed persons with disability was that the measures implemented, while necessary were not nuanced enough to accommodate the disability sector.

Services offered to persons with disability: The experience of services during the Covid-19 restrictive measures was one of frustration and fear by persons with disabilities and their families. Participants made use of a number of services such as Occupational therapy, physiotherapy, CDAU, appointments with hospital consultants as well as services from the Ministry for Education and Employment (Parent 2, Person with a physical disability). While the participants did not expect that the services would keep going as before, the tremendous variation in the level of service offering was disappointing, frustrating and worrying (Parent 2, Person with a physical disability). In certain instances, stopping services in such an instant manner also resulted in potentially perilous situations where persons with disabilities ended roaming the streets without the support required and were found by ambulances and police officers (CRPD).

RECOMMENDATIONS

1. Provide psychological support for persons with disability.
2. Provide emotional support for parents and family members of persons with disability.
3. Provide training for parents and family members of persons with disability who struggle with dealing with challenging behaviour.
4. Provide training to front line professionals who interact with persons with disability and their families on questioning techniques.
5. Enhance awareness amongst decision-makers.

6. Ensure fair representation of persons with disability across services.
7. Persons with disabilities of schooling age who are followed by LSE's to be given tailored program.
8. Create a system that categorizes persons receiving treatments and therapies according to the urgency that these are required.
9. Create a structure where urgent and serious cases continue to receive treatment.
10. Carry out a complete IT overhaul of systems and operations audit.
11. Ensure adequate logistical provision of IT equipment.
12. Provide training opportunities for persons with disabilities and their families to use IT communication platforms.
13. Provide training opportunities to staff and service providers on how new technologies can be incorporated into service provision.
14. Provide training to management on AGILE decision making.
15. Review and remove unnecessary bureaucratic processes.
16. Review policies in light of Covid-19 exigencies.
17. Enforce recommendations 10 -16 by creating a set of standards and operating procedures that service providers must orient towards during any form of restrictive measures arising from emergency situations.
18. Ensure consistent service provision all throughout each service.
19. Carry out an entire review of current policies to ensure that there are no policies in place that are not in line with the principles of social distancing and the new Covid-19 realities.
20. Provide free telephony and internet services particularly to people who are further isolated during the restrictive measures such as persons with visual disability.
21. Second a person well-versed in disability issues in public health.
22. Ensure that all health policies are nuanced enough to capture the particular needs and possibilities of persons with disabilities.
23. Issue directives specifically dealing with disability issues.
24. Recruit more resources and personnel to deal with periods of restrictive measures.
25. Provide psycho-social services to support frontliners.
26. Provide support to the families of frontliners.
27. Engage in talks and negotiations with employer associations and the Chamber of Commerce.
28. Provide support to persons with disability who are afraid of losing their jobs due to the Covid economy.
29. Carry out further research to establish the intersectoral relationship within the welfare ecosystem in supporting persons with disability throughout the pandemic.
30. Carry out a more comprehensive mixed-methods comparative study in a few months time to assess improvement or otherwise in the field.

CONCLUSION

The Covid-19 restrictive measures provided challenges on many fronts to all stakeholders within the disability sector. Services were stretched, caregivers were required to take up the slack that closure in services caused and persons with disability bore the brunt of the restrictive measures with a number of impacts. Responses to Covid-19 however indicate that the disability sector was not prioritized during the national response, with precious resources being diverted to other sectors. Additionally, the 'vulnerabilization' of persons with disability concurrently dispowers and justifies persons with disability's mortality while being required in order to be eligible for specialized treatment. Moving forward, greater awareness of disability issues by politicians and policy-makers is imperative as well as a systemic re-evaluation of how worth and value, and consequently political power and resources are allocated to persons with disability.

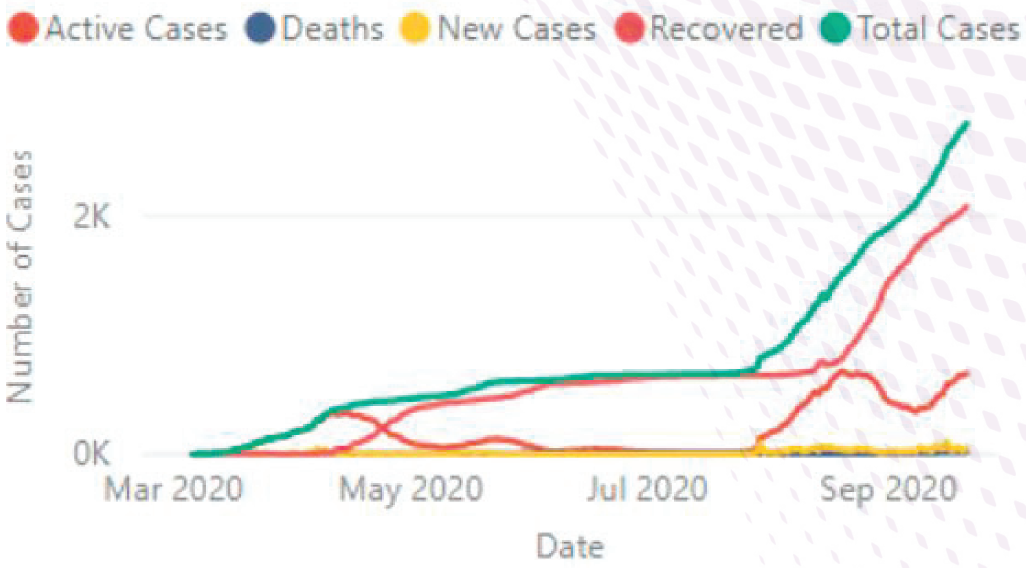
Introduction

1. INTRODUCTION

On March 11, 2020, the World Health Organisation (WHO) declared a global health pandemic, due to the spread of a novel coronavirus, later named "Covid-19". This virus was first identified in Wuhan, China at the end of 2019, due to an outbreak of pneumonia cases of an unknown cause, which was related to the Huanan Seafood Market (WHO, 2020). By January 30, 2020, Dr Tedros Adhanom Ghebreyesus, WHO Director-General, declared a "Public Health Emergency of International Concern" as cases of Covid-19 had been found in five WHO regions. While WHO declared that "early detection, isolating and treating cases, contact tracing and social distancing measures – in line with the level of risk – can all work to interrupt virus spread" (2020), the spread of Covid-19 led to social isolation, distancing and lockdowns across the globe. The International Monetary Fund (2020) referred to this era as "The Great Lockdown", with a major impact on the socio-economic, psychological and cultural aspects of our wellbeing (Gahatraj, 2020). Initially, WHO established guidelines for workplaces (February 26, 2020) and education settings (March 10, 2020) to continue operating taking in consideration measures to prevent the spread of the virus. This was later followed by the temporary closure of numerous sectors, thus affecting the lives of many in different ways.

In Malta, the first cases of Covid-19 were identified on March 7, 2020 (Ministry of Health, 2020). To this date (September 23, 2020), the total number of cases added up to 2,814, with 2,113 persons recovered, and a total of 23 deaths, as presented in Figure 1 below. No lockdown was announced in Malta, until the date of writing (September 23, 2020); yet within a few days from the first cases, the Government of Malta announced that schools were to close down, major events and mass gatherings cancelled and that persons travelling from a number of European countries were to undertake obligatory quarantine for a duration of 14 days, with fines being imposed on those who did not abide by the new regulations (March 12, 2020a), eventually closing the Malta International Airport (March 20, 2020b).

Figure 1:Situation Overview in Malta (Ministry of Health, September 23, 2020).



To support persons and sectors influenced by the spread of the virus, a number of measures were introduced, such as financial support for those who had to stay-at-home due to being considered vulnerable or to take care of their children, those who were made redundant, as well as to prevent mass redundancies and sustain businesses that had to close down (Malta Enterprise, 2020). Throughout the initial phases daily briefings were held by Professor Charmaine Gauci, Superintendent of Public Health. Prof. Gauci constantly reminded the public of the importance of self-isolation for those who were at greater risk of severe consequences or vulnerable persons, such as the elderly, those with chronic diseases and pregnant women. While "we are all in this together", a statement reiterated by many, the impact will be felt disproportionally by those who are socially excluded (iHuman, 2020) or lack social protection (Grech, 2020); including persons with disability, who like the rest of society have had to adapt their lifestyle. The current pandemic may open up further room for discrimination against persons with disability (Tsakiri & Mavrou, 2020), even as "[m]ost member states rightly imposed social distancing measures to reduce the spread of the virus, but they have not been systematically attentive to the specific circumstances and needs of persons with disabilities" (Council of Europe, 2020). To protect persons with disability from discrimination through challenging times such as these, the UN Convention on the Rights of Persons with Disability clearly establishes that;

> *States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.*

Persons with disability are considered to be the largest minority group across the globe, making up 15% of the global population (WHO, 2018). They are a diverse group of individuals rather than a homogeneous group (Gahatraj, 2020). Their impairments may vary, possibly affecting physical, sensorial and/or intellectual abilities, ranging from severe to mild. Even persons with the same impairments and similar level of severity, may have different needs, even as a result of diversity in personalities and variations in pre-existing health conditions. Additionally, their socio-economic backgrounds, the environments in which they live and the social support networks also vary, with the disability community being at a greater risk of higher rates of poverty (Campbell et al., 2009) due to socio-economic disadvantages and housing conditions (Fundamental Rights Agency, 2020). Thus, through an intersectionality approach, this study assumes that diversity amongst various aspects of one's life may influence the persons in question differently, due to the interaction between different components (Shaw, Chan & Mcmahon, 2012).

This report by the Faculty for Social Wellbeing was commissioned by the Commission for the Rights for Persons with Disability and highlights ways through which the disability sector is being impacted by the Covid-19 pandemic, reflecting on underlying experiences of individuals with disability, their caregivers and service providers. A human rights approach is adopted, with the UN Convention for the Rights of Persons with Disability, hereinafter UNCRPD (2006) established as the underlying legal framework as 181 countries, including Malta. ratified the Convention. Literature and international reports were understandably scarce in the area given the novelty of the situation. Nonetheless the researchers have collated theoretical knowledge in the area, as well as descriptions of experiences made by persons with disability themselves and scholars in the field.

2. LITERATURE REVIEW

2.1 A SYSTEM OF VULNERABILITY

A traditional approach to disability is that it is perceived primarily as a private tragedy and thus the responsibility of the individual (Karagianni, 2020; Monforte & Úbeda-Colomer, 2020). Van Hove (2020) claimed that within a capitalist system, caregivers of persons with disability are expected to address challenges by themselves. Such perspective allows for victim blaming and lack of empathy, especially during this pandemic, as when one contracts the virus, it is seen to be the individual's fault as they did not adhere to correct social distance practices (Schippers, 2020). For instance, when persons with disability had their right for therapeutic walks legally recognized, harassment was experienced (Monforte & Úbeda-Colomer, 2020). Families in these situations were demonized, considered to be criminals and recorded and reported to the police, as well as finding themselves in situations where they felt obliged to justify their actions despite their legality, Monforte & Úbeda-Colomer claimed that being discriminated against throughout the crisis presented persons with disability with a "double nightmare" (2020, par. 5).

Despite the additional challenges faced by persons with disability and their caregivers throughout Covid-19, they were overlooked and marginalised in public discourse (Karagianni, 2020; Pilson, 2020; Schippers, 2020). From the initial stages of the pandemic, authorities have consistently focused on the high risk of vulnerable people, including elderly and persons with chronic illnesses, excluding persons with disability. Even amongst the European Association of Service providers for Persons with Disabilities (2020), there was a general feeling that services for persons with disability were not given due importance on a political level during the Covid-19 pandemic. Such remarks may support claims that the disability sector may hold quite a low standing in the hierarchy of prioritisation (Adams Lyngbäck et al., 2020; EASPD, 2002; Tremain, 2020).

The term 'vulnerability' may be contested by the disability sector due to the socio-political connotations of such a term (Ignagni, Chandler & Erickson, Ktendis, 2020). Vulnerability has been attached to bodies as a manner of legitimizing the deaths that occurred amongst elderly, ill or persons with disability (Ktendis, 2020; Watts Bestler, 2020). Tremain (2020) explained that contrary to popular conceptions of vulnerability as a characteristic that certain individuals possess or embody, those that fit in the categories of old age, have an illness and/or a disability "are vulnerablised through (for instance) the asymmetrical relations of power that discipline virtually every aspect of their (institutionalized) daily lives'' (par. 10), including limited resource allocation by service providers and/or their caregivers and communities who leave them behind. Similar to arguments made by the disability sector, Tremain (2020) claimed that "vulnerability is a naturalized apparatus of power that differentially produces subjects, materially, socially, politically, and relationally", and therefore "[v]ulnerability isn't a characteristic that certain individuals possess or embody'' (par. 6); which in turn might lead to the rendering of such individuals, or populations, as disposable (Haraldsdóttir, 2020; Runswick-Cole, Goodley & Liddard, 2020).

It may also be said that Covid-19 had an impact on the mental health of the general population. An online survey by Richmond Foundation (2020) showed that in Malta, many were struggling with mental health due to the Covid-19 pandemic, especially specific cohorts, such as young people, women (Brooks, 2020; Stevens, Agho, Taylor & Raphael, 2008), and those who are unemployed or anticipating a decreased income. The latter struggled with mental health more than others when drastic measures such as quarantine were taken. Yet, the survey did not include segregated data based on disability to be able to identify whether persons with disability were being impacted differently.

Altermark (2020) claimed that the management of the Covid-19 pandemic protects the ableist mentality, with a focus on one's abilities (Goodley & Runswick-Cole, 2016), safeguards what and who is desirable. Altermark (2020) explained that "risk groups"“shield[ed] the ableist collective consciousness from important insights" (par. 3), creating an illusion of and reproducing the notion of otherness through risk. Runswick-Cole et al. (2020) also established that the notion of human disposability featured in public discourse has implications on the disability sector not just for the current pandemic, which are serious nonetheless, but also in the long-term, dismantling progress made in recent years. Such approach to addressing the crisis re-inforces the idea that it is those who are more productive that are more valuable(Ignagni et al., 2020), which Goodley and Runswick-Cole claimed that persons with disability "have been denied the opportunity to occupy the position of the modernist humanistic subject: bounded, rational, capable, responsible and competent" (2016, p. 4); in turn leading to inequalities and discrimination against persons with disability.

2.2 UNEQUAL TREATMENT IN HEALTH CARE DURING A PANDEMIC

The literature discussed below shows that the spread of Covid-19, also led to experiences of discrimination in healthcare provision, with some cases also leading to triage (Haverkamp, 2020; Ignagni et al., 2020; Schippers, 2020). Inevitably, the pandemic brought light towards scarcity of resources, leading to higher consciousness on their efficient and effective use (Liddard, 2020). This led to concerns about the current biopolitical (Ktenidis, 2020) and necropolitical (Lee, 2020; Tsakiri & Mavrou, 2020) scenario, whereby both terms relate to the extent of which power and politics influence which lives should be saved (Mbembe, 2008; Saltes, 2013), with the former being based on normative assumptions and the spectrum of economic productivity (Saltes, 2013). Some authors, also linking necropolitics to neoliberal politics, have argued that the case of the Covid-19 pandemic can be characterized as such (Lee, 2020; Tsakiri & Mavrou, 2020).

Article 25 of the UNCRPD establishes that States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

Nonetheless, pressure on intensive care professionals to treat those with the highest chances of survival, bypassing ethics committees, multidisciplinary teams, and consultation processes with patients and their families, raising concerns on equal rights in health care provision of persons with disability (Liddard, 2020). This led to an act of protest in the United Kingdom, with over 2,300 individuals supporting a letter addressed to the National Health Services, claiming their fear of their lives being undervalued and their rights not being upheld during the crisis (Disability Rights UK, 2020; Runswick-Cole et al., 2020). Similar concerns were raised through complaints in six (6) States across the United States of America "alleging that guidelines put forth [...], illegally discriminated against persons with disabilities" (Mello, Persad & White, 2020, p. 1).

Haraldsdóttir (2020) also re-iterated her experience of limited access to healthcare. Although she spoke of her body as being "labelled as weak and unworthy – disposable" (par. 5), her argument focused on the lack of knowledge about her impairment, and the fear and perception of added stress by health care professionals. Moreover, since no accompanying persons are being allowed when an individual is hospitalized, persons with disability felt that they had lost an advocate, as they are not taken seriously (Haraldsdóttir, 2020), as well as continue to struggle to communicate as no one would be assisting them with interpretation (Ignagni et al., 2020).

Persons with disability faced challenges with regards to communication beyond hospitals, which shortcomings could have had a direct impact on their lives. A number of countries were giving daily press briefings to inform the general population about developments on the Covid-19 situation in their respective country, announcing numbers of cases, as well as measures being undertaken to control the spread of the virus. Many of such briefings were not considered to be inclusive in their early stages, as no national sign language interpretation was used (Adams Lyngbäck et al., 2020), with civil society having lobbied successfully for the introduction of sign language interpretation (Schippers, 2020) and to address needs of those with literacy issues. Nonetheless, there seemed to be lack of guidance for people with disability on the use of personal protective equipment (PPE), masks and/or gloves and maintaining social distancing (Ignagni et al., 2020), again leaving persons with disability at greater risks (Campbell et al., 2009).

The UN CRPD also safeguards the right to information and communication under Article 9 entitled "Accessibility", discussed in further detail below. Article 21 also establishes that persons with disability have "the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice". Communication, under article 2 of the same Convention is considered to include
languages, display of text, Braille, tactile communication, large print, accessible multimedia, as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.

In practice this could be translated into an obligation for agencies to deliver accessible content in terms of format and presentation, language, and strategies used for communication; including the use of transparent masks by healthcare professionals in order for the deaf community to be able to lipread when they are communicating health related matters (Tsakiri & Mavrou, 2020).

As these situations developed, questions were raised regarding the lack of preparedness from service providers on the provision of services for persons with disability (Adams Lyngbäck et al., 2020; Grech, 2020). According to Campbell et al. (2009), whose study focused on the preparedness and response for the disability sector in the case of an influenza pandemic, few emergency strategies provided guidelines on how to address the needs of persons with disability prior to, during and post such situations.

Moreover, while persons with disability are discriminated against in the health care systems across the globe, other measures undertaken which limit accessibility to provision of goods and services have put persons with disability at a higher risk of contracting the virus.

2.3 THE CONSTANT STRUGGLE OF ACCESSIBILITY

Haraldsdóttir (2020) wrote about the constant fight to get "personal assistance services and keeping it functioning without much interest or support from the social service system" (par. 5). Amber (2020) expressed her amusement due to the sudden availability of support for vulnerable persons, in contrast to the otherwise never ending battle for resource allocation and support measures for persons with disability. Karagianni (2020) argued that even though there has been a relation between poverty and disability, persons with disability were not included in financial support measures given to other specific social groups to compensate for the economic implications of the crisis. Persons with disability are at risk in this situation, not just due to Covid-19 but may have also excaberated discrimination and bias present in employer-employee relationships, particularly when employers were put under financial strain due low level of value, and therefore priority, assigned to persons with disability as previously discussed (Monforte & Úbeda-Colomer, 2020).

Accessibility is one of the guiding principles of the UN Convention. Article 9 establishes that

> *To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.*

In the early days of the pandemic, families resorted to panic buying, and those who were considered vulnerable were provided with support to avoid going out of their home. However, those persons with disability (who were not considered as vulnerable), and who relied on online shopping for their essentials were also put at a disadvantage, as priority was given to the elderly and vulnerable and an influx of families started using delivery services, making it harder for operators to deliver to these people's homes as frequently as needed (Amber, 2020), leaving some to fall through the gaps. Pilson (2020) further explained that to abide by social distancing regulations, "a visually dialogic process that automatically absents visually-impaired people from possessing equality of power in public places" (Pilson, 2020, par. 6), visually impaired individuals had to rely on the goodwill of other individuals if they had to go to the shops. They also had to sense products to identify them, while authorities encouraged the public to avoid contact. In more rural areas, such as the case in Guatemala, social distancing meant that persons with disability had the little care services which relied on the solidarity of family and the community removed (Grech, 2020). To ensure that persons with disability had access to the basic necessities, in Malta, Aġenzija Sapport provided persons with disability with the required support for delivery of food and medicine (European Social Network, 2020). Challenges with the provision of public transport also arose throughout the crisis. Grech (2020) stated that as transportation was becoming more limited and less frequent, solitude started being felt by those living in remote areas. In Belgium, the rail operator announced that assistance to persons with disability would no longer be provided (Jurviste U., personal communication, May 11, 2020). Moreover, even when transportation was still available, Amber (2020) claimed that the use of public transport brought fear as social distance regulations may not be adhered to by others, and therefore was more dependent on the social support provided by her network for necessities, essentially due to people with disability not being considered as vulnerable for support.

Additionally, the nature of the Covid-19 pandemic re-directed many towards increased dependency on online communication (Adams Lyngbäck et al., 2020), for work as well as leisure activities, education services as well as other goods and services. Challenges arise due to the lack of investment in IT literacy of persons with disability (Van Hove, 2020), as well as due to the inadequate design of hardware, software and the content created (Johansson, 2019), hence posing difficulties for persons with disability to access information (Adams Lyngbäck et al., 2020). On a more positive note, social distancing also led to "re-imaging communities" as new opportunities for online connection emerged (Runswick-Cole et al., 2020). The shift to online platforms allowed persons with disability to engage in activities which they had previously thought they would never be able to do, including education, but also visiting a museum or music concert (Frances, 2020). While this has created opportunities for persons with disabilities who may have been hindered from engaging in such activities due to physical barriers, others have expressed disappointment as such possibilities existed but arrangements would not be made to accommodate persons with disability.

The provision of services within the disability sector was also influenced. Residential services for persons with disability continued operating (EASPD, 2020), yet the United Nations (2020a) sought institutional settings to be at greater risks for the spread of Covid-19, with higher mortality rates, due to lack of access to information and testing, and barriers in the implementation of social distancing and hygienic measures. As part of the efforts undertaken to limit the spread, individuals living in institutional and group residential settings were not allowed visitation from their loved ones (Schippers, 2020), including Malta (European Social Network, 2020); possibly leaving some, especially those with intellectual disabilities, wondering why their family abandoned them. In certain situations, such as in Belgium, parents and/or guardians could opt to take their children home under their care.

With such opportunities, as well as lockdowns on educational institutions and less persons with disability engaging in employment, the United Nations (2020a) recognized that there was an influx in the demand for community support services for persons with disability. In Malta, this was not met with the same increase in the supply, but rather decreased, since day care and respite services had been shut down (European Social Network, 2020), sometimes being replaced with the provision of online services, while still operating for emergency situations. Such changes resulted in additional pressure on informal caregivers and family members who provide unpaid support, especially women (UN, 2020a).

Another major concern in the disability sector related to the availability of PPEs (EASPD, 2020) and directives for safe practices, including for state institutions (Karagianni, 2020). On March 3, 2020, WHO declared that there was a global shortage of PPEs which has left health workers endangered. Nonetheless, the European Social Network (2020) reported that in Malta, frontliners working with the National Agency for the Provision of Services of Persons with Disability, Aġenzija Sapport, were provided with PPEs. Scholars explained that such shortage in PPEs was due to service providers in the sector not being considered a priority in the hierarchy of distribution evident due to the scarcity in availability of such equipment (Adams Lyngbäck et al., 2020; Tremain, 2020). Additionally, Dr Amina Jabbar, a geriatric physician and social policy activist, on a twitter post, on March 30, 2020, expressed her thoughts on shortages of human resources in terms of staff members with expertise on the management of chronic illnesses, limited infection control protocols, Covid-19 testing and difficulties in logistics for grouping individuals testing positive with the virus within caring homes. Tremain (2020) also argues that such limitations within institutions prevailed due to austerity measures influenced by neoliberalism and privatization of social services, which again could be linked to the lack of prioritization of the disability sector on a political level (EASPD, 2020).

Moreover, Lee (2020) highlighted that the pandemic may have brought to light the implications of discriminatory practices that have been happening in the pre-Covid-19, especially in countries where the outsourcing and privatization of services has become normalised, making critical services less accessible to those who do not have the economic capacity to access them.

2.4 LIMITATIONS BEYOND THE PANDEMIC

In the early stages of the pandemic, as lockdown measures were being announced across the globe, many places of education and employment shifted to an online virtual set-up. With regards to the education setting, a right established under Article 24 of the UNCRPD, Van Hove (2020) argued that by sending children with a disability to special schools which may not be adequately equipped with resources to teach computing to these students, based on the assumption that these children are not capable to learn, then distant learning in the time of crisis would be more problematic. Moreover, the shift to virtual environments may safeguard employment for those providing care in formal structures but does not necessarily meet the needs and requirements of persons with disability during the crisis (Ignagni et al., 2020; Tsakiri & Mavrou, 2020). Individualised learning and daily practice are required to ensure that lessons previously learnt are not lost, especially with regards to communication and social skills (Tsakiri & Mavrou, 2020), which may not be happening during the pandemic. Other concerns regarding lack of access arrangements include reference to content which is not compatible with screen-readers and specialist assistive technology being refused to be sent home to students (Pilson, 2020). To address such challenges, a few countries established guidelines, which may also have included guaranteeing education for persons with disabilities and the evaluation of students' progress (Jurviste, U., personal communication, May 11, 2020).

With regards to employment, a number of persons with disability have been discouraged from attending for employment activities, which may be considered to be the primary source of socialisation, leading to a higher rate of loneliness and mental health difficulties (Adams Lyngbäck et al., 2020); others continued to contribute in essential services (EASPD, 2020). Even though work and employment are safeguarded under Article 27 of the UNCRPD, with sub-article (a) "prohibit[ing] discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions"; concerns rise with regards to the long-term detriment of employment opportunities for persons with disability across Europe as the economic impact of the Covid-19 pandemic continues to be felt and services related to work, training and employment have been shutdown (EASPD, 2020). Persons with disability are already experiencing exclusion from employment, losing their jobs and are more likely to find it difficult to return to their place of work after the pandemic (UN, 2020a). Moreover, in Malta, to safeguard redundancies of those persons with disability employed in the private sector, who were advised to work from home due to medical reasons, but whose job did not allow the possibility of telework became eligible for the "Covid -19 – Person with Disability Benefit" (Government of Malta, 2020c).

Exclusion from decision-making processes, absence of understanding at governmental level of the barriers faced by persons with disability (Pilson, 2020), and limited visibility in the media (Van Hove, 2020) including during the Covid-19 pandemic, results in further lack of understanding of the complexities and complications experienced by persons with disability (Adams Lyngbäck et al., 2020). These elements in turn feed to continued structural barriers, inequalities and discrimination, for persons with disability to access their social rights; with Tsakiri & Mavrou (2020) claiming that "decisions of governmental agencies around the world reflect disableism, ageism, medical racism, and reinforce the imposition of idealised normalcy" (par. 3). A long call for a culture shift challenging the human value based on productivity and economic contribution (Abberley, 1997), as well as social factors such as "activity, measurable achievement, vigour, bodily control" (De Wolfe, 2002, p. 264).

2.5 INTERSECTORAL POST-PANDEMIC APPROACH

The role of solidarity through family and friends, and other persons with disability; hence, the social support network, was emphasised (Amber, 2020; Haraldsdóttir, 2020; Runswick-Cole et al., 2020). There has been a rapid and effective response from the disability community as well as solidarity from allies coming in different forms throughout the pandemic with activism, advocacy and more concrete support initiatives (Karagianni, 2020; Pilson, 2020; Runswick-Cole et al., 2020; Schippers, 2020). Examples of such practices include exploring different forms of treatment services and distribution of information (Schippers, 2020), creating collections of useful tools, resources and awareness campaigns (Pilson, 2020), and online platforms to inform on situations of discrimination (Monforte & Úbeda-Colomer, 2020). Moreso, the disability community has attempted to reverse "the narrative of absence" (Pilson, 2020, par. 9) by increasing its efforts to ensure that their presence is felt, through recording experiences and the creation of solidarity online platforms (Runswick-Cole et al., 2020).

In their policy brief focusing on a disability inclusive response, the United Nations (2020a), supported by 137 countries and the European Union (UN, 2020b), claimed that due to the economic impact brought by the pandemic, more austerity measures, including cuts within existing services, may occur after the crisis period. Furthermore, as discussed above, the current pandemic has highlighted systematic ways through which the disability community is being left behind. A disability inclusive response, and commitment to the UNCRPD are imperative to ensure that persons with disability enjoy their fundamental human rights. Schippers (2020) argued that a systemic change from neo-liberal policies to practices based on the principle of solidarity are essential during what is being labelled as "post-pandemic times".

Scholars from the disability sector hope that post-pandemic times will include the adoption and mainstreaming of practices from the disability lobby (Ignagni et al., 2020; Pilson, 2020), leading to social transformation amongst the non-disabled community, and that measures provided to support different social groups in society during the crisis will remain for the long-term as challenges for disadvantaged groups have been highlighted during the crisis (Amber, 2020). Nonetheless, Ignagni et al. (2020) recognized that "this is not the time of promise and innovation because any crip hope carries, as it always does, the threat of death" (Ignagni et al., 2020, par. 10).

Nonetheless, the United Nations (2020a) established a number of practical policy actions that would facilitate the transition to a post-pandemic period to re-focus on the attainment of the Sustainable Development Goals. The first consideration is to ensure meaningful engagement of persons with disability through the promotion, funding and monitoring of the design and execution of inclusive measures. Recognizing the disproportional socio-economic impact on persons with disability due to underlying assumptions and economic models is also essential to ensure that the disabled community is prioritized. Moreover, this policy brief also includes reference to the need for empowerment of persons with disabilities in response and recovery plans, highlighting the need of more preparedness with regards to addressing needs of persons with disability in emergency situations.

This document (UN, 2020a) also addresses tangible aspects that require attention and investment, including the need of improved health outcomes for persons with disability, such as having accessible infrastructure, adequate training adopting a rights-based approach, and ensuring health care provision. Social protection is also central to ensure an inclusive and equal society in a post-Covid-19 era, and thus supporting measures for persons with disability are encouraged to address the life cycle of these individuals and be compatible with other aspects of one's life, including employment and additional social security initiatives. Emphasis was also placed on the need for deinstitutionalization of persons with disability; therefore striving for community-based solutions.

Furthermore, the precarious situations of a number of workers in the disability sector is also considered as crucial for rebuilding after the pandemic (UN, 2020a). Overdue attention has been given to the conditions of work and economical and social undervalue assigned to frontline care workers and support workers (Ignagni et al., 2020). Karagianni (2020) highlighted that such positions are usually occupied by migrant women with no legal registration, thus not enjoying social security benefits. Therefore, such undervalue is considered to be assigned due to "the interlocking structures of racism, classism, and ableism that maintain their economic precarity" (Ignagni et al., 2020, par. 8). The disability community has shown its support and solidarity also towards the urgency of increased remuneration, security in employment, and "attention to their dignity to commence immediately and continue past the imagined end of the pandemic" (Ignagni et al., 2020, par. 8).

Finally, the United Nations (2020a), supported by 137 countries and the European Union (UN, 2020b), established the importance of inter-sectoral dialogue and collaboration, with the full participation of the private and public sectors, as well as civil society, to be able to address barriers and hindrances that arise from the multi-dimensional reality of disability; and to safeguard inclusion in the rebuilding of society in a post-pandemic period. Such collaboration between stakeholders, the establishment of structures that support such dialogue, and possibly funding for research and development, are also found to be effective methods for the development and implementation of socially innovative solutions (Pace Gasan, 2020).
The planning towards a post-pandemic time gives us the opportunity to "focus on building more equal, inclusive and sustainable economies and societies that are more resilient in the face of pandemics and the many other global challenges we face" (UN, 2020a, p. 16). A disability inclusive response is based on the principles of non-discrimination, intersectionality, accessibility, participation, accountability and data disaggregation. More so, mainstreaming as well as targeted policy measures are to be ensured. Information, services and programmes should be accessible, during the pandemic as well as after the time of crisis. The disabled community is to be represented and engaged in meaningful consultation and decision-making processes, as well as safeguarding the rights of persons with disability through accountability mechanisms (UN, 2020a).

Actions highlighted above and those generated by the respective countries are to be thought of, designed and executed in a timely manner, which due to the nature of the developments of the current pandemic, seem to be shifting.

2.6 CONCLUSION

As the pandemic is still ongoing, the psychological, social and physical implications of discrimination and public discourse are far from being understood. Neither can conclusion be drawn on the ethical and political implications of the Covid-19 pandemic (Altermark, 2020, Lee, 2020). Yet, persons with disability continue to be treated unequally, and their human rights breached, in some cases at the expense of their lives.

How societies will respond to the Covid-19 pandemic will continue to define how we live our lives, and how governments and the public relate to the disabled community (Tsakiri & Mavrou, 2020). Disability politics may ultimately not only address challenges that the disability sector is facing during the pandemic, but as it allows to consider alternatives to neoliberal-ableism (Goodley, Lawthom & Runswick-Cole, 2014), disability politics may enable society to think of socially innovative solutions for the post-pandemic times, exploring new perspectives from focusing on normative labouring standards to humanness, where valuing care and enabling each other are the epicentre.

While the value assigned to the lives of persons with disability needs to be on an equal level of any other individual, and thus their human rights as established in the UNCRPD should be safeguarded, the Covid-19 pandemic may very well have brought to the forefront discriminatory practices and disadvantages experienced by persons with disability. It may have helped us recognize the extent to which neoliberal-ableism (Goodley & Lawthom, 2019) and basing lives' worth on someone's ability to be productive in a capitalist post-modern society hinders the quality of life of those who are undervalued. A post-pandemic time should further strengthen the disability sector's network (Goodley & Lawthom, 2019), and its long-term call for a cultural shift to challenge the basis of human value as identified by Abberley (1997) and De Wolfe (2002).

Methodology

3. METHODOLOGY

The literature highlighted in the previous section highlighted that the lives of persons with disability was influenced by Covid-19 and the spread of the pandemic, but essentially by decisions taken on a micro, meso and macro level. It was therefore considered important to look into the experiences of persons with disabilities, their caregivers and decision-making entities through by adopting a qualitative approach to the study, and delve into understanding the impact of the socio-political complexities surrounding the disability sector in relation to the Covid-19 pandemic.

This section aims to present the research design and methods used throughout this project, including: the rationale behind the study; data collection process; data analysis; ethical considerations; and limitations.

3.1 RATIONALE

The scope of this study was to identify the impact that the Covid-19 pandemic has on the lives of persons with a disability and their families. To address this scope, clear objectives and research questions were developed.

The objectives included:

- identifying the key aspects in the lives of persons with disability which have been impacted by the Covid-19 pandemic, either in a positive or negative manner; and
- developing practical and policy recommendations to address needs arising from the Covid-19 pandemic.

The research questions compiled for this study were:

- How has the Covid-19 pandemic impacted the lives of persons with disabilities?
- How has the Covid-19 pandemic impacted the lives of families and caregivers of persons with disabilities?
- How has the Covid-19 pandemic impacted the disability sector?
- How can the negative implications of the Covid-19 pandemic on the lives of persons with disabilities be mitigated?

3.2 RESEARCH DESIGN

Limited published research focusing on the impact of medical epidemics and/or other emergency situations, such as natural disasters, focused on the impact on the lives of persons with disability. To this end, an exploratory approach, to help investigate this new and emerging reality (Swedberg, 2018), was considered.

Data collection from primary sources was necessary to be able to address the research questions and document the impact that this pandemic is having on the lives of persons with disability in Malta and Gozo. Thus, an emancipatory research approach was also adopted, as key players in the disability sector, including persons with disabilities and their primary caregivers, were involved.

Furthermore, the study adopted a qualitative approach, for an in-depth understanding of different scenarios experienced by various individuals, their main caregivers as well as key stakeholders in the field. A cross-sectional design was assumed since data was collected from multiple respondents at a single point in time with the scope of potentially identifying patterns across sources (Bryman, 2012).

Through the participation of different sources involved in the disability sector, triangulation of data, hence "the use of more than one method or source of data in the study of a social phenomenon so that findings may be cross-checked" (Bryman, 2012, p. 717), was established.

3.3 DATA COLLECTION

Semi-structured interviews were chosen as the data collection method, as it allows for in-depth understanding of the participants' experiences and their interpretation of events. The interviews were held between July and August 2020.

The interview guide was informed through the literature review. A copy of the interview guide for participants and caregivers can be found in. Further detail on the rationale that formed such an interview guide can be found in Table 3.1 below:

Table 1: Interview guide - Persons with Disability or Caregiver

Question	Rationale
1. Can you describe your typical day prior to Covid-19?	To give an insight on the participant's routine prior to the Covid-19 pandemic.
2. How has this changed due to Covid-19?	To highlight changes in the participant's routine due to the Covid-19 pandemic.
3. Has there been any disruption with regards to services?	To highlight changes in disability specific and/or mainstream services, such as education, employment, transport, and health; brought about due to decision-making.
4. Are you making use of any new services/ adaptations made due to Covid-19?	To provide insight on the use of any new services which were being provided in relation to the Covid-19 pandemic.
5. How are you feeling because of Covid-19?	To raise discussion on any feelings brought about by the Covid-19 pandemic.
6. How can you be better supported at the moment?	To understand the current unmet needs of the participants, and also any ideas that participants might have for these needs to be met.
7. How can you be better supported after the Covid-19 pandemic, especially to ensure a smooth transition back to your typical day prior to the pandemic?	To highlight participants' opinions on support that can be provided to ensure a smooth transition back to normality.
8. As a person with a disability, how do you want your life to be improved?	To provide space for participants to discuss any ideas and/or concerns that may also be presented in this research.
9. Any additional comments?	To allow for participants to highlight any themes that may not have rose throughout the interview.

The following table presents further explanation of the rationale behind questions included in the interview guide for stakeholders:

Table 2: Interview guide - Stakeholders

Question	**Rationale**
1. How did the Covid-19 pandemic influence your organisation?	To understand the impact of the Covid-19 pandemic on the respective entity.
2. How did the Covid-19 pandemic influence the disability sector?	To allow for stakeholders to give their perspective on the impact of the Covid-19 pandemic on the disability sector at large.
3. Did you see an influx in needs? What are the prominent challenges amongst service users/ members?	To provide an insight on demands arising from persons with disability and/or their caregivers, deriving from the Covid-19 pandemic.
4. Have there been any disruptions with service provision from your end?	To highlight changes in disability specific services provided, and potentially understand the reasoning behind such decisions.
5. Did your organisation start any new services to address needs arising due to Covid-19?	To provide insight on the use of any new services which were being provided in relation to the Covid-19 pandemic.
6. Was your organisation consulted / involved in mainstream decision-making processes, such as those related to education, health and transport?	To understand the involvement of the respective organisation, as well as the disability sector, in decision-making processes involving mainstream services.
7. What do you expect from mainstream policy-makers with regards to the inclusion and consultation of disabled persons in the decision-making processes?	To delve into the stakeholders' perspective on the inclusion of the disability sector by mainstream service providers.
8. How does this all impact the disability sector in the long-term?	To allow stakeholders to highlight their opinion on the long-term impact of the Covid-19 pandemic on the disability sector.
9. Any additional comments?	To allow for stakeholders to highlight any themes that may not have rose throughout the interview.

Since social distancing practices were being recommended during the data collection phase, participants were given the opportunity to choose whether the interviews be held via video conferencing or telephone. Interviews were held mainly through online video conferencing platforms, with one interview occurring face-to-face. Moreover, those interested in participating were informed that further accessibility arrangements, such as the provision of sign language interpretation services, could be made. Such options would ensure that inclusion of persons with disability who may not have access to an internet connection or computing device, as well as those who required further assistance would still be able to participate.

3.4 SAMPLING AND RECRUITMENT OF PARTICIPANTS

Data collection was based on a purposive sample. Semi-structured interviews were conducted with five (5) persons with disability, three (3) informal carers, one (1) individual representing a non-governmental organisation (NGO) and three (3) entities in the disability sector.

As to be able to document the different experiences of persons with different disabilities, participants engaged in the study represented a diversity of disabilities, including cerebral palsy, autism, visual impairment, intellectual disability and mental health challenges. Caregivers involved were all parents of persons with disability, two (2) of which had children with autism, and another (1) with delayed development. Furthermore, entities involved in this phase included: the Commission for the Rights of Persons with Disability (CRPD); Aġenzija Sapport; and the Social Care Standards Authority.

Recruitment of participants with disability was done through the distribution of an information letter with approximately 21,000 members on the CRPD membership database, whereas parents were contacted via the National Parents' Society of Persons with Disability members list. The information letter was also sent in Maltese language, easy-read versions and sign language format. Interested persons were encouraged to contact the research team and further arrangements would be discussed. Stakeholders involved the respective entities mentioned above were also sent an information letter via email.

3.5 DATA ANALYSIS

Following the data collection phase, data collected from the interviews started being analysed. Thematic analysis was used, hence common themes arising from the interviews were brought together to better understand similarities and differences highlighted by participants in that respective area. The themes highlighted are presented in the next chapter.

3.6 ETHICAL CONSIDERATIONS

In line with the University of Malta research ethics regulations, a Research Ethics and Data Protection (REDP) Form was submitted to the Faculty Research Ethics Committee (FREC) within the Faculty for Social Wellbeing.

The research team abided by the Ethical Guidelines for Carrying Out Research with Disabled People. Accessibility matters were taken into consideration throughout the whole process, as information letters and consent forms were presented in different formats, including easy-read versions and in sign language. Potential use of assistive technology, such as screen readers was also taken into consideration. The need for further accessibility arrangements was discussed with participants following their agreement to engage in the study. Arrangements would have been made according to their needs.

The situation brought about due to the current Covid-19 pandemic may leave individuals, including persons with disabilities and their families or caregivers, feeling distressed. It was considered that the study may have further amplified such feelings due to the questions being asked. While these were unavoidable due to the nature of the study and its objectives, support and mitigation measures included:

- providing contact details of psychological support services, including Richmond Foundation free helpline 1770, during the information / consent stage, and providing them again at the end of the interview;
- providing contact details for access to disability related services through the social work team at Aġenzija Sapport;
- asking questions in a considerate manner; and
- adopting an empathetic approach during the interviews.

Participation in the study was completely voluntary. Furthermore, if during the interview, any of the participants communicated in any way signs of distress, they would have been encouraged to take breaks and/or withdraw their participation should they request it. Moreover, in case that a participant withdrew, all the information collected pertaining to them would have been destroyed.

Finally, through the documentation of findings, as evident in the next chapter, all details that could have exposed the participants, such as gender, age, location of residency, or engagement in a particular event, organisation and/or other activities, were anonymised.

3.7 LIMITATIONS OF STUDY

While semi-structured interviews provide for an in-depth understanding of one's experiences and their interpretation of events, due to the limited number of participants that often comes with qualitative research, it has been argued that this can present obstacles for generalization to the population. Nonetheless, establishing triangulation of data through the engagement of different sources provided for a stronger reliance of the information deriving from the sources. The restrictive time-frames of the study due to this being an action-based research project, with the intention of informing practical and policy recommendations in relation to the Covid-19 pandemic and persons with disability, meant that the sample was chosen on the basis of various disabilities. Demographic data which could have provided further insight in the analysis of findings and highlighted further challenges due to intersectionality of different aspects of one's identity, such as gender, age, and/or ethnic background was not included.
Should further resources have been dedicated and more time allowed for this project, it would have also been interesting to delve into the consideration of the persons with disability in the decision-making processes of mainstream services. Moreover, an intersectoral overview would have presented insights into how the private sector and non-governmental organisations may have contributed towards further inclusion of persons with disability throughout Covid-19.

Results

4. RESULTS

4.1 IMPACT OF COVID-19 ON THE LIVES OF PERSONS WITH DISABILITY AND THEIR FAMILIES

4.1.1 Disruption of Routine and life prior to Covid-19

"Routine is important, even if you don't have a disability" (Parent 3)

When participants and their carers/guardians were asked what their life was like pre-Covid, a frequent response was a very detailed overview of what a typical week consisted of. Participants such as a person on the Autism Spectrum would claim:

> *"Before Covid [I] used to go to school, then in the afternoon come home to eat, then listen to music on the phone, after 3 had lots of activities such as music. All these activities had to stop. We had to cancel everything on the calendar. From a very busy schedule everything had to be stopped. I like my schedule. All the plans were gone. Covid-19 was a very huge problem" (Person on the autism spectrum)*

The loss of routine was particularly onerous on persons with disability and their family. This was especially the case if the routines were finely crafted over a number of years and involved concessions from work (Parent 1, 2), arrangements with other members of the immediate or extended family and involved professionals.

> *"Prior to Covid on some days she went to nursery child care, 1 day at home, 1 day at nanna, 3 days at nursery. Sometimes there is early intervention specialist" (Parent 2)*

> *"Used to go to work at […], and [carry out certain activities]1, would then do chores, and on Saturday my mum comes to help me. On Sunday I went to see the family." (Person with a visual impairment)*

Routines also helped persons struggling with mental illness to manage their condition better (Person with a mental illness). A strong routine meant that they were kept busy all the time and that they therefore had less opportunity to "live a lot in their own world" (Person with a mental illness).

> *"It is important that I occupy my time and that I stay on the go […]. People speak less in my mind, when I am passive I struggle more." (Person with a mental illness)*

Shifting into a new normal was difficult especially for persons and family members of persons on the autistic spectrum. In certain situations, the change brought about by restrictive measures resulted in persons with disability disrupting their sleeping/waking cycles completely with children on occasion staying awake until 7am (Parent 1).

> *"The transition was very difficult in the beginning but being prepared ahead of time I would have made sure that I have a schedule ready. I had to find my way as I went along, that was a struggle. After a month we were on schedule." (Parent 3)*

While one can argue that this kind of disruption was not uniquely suffered by persons with disability and their family members, the disruption of routine left a large negative impact on persons receiving daily treatment. One of the participants interviewed was receiving therapy 2-3 times a day, the immediate stop to this treatment, left the participant vulnerable to losing the benefits, or possibly be harmed due to an important operation they had undergone (person with a physical impairment).

> *"The timing was horrendous, and I was very unfortunate because before I was registering a big amount of improvement in my life." (Person with a physical impairment)*

4.1.2 Impact on Education

A number of participants within the study had children that were of schooling age and once the restrictive measures were put in place, they could not attend school. Initially the continuous homestay had mixed results

> *"Initially the child was happy not to go to school, after a few weeks the child got bored." (Parent 1)*

> *"The child spent whole days on the tablet but wanted to go out after a while, they got bored of toys." (Parent 1)*

While others felt differently:

> *"I missed school the most. I missed my friends and my teachers" (Person on the autism spectrum)*

Schools and educational services reacted in different manners to the closing of educational facilities. Some schools took some time to offer online platforms and did not offer tailored teaching for persons with disability (Parent 3).

> *"In the class the teacher was addressing the whole class and the teacher would not give them one-to-one attention, which I would not have expected. They provided the same service to every situation but knowing [child's] difficulty and because they have a full time LSE with them at school, the fact that [child] had a full time LSE, it would have made sense to give her a couple of hours a day of tuition one-to-one." (Parent)*

When the online adaptations made by educational institutions were not sufficient, this led to additional stress on the parents. Parents responded in the ways that were possible, some opting for homeschooling at great personal cost (Parent 3), while others chose services provided by NGOs for a short time

> *"Inspire organized meetings with teachers, but since the child did not do any of the homework while they were at home, I eventually stopped attending meetings and did not open emails" (Parent 1)*

The different responses depended greatly on the support structure the parent and the person with disability had at their disposal.

Certain educational services adapted quickly

> *"Equal partners foundation was fantastic, they reduced the time of a session but added an additional session." (Parent 2)*

> *"Sessions used flashcards, music and PowerPoint and hard copies. They modified their approach and this really worked" (Parent 2)*

Unfortunately, others did not respond as quickly, which left lasting impacts on persons with disability

> *"There were three children in [town] who were blind and were given 2 braille machines for school, this was important for them to read, learn and write. During Covid there was no learning support for these kids as they did not have access to a braille machine. An agreement with government to have them buy their braille machine fizzled out." (Visual disability organization)*

An interesting development that arose out of online sessions was that for particular sessions such as ABA (Applied Behavioral Analysis) sessions for persons on the autism spectrum may have actually been more effective (Parent 3).

> *"One-to-one is a better option because a lot of social cues and body language which I would want them to pick up on, but when it comes to language she had to work harder online. A mixture of both might help them in fact we kept ABA sessions online in terms of language." (Parent 3)*

> *"Covid may have opened new ways of communicating and educating persons on the spectrum." (Parent 3)*

All persons within this research claimed that the transition back to schooling (throughout summer 2020) was easier than they imagined it would be. The impact of educational adaptation by service providers was the difference between children improving during Covid-19 or losing progress they had made before (Parent 1, Parent 2, Parent 3).

4.1.3 Impact of Restrictive Measures

> *"We all had to stay at home and all the dynamics changed and we had to adapt to this new life that was imposed on us." (Parent 3)*

> *"[Covid-19] created a sense of loneliness and abandonment. These are very complex problems. Each case is different and complex." (Aġenzija Sapport)*

One of the most strongly felt impacts that was experienced by persons with disability was the increased sense of isolation (Person on the autism spectrum). The sense of isolation was not unique to persons with disability but particularly for persons with disability that struggled with social contact, the sense of isolation had a double effect. On the one hand, it meant an increase in loneliness and more time spent alone (Person with an intellectual disability) but also the deteriorating of certain social skills that were hard acquired (Person on the autism spectrum). Persons with disability who had been making steady progress and who in some circumstances were even living alone or in a residence, ended up regressing and losing independence, which in certain instances could result in persons with disability moving back into their family's home (Aġenzija Sapport, person with a visual impairment). For persons with disability who did not live with their families, the separation could be heartbreaking (Person with a visual impairment).

> *"Visits stopped from the family, my sister's son had a baby. I made a vow to saint [Name of Saint] so that the virus passes. I wanted to give a present I bought for my nephew's baby." (Person with an intellectual disability)*

Even within residences, which normally encourage a family like atmosphere and a sense of community, carers had to separate individuals within flats so that they are not all together at the same time to reduce possibility of infection (Carer for person with an intellectual Disability). With outings being limited to simply going for car drives and never leaving the car to go outside, outings were the cause of conflict and jealousy between persons with disability who would have their turn to go out (Carer for Person with Disability).

Restrictive measures also had an impact on persons with disability staying within hospital premises. The thought that they might go into lockdown or quarantine and would not be able to leave hospital raised concerns (Person with a physical impairment). This led to shifting their aims from completing their treatments well to completing their treatments quickly.

> *"My aim was to make sure that instead of focusing on the quality of the therapy, [I] focus[ed] on the speed, to ensure I get out of hospital as fast as possible." (Person with a physical impairment)*

In fact the person left the hospital with the minimum amount of therapy they could not to deteriorate, so that they could continue the therapy at home. This prompted a conflict between professionals overseeing his recovery.

> *"The consultant cleared me to go home and the physio did not clear me as I was not in an advanced enough stage in the therapy." (Person with a physical impairment)*

The person with a physical impairment claimed that although the hospital is more sanitized the fact that there is a lot of staff coming in and out made him feel like their home was safer. This person felt that they were being forced to choose between their therapy and their safety. Such a choice was made much harder by the fact that if they left without authorization and against medical advice they would be effectively cut off from outpatients and other services (Person with a physical impairment). This was a particularly unjust policy which luckily was not strictly enforced during the Covid period but could have still been put to use in negative ways.

Throughout the period of restrictive measures, accessing food and groceries became particularly important. The person with a visual impairment had previously used online services frequently, particularly. online shopping via a supermarket. Prior to Covid this wasn't difficult to access and they would book two weeks in advance. However, in the first month of the restrictive measures it was a "nightmare", as all slots were taken and they were running out of food (Person with a visual impairment). Eventually this required that they phone the manager of a supermarket and found that the slots opened at midnight, however even then, only a few slots were available. After the first month this issue was mostly resolved (Person with a visual impairment).

Working from home also created problems, particularly when the infrastructure necessary such as laptops or space to work was missing (Person with a mental illness). Shifting meetings online also presented some obstacles as the online platform used was not easily readable with screen readers, and challenges with the internet connection also hindered communication (Person with a visual impairment).

Restrictive measures impacted organizations for persons with disabilities including forced cancellations of meetings and adding many logistical challenges such as logging, visor, taking the temperature, liability waiver and had to change office for more appropriate social distancing (Visual disability organization).

4.1.4 Psychological Impact on Persons with Disability

The introduction of restrictive measures, which included the immediate stopping of a number of services provided to persons with disability resulted first and foremost in panic (CRPD). Persons with disability would phone CRPD in large volumes querying about various services that were stopped immediately and without being informed of what alternative arrangements were going to be made.

Such a disruption caused immediate reactions from persons who were non-communicative persons (Carer for person with an intellectual disability). People with psychosocial problems struggled tremendously and acted out these situations with challenging behaviour (CRPD). For those who could communicate, the pain of isolation was expressed in a heartbreaking manner

> *"Some residents who could not meet their family were hurting, those who communicated showed their sadness." (Carer of person with an intellectual disability)*
>
> *"[There was] a huge sense of uncertainty and frustration even from persons with disabilities themselves." (Carer of person with an intellectual disability)*
>
> *"Persons with visual impairment had no one to communicate with, they only had their radio and this was very painful, you can't see anything but have to stay inside." (Visual Disability Organization)*

Another psychological impact that was registered throughout the restrictive measures was fear. Certain disabilities were either not categorized or incorrectly categorized as not being amongst the vulnerable, which meant that persons with disabilities were required to go to work normally, even though they had particular vulnerability (CRPD). One of the participants felt afraid that they would lose their employment and were anxious to be seen that they are performing.

> *"In lock down I was afraid of being fired because I was afraid that management does not see me working. I kept on working and did not take a break." (Person with a mental illness)*
>
> *While for some persons with disability, the restrictive measures were initially welcomed, because they felt better and more productive because they had no distractions, the feeling of loneliness and isolation would eventually become very strongly felt, particularly when the isolation was experienced due to reduced contact with family or when it was completely stopped (Person with a visual impairment).*

4.1.5 Impact on the Family

The impact of the restrictive measures did not stop with persons with disability, but left a huge impact on their families, particularly parents or guardians. Family members are not necessarily experts when trying to support persons with disabilities, particularly those who communicate their frustration and boredom through challenging behaviour (CRPD, Aġenzija Sapport). Parents in fact phoned in desperation when dealing with challenging behaviours. They were either not accustomed to dealing with this, as these would take place during schooling or activity hours or did not have the expertise to manage this behaviour (Aġenzija Sapport). Some resorted to coping mechanisms such as allowing their children to utilize technology such as tablets for hours on end, something that in pre-Covid times they would not allow.

> *"It was very time consuming and I had to step away from other responsibilities." (Parent 3)*
>
> *"It worries me having them on the computer all the time." (Parent 3)*
>
> *"Families were tired, frustrated and afraid and this changed reactions [towards persons with disabilities]." (Aġenzija Sapport)*
>
> *"Parents had no idea how to keep children entertained and calm under limitations currently available to them" (CRPD)*

A factor that determined how well family members could cope throughout the restrictive measures was the support structures from other family members and their work.

> *"Throughout Covid period my [partner] was caught abroad and I therefore had even less support. I stayed alone with the child for four months. Luckily I could work from home." (Parent 1)*
>
> *"We both work full time, I used to [benefit from] teleworking prior to Covid 40%. [Partner] takes a lot of leave. With Covid, telework switched to full time but my [partner] still went to work as it was deemed an essential occupation" (Parent 2)*

Support structures notwithstanding, parents felt that their work life was impacted due to the additional care responsibilities that were thrust upon them (Parent 1). Family members also felt that at times they were abandoned and that their needs were not met (Aġenzija Sapport, Parent 1).

> *"They do not allow me to work because they constantly want to eat, play and need to be distracted." (Parent 1)*

In certain instances, restrictive measures interfered in family gatherings and prohibited persons from participating fully in family life.

> *"Normally we celebrate birthdays as a family, this year we did not , maybe a telephone call. You feel the difference living alone and you feel it more [...]. Human being is a social animal and losing contact with people was very tough." (Person with a visual impairment)*

4.1.6 Secondary and unforeseen effects of Covid-19 Restrictive Measures

While the effects of the Covid-19 restrictive measures were indisputably borne by the entire population, the disability sector was particularly affected, in ways which were not easily foreseeable, especially if no prior consultation with persons with disabilities took place.
One of the difficulties that was not taken into account when issuing policies was the mandatory usage of masks in public spaces and shops.

> *“Child cannot put on a mask and therefore was not allowed in shops. [The] child does not understand.” (Parent 1)*

Persons on the autism spectrum and other disabilities found the mandatory wearing of masks particularly onerous. On occasions, the need for masks was not always easily explained and when this was imposed nonetheless, this resulted in the persons having a meltdown (CRPD, Parent 1, Parent 3, Aġenzija Sapport). Persons with auditory impairment were also particularly disadvantaged since the mask would impede lip reading which was an essential part of their communication process (CRPD).

Washing hands continuously was also a new behaviour that took time to adapt to. Social stories were seen to be particularly successful in helping to reinforce this new behaviour (Person on Autism Spectrum).

> *“They had problems learning to wash their hands every five minutes, they did it and they complained, eventually they phased it out and adapted. Everything that changes is met with resistance.” (Parent 3)*

Another secondary effect that was not immediately obvious was the health risk that Covid-19 posed to certain disabilities over and above the immediate health complications. For persons with disability on the spectrum or with intellectual disability, the trauma of going to hospital was overwhelming. Hospitals with the multiple stimuli it presents could easily lead to sensory overload, which would have been traumatic particularly for persons on the spectrum (Parent 1, Parent 3). However, secondary health effects of the virus could also present themselves adding the vulnerability to the person with disability. In the case of cerebral palsy, there isn’t an inherently bigger risk of contracting or succumbing to Covid-19 per se, but if the situation escalated and the person would need to use a ventilator, complications might arise due to the disability (Person with a physical impairment). In this situation, the person with the physical disability got to know this information much later and was potentially exposing themselves to greater risk given their circumstances (Person with a physical impairment).

Additionally, the restrictive measures meant that less people could get on the bus, isolating persons with disability and wheelchair users even further (Person with a physical impairment). This was further exacerbated with the lack of safety on the bus, with people not wearing or wearing their protective masks incorrectly (Person with a physical impairment).
“Is it worth it to use public transport, now that they may endanger my life?” (Person with a physical impairment)

4.1.7 Transition out of Restrictive Measures

Moving out of restrictive measures was not a seamless transition for both parents and persons with disability. Tying in with the difficulties to change routine at the beginning of the restrictive measures, it was similarly difficult to transition back out of restrictive measures once again.

> *"They love staying at home, so having them stay at home is no problem but taking them back out was a problem. If you keep them at home they're happy. Home is a safe place, they will complain everywhere." (Parent 3)*

> *"[When I went back to work, at the] office I was more anxious that I could get infected, particularly with numbers going back up [...]. No one comes to the office I work in with a mask." (Person with a mental illness)*

A participant who used residential services did not receive frequent visitors, and once the restrictive measures were eased, started receiving visits from relatives wearing masks. The person could not recognize the family member and got very frightened (Carer for person with an intellectual disability).

Parents were initially afraid to send their children to the nursery once this was opened. Over time, however, they gained more confidence and eventually took them to pools, went to hospital for tests and even attended a carefully chosen restaurant (Parent 2). As stated above, parents with children with disability are doubly afraid of their children contracting Covid-19, not merely for its health impacts, but also for the ordeal and trauma of having to admit the child into hospital (Parent 2).

Conversely, some persons with disability on the autism spectrum were rejoiced once the restrictive measures were eased with certain instances in which

> *"[The] child was so happy coming out of lockdown that actually looked forward to going to hairdressers when before this was problematic, now the child sat in the seat on their own." (Parent 1)*

It is likely that the age, personality and type and severity of the disability will modify the reaction to eased restrictive measures.

4.1.8 Anticipated effects of restrictive measures during Covid-19

The effects of Covid-19, particularly of the restrictive measures are still to be fully appreciated. Social problems that existed prior to Covid-19 are likely to have been exacerbated particularly for persons with disability living in situations of abuse or being cared for by the elderly (Aġenzija Sapport).

Additionally, another challenge going forward will certainly relate to staffing of disability services, particularly if restrictive measures are re-introduced and staff are required to enter into lockdown within residential and respite services for days and weeks at a time (SCSA, Aġenzija Sapport).

4.2 POLICIES RELATING TO PERSONS WITH DISABILITY

The Covid-19 response within Malta throughout the first few months after the first few cases was rapid. However, the consensus amongst the interviewed persons with disability was that the measures implemented, while necessary, were not nuanced enough to accommodate the disability sector.

> *“At the start of the panic in implementing things, the disability sector was left out of the equation which did not make sense as persons with disability are some of the most vulnerable in society.” (CRPD)*
>
> *“When [my partner] came back, the 15 days quarantine had a very bad impact on the child […]. We phoned 111 and asked for an exception to go out with the car for a drive as the child could not cope but this was rejected because that was the policy, unlike in [Country] and England where exceptions were made.” (Parent 1)*
>
> *“Lockdown should make exceptions for persons with disability.” (Parent 1)*

From issues such as the vulnerable list not being comprehensive enough, to policies on leaving hospital against medical advice, seemingly forcing persons with disability to choose between their immediate safety, and access to outpatients, it was clear that the policies were not well thought out (CRPD, Person with a physical impairment). Experts wanted to stop the disease immediately but were not well-versed in disability issues, and did not consult with the disability sector, or cater for rights of persons with disability. The rapid pace of the changes brought a great degree of panic within health officials and the disability sector was forgotten (CRPD).

> *“People were overlooked because we were in survival mode.” (SCSA)*

4.3 SERVICES OFFERED TO PERSONS WITH DISABILITY

4.3.1 The Experience of Persons with Disability

> *“Services were stopped to protect service providers and didn’t see people for days. This was a knee jerk reaction and persons with a disability panicked.” (CRPD)*
>
> *“All the services stopped once Covid-19 broke out except equal partners foundation” (Parent 2)*

The experience of services during the Covid-19 restrictive measures was one of frustration and fear by persons with disabilities and their families. Participants made use of a number of services such as Occupational therapy, physiotherapy, CDAU, appointments with hospital consultants as well as services from the Ministry for Education and Employment prior to Covid-19 (Parent 2, Person with a physical impairment). While the participants did not expect that the services would keep going as before, the tremendous variation in the level of service offering was disappointing, frustrating and worrying (Parent 2, Person with a physical impairment). In certain instances, stopping services in such an instant manner also resulted in potentially perilous situations where persons with disability ended roaming the streets without the support required and were found by ambulances and police officers (CRPD). In other instances, stopping the services for such a long time could have resulted in regression of previous progress and situations where persons with disability could be indirectly harmed through very time constrained interventions (Person with a physical impairment).

The first bone of contention was that the services were very slow to reach out, with some never even reaching out (Parent 2, Visual Disability Organization). This meant that in some cases such as the CDAU, the person had to reach out and phone themselves, with the appointment that was meant to be in May 2020 being postponed to January 2021 (Parent 2). Another point of critique was that the services were very slow to migrate online, with management citing security concerns; however, it was felt that drawing an IT policy did not require months as was the case with a number of services the person utilized (Parent 2).
“The transition was slow and inconsistent.” (Parent 2)

Another impact of the restrictive measures on the services provided to persons with disability is the large discrepancy in the service offering between individuals in the same profession. While some professionals took time to call on their private number, essentially breaking the policies and guidelines of their organization to speak to parents, others took a less committed approach and it was perceived that they used the restrictive measures to slack off (Parent 2).

> *“The level of service is still dependent on the commitment of the individual and is not guaranteed all throughout.” (Parent 2)*

Some services such as those offered by the Equal Partners Foundation, despite the initial scepticism of the parents migrated online almost seamlessly and resulted in progress during the restrictive measures (Parent 2).

The issue that was constantly raised by the participants was what was going to happen in case of a second wave, or even in a future where there were no restrictive measures, but a vaccine was not immediately found in relation to service provision. The thought caused a significant amount of anxiety and doubt in the persons interviewed (Parent 1, Parent 2, Parent 3, Person with a physical impairment).

> *“I was getting momentum and had my goals, I needed professional help and guidance.” (Person with a physical impairment).*

4.3.2 Service providers as employers

When restrictive measures intended to tackle Covid-19 were introduced, these measures happened so quickly that organizations were not prepared for it (SCSA, Aġenzija Sapport). Management had to balance between the needs and rights (as well as the added dependency on the services because of disability) of persons with disabilities and the needs and rights of workers within these services (Aġenzija Sapport).

> *“Management had to balance between users and workers.” (Aġenzija Sapport)*

The job of workers working within the various services offered by Aġenzija Sapport and other agencies that offered services to persons with disabilities was particularly dangerous, especially because certain persons with disabilities cannot control bodily liquids or are inclined to touch the workers (Aġenzija Sapport).

This created in workers within these services a sense of anxiety and mixed feelings. Workers on the one hand understood that persons with disability depended on their services, but at the same time were scared and questioned particularly why they had to go out in the community (Aġenzija Sapport). The difficulty faced by workers in front line positions extended beyond their working duties, but entered into their family life, where a number of conflicts arose as to why the worker had to keep going to work, potentially endangering the entire family (Aġenzija Sapport).

Such difficulties created a lot of stress within the front liners, who apart from managing the stress of their jobs, which is not negligible due to the Aġenzija Sapport already being stretched to provide all the services it needs to provide, and their family, had their own personal stress and anxiety to deal with (Aġenzija Sapport). While they were provided with support and supervision in the workplace, the challenges of dealing with this multi-faceted reality did not simply dissolve and taxed workers' mental and physical health.

4.3.3 Service Providers Perspective

4.3.3.1 CRPD Services

Throughout the restrictive measures CRPD closed the offices and everybody worked from home. Messengers picked up the post and this was then sorted according to the recipient. Work continued particularly with regards to the Blue badge and the EU Disability card. Complaints and issues increased exponentially, and they did not stop being addressed. A Facebook group was created to include the office support workers and keep them abreast of developments throughout the period during which they did not go into the office.

Presently, the organization works on a roster and meetings are held every Monday. In effect they are in a semi-shutdown state (CRPD).

4.3.3.2 Aġenzija Sapport Services

The Covid-19 restrictive measures were implemented at such great speed that the agency found it difficult to make the transition having no prior plan for the transition. While certain services and tasks could be carried out from home, others could not be done from home. This had a particular impact on social workers who usually worked in a team but eventually they adapted (Aġenzija Sapport). Home visits, counselling sessions, referrals or interventions could not be carried out in person. Assessments that had started before the restrictive measures continued but those that were required during Covid-19 presented logistical challenges. All throughout Boards kept meeting (Aġenzija Sapport).

Clients were contacted via telephone, email, and internet; however, connectivity problems arose when clients did not have the knowledge or the facilities to use online platforms such as Zoom and Microsoft Teams. Another phenomenon that was encountered was that clients were not always free to talk because of domestic situations, which included the lack of privacy from their parents. Professionals tried to keep in contact with their clients but managed to do so less than in pre-Covid times (Aġenzija Sapport).

The voluntary service, Sharing Lives, which includes volunteers and professionals to help persons with disability integrate into society shifted sessions online and social workers called users regularly. Services within the community were disrupted from every aspect, there were less attendees and service users and less sessions were offered (Aġenzija Sapport). Day centers were closed but occasionally had some outings and engaged in video calls with persons with disability. Respite services were initially stopped but were then offered for a longer period of time, requiring users to do swab tests, and when this was not possible checks on the family were carried out to mitigate risks as much as possible (Aġenzija Sapport).. In this respect, Aġenzija Sapport helped mediate between parents and respite services who were in conflict on the length of the stay of the respite service. Aġenzija Sapport helped nurses and front liners who had caring responsibilities for persons with disability by taking care of their children or family members. Additionally, Aġenzija Sapport provided assistance in manning a helpline provided for the elderly by the Ministry for the Family, Children's Rights and Social Solidarity.

When looking back at what could be done better, an earlier resort to webinars would have probably been of great help to services users and their families. Ensuring that the resources available were used for the benefit of persons with disability and that service provision was consistent towards different clients; thus ensuring that standard operating procedures for such circumstances, would have ensured a better service. Another issue which was eventually resolved was that initially all calls went through reception, when restrictive measures were imposed, this was rerouted to managers. Such an action resulted in managers being inundated with calls and not being able to give the quality that they deserved. An application called Rainbow was utilized and now calls are directed immediately to the necessary professional.

4.3.3.3 SCSA services

Throughout Covid-19, the SCSA was tasked with issuing circulars and ensuring the safety of personnel and service users across the board. To this end, the organization issued circulars on infection control and that part-timers cannot be used in multiple services and training (SCSA). Every organization that provides a service to persons with disability were asked to produce a contingency plan. The level of detail provided was not equal across the board. Throughout the restrictive measures, there were frequent meetings with stakeholders and it is held that these meetings together with the timeliness of interventions and restricted access to day centres and respite services (with exceptions) were the reason that there were no infective clusters to be found within organizations (SCSA).

4.3.4 Additional Services developed during Covid-19

Throughout the initial restrictive measures period additional services were developed for persons with disability. CRPD provided services in the form of meals on wheels wherein persons with disability had meals delivered to them (CRPD).

Aġenzija Sapport developed webinars on topics such as self-care which had a weekly attending of between 80-100 persons. In retrospect, the need for the latter was so strong that it would have probably been better if they started earlier (Aġenzija Sapport).

4.4 BROADER AND UNDERLYING ISSUES WITHIN THE DISABILITY SECTOR

A major theme that emerged throughout all interviews is the issue of awareness of disability issues.

> *"You are only aware of disability issues if you have a disability or if someone in your family with disability issues." (CRPD)*

> *"There is a lack of empathy and thought from leaders who do not consider how small things affect the lives of persons with disability." (Person with a physical impairment)*

Such ignorance was brought out sharply during the Covid-19 response by authorities, who acting on fast changing circumstances put public health considerations first without consulting the disability sector. Some of the interviewees felt that this was not systemic prejudice but rather the result of politicians and policy makers not yet having a working understanding of disability issues and because the disability sector comprises numerically a minority (CRPD). Others were less forgiving.

> *"We say that we care and respect people with disability but it's not true, there is no respect for persons with disability." (Visual Disability Organization)*

Another theme that emerged from the various interviews is that the experience of disability is not a consistent one, particularly when interfacing with services. In fact, persons who are well-connected, assertive, well educated, and who had prior knowledge of services and the way they work were able, even during the trying period of restrictive measures, to get the best possible outcomes and go through the process relatively smoothly (Parent 2, Person with a physical impairment). Conversely, those who were not knowledgeable about the system or who were in the initial phases of interfacing with the various services, as well as those who did not benefit from strong support structures such as familial support struggled disproportionately (Parent 1, Parent 3).

> *"Covid did not affect everyone equally, for those who were well settled, had done their initial grieving and were well into the system, coping was not impossible but for those who were still out of the system and coming to terms emotionally and psychologically with the impact of a person with disability in their family, they struggled a lot. This was multiplied by ten during Covid." (Parent 2)*

While support structures are a predictor for resilience (Parent 2) through many challenges whether within the sector of disability or not, assertiveness with service providers, and doing background research is vital to obtain the best service.

> *"[The] parent has to push for things to get done, you have to be the manager of the services. I am lucky that I knew the services well, children need to be seen holistically, for example CDAU called for a case conference after 2.5 years, which is too late." (Parent 2)*

"Maybe I know very little about my condition, for example I need to do a lot of stretching, but what about older and younger people, I ask a lot of questions and being empowered makes a difference." (Person with a physical impairment)

> *"A parent needs to be proactive, but they shouldn't be the ones that have to email and phone themselves." (Parent 2)*

> *"With disability, one has to be very assertive." (Person with a visual impairment)*

Such assertiveness, however, might not be present universally, particularly when there are cross-sectional marginalized identities such as ethnicity, religion, gender, social class or educational attainment. Persons who are not somewhat empowered have a very different experience of disability, especially in their interactions with service providers. This could continue reinforcing systemic inequalities and is not conducive to the social justice aims many of the service providers claim to pursue.

A final note that was observed throughout several interviews was the lack of convergence and disharmony between the various types of disabilities. On occasion the discourse and language used also conveyed the idea of a hierarchy within the disability sector, with some proposing that the aims of particular disabilities ought to be pursued separately rather than as a sector.

4.5 ANCILLARY ISSUES

Throughout the interviews, several issues within the disability sector arose but which are not strictly related to Covid-19 or restrictive measures.

One of these issues was the fact that while buses are accessible, bus stops are not. This could mean that alternative forms of transport are required that are very expensive and not sustainable economically. A suggestion was put forward that perhaps a service for frequent users of transport can be set up particularly to common destinations such as University (Person with a physical disability).

Other suggestions related to the premises for persons with Visual Disability namely Spero. Here it was claimed that the fact that it was on the third floor with a small lift and very irregular stairs, could present itself as a fire hazard (Visual Disability Organization).

Another point of contention was the fact persons who are visually impaired are forced to make known their vote in front of politically biased district commissioners. A query was brought about relating to the 'trusted friend' institution. Such a person would take an oath and would be allowed in the presence of one commissioner. This, it was claimed, was the case with 43 other countries of the European Union. Forcing visually impaired persons to vote in front of everyone leads to great humiliation and possibly social consequences if their vote were to be known (Visual Disability Organization).

Queries were also raised on the reason why the REACH centre was scrapped, particularly as the Spero Centre was full. Additionally, questions were raised relating to the age limit of 60 to benefit from services within Aġenzija Sapport. It was held that revising this policy and creating the possibilities to make reasonable exceptions was the way forward (Visual Disability Organization).

4.6 CONCLUSION

In light of the findings discussed above, Table 4.1 below represents the pressing themes emerging and the evidence to support such claims:

Table 3: Comprehensive presentation of findings

Theme	Statements	Outcome
Disruption of routine	"From a very busy schedule everything had to be stopped. I like my schedule. All the plans were gone. Covid-19 was a very huge problem" (Person on the autism spectrum). "The transition was very difficult in the beginning but being prepared ahead of time I would have made sure that I have a schedule ready. I had to find my way as I went along, that was a struggle. After a month we were on schedule." (Parent 3)	The loss of routine was particularly onerous on persons with disability and their family.
Impact on Education	"Initially the child was happy not to go to school, after a few weeks the child got bored." (Parent 1) "I missed school the most. I missed my friends and my teachers" (Person on the autism spectrum) They provided the same service to every situation but knowing [child's] difficulty and because they have a full time LSE with them at school, [...] it would have made sense to give her a couple of hours a day of tuition one-to-one." (Parent 3) "During Covid there was no learning support for these kids as they did not have access to a braille machine. An agreement with government to have them buy their braille machine fizzled out" (Visual disability organization) "Covid may have opened new ways of communicating and educating persons on the spectrum." (Parent 3)	The adaptation of educational services was the difference between children improving during Covid-19 or losing progress they had made before.

Theme	Statements	Outcome
Impact of restrictive measures	“We all had to stay at home and all the dynamics changed and we had to adapt to this new life that was imposed on us.” (Parent 3) “[Covid-19] created a sense of loneliness and abandonment. These are very complex problems. Each case is different and complex.” (Aġenzija Sapport) “Visits stopped from the family, my sister’s son had a baby. I made a vow to saint [Name of Saint] so that the virus passes. I wanted to give a present I bought for my nephew’s baby.” (Person with an intellectual disability). “The consultant cleared me to go home and the physio did not clear me as I was not in an advanced enough stage in the therapy.” (Person with a physical impairment)	Restrictions, social distancing and social isolation increased feelings of loneliness.
Psychological impact on persons with disability	“Some residents who could not meet their family were hurting, those who communicated showed their sadness.” (Carer of person with an intellectual disability) “[There was] a huge sense of uncertainty and frustration even from persons with disabilities themselves.” (Carer of person with an intellectual disability) “Persons with visual impairment had no one to communicate with, they only had their radio and this was very painful, you can’t see anything but have to stay inside.” (Visual Disability Organization) “In lock down I was afraid of being fired because I was afraid that management does not see me working. I kept on working and did not take a break.” (Person with mental illness) “It is important that I occupy my time and that I stay on the go [...]. People speak less in my mind, when I am passive I struggle more.” (Person with a mental illness) “The timing was horrendous, and I was very unfortunate because before I was registering a big amount of improvement in my life.” (Person with a physical impairment)	The pandemic and restrictive measures brought about negative feelings of sadness, frustration, uncertainty and fear. In cases when individuals suffered from a mental illness, the psychological impact was greatly felt.

Theme	Statements	Outcome
Impact on the family	“It was very time consuming and I had to step away from other responsibilities.” (Parent 3) “Families were tired, frustrated and afraid and this changed reactions [towards persons with disabilities].” (Aġenzija Sapport) “Parents had no idea how to keep children entertained and calm under limitations currently available to them” (CRPD) “Normally we celebrate birthdays as a family, this year we did not , maybe a telephone call. You feel the difference living alone and you feel it more [...]. Human being is a social animal and losing contact with people was very tough.” (Person with a visual impairment)	The spread of the virus led to no family visitations in residential homes, and more caring responsibilities in cases where the person with disability lived with their parents; hindering their work life and leaving parents feeling that their needs were not met.
Secondary and unforeseen effects of Covid-19 Restrictive Measures	“Child cannot put on a mask and therefore was not allowed in shops. [The] child does not understand.” (Parent 1) “Everything that changes is met with resistance.” (Parent 3) “Is it worth it to use public transport, now that they may endanger my life?” (Person with a physical impairment)	Measures taken in response to the spread of Covid-19 showed that there was little consideration or no consideration on how measures would impact persons with disability.
Transition out of restrictive measures	“They love staying at home, so having them stay at home is no problem but taking them back out was a problem. If you keep them at home they’re happy. Home is a safe place, they will complain everywhere.” (Parent 3) “[When I went back to work, at the] office I was more anxious that I could get infected, particularly with numbers going back up [...]. No one comes to the office I work in with a mask.” (Person with a mental illness) “[The] child was so happy coming out of lockdown that actually looked forward to going to hairdressers when before this was problematic, now the child sat in the seat on their own.” (Parent 1)	Transitioning back to routine, hence further changes when one would have resettled into their new routine, caused different reactions.

Theme	Statements	Outcome
Anticipated effects of restrictive measures during Covid-19	N/A	The effects of Covid-19, particularly of the restrictive measures are still to be fully appreciated; yet, it is evident that the issue of shortage of staff needed to be addressed in case restrictive measures were to be introduced again.
Policies relating to Persons With Disability	“At the start of the panic in implementing things, the disability sector was left out of the equation which did not make sense as persons with disability are some of the most vulnerable in society.” (CRPD) “… the 15 days quarantine had a very bad impact on the child [...]. We phoned 111 and asked for an exception to go out with the car for a drive as the child could not cope but this was rejected because that was the policy, unlike in [Country] and England where exceptions were made.” (Parent 1) “Lockdown should make exceptions for persons with disability.” (Parent 1) “People were overlooked because we were in survival mode.” (SCSA)	Representatives of the disability sector were left out of discussions, and therefore exceptions to cater for the needs of persons with disability was not considered. Evidently stakeholders were unprepared for the restrictive measures that needs to be taken.
The Experience of Persons with Disability with services	“Services were stopped to protect service providers and didn’t see people for days. This was a knee jerk reaction and persons with a disability panicked.” (CRPD) “The transition was slow and inconsistent.” (Parent 2) “The level of service is still dependent on the commitment of the individual and is not guaranteed all throughout.” (Parent 2) “I was getting momentum and had my goals, I needed professional help and guidance.” (Person with a physical impairment).	The instance stop and inconsistencies in service provision had various implications on persons with disability.

Theme	Statements	Outcome
Service providers as employers	"Management had to balance between users and workers." (Aġenzija Sapport)	With Covid-19 increasing anxiety and fear amongst the general population, front liners and their families were also influenced. This led to further managerial challenges for the service providers as employers. A number of services were put on hold, others shifted online, whereas only two new services were introduced by the interviewed disability stakeholders: meals on wheels, and self-care webinars.

Theme	Statements	Outcome
Broader and Underlying Issues within the Disability Sector	"You are only aware of disability issues if you have a disability or if someone in your family with disability issues." (CRPD) "There is a lack of empathy and thought from leaders who do not consider how small things affect the lives of persons with disability." (Person with a physical impairment) "We say that we care and respect people with disability but it's not true, there is no respect for persons with disability." (Visual Disability Organization) "Covid did not affect everyone equally, for those who were well settled, had done their initial grieving and were well into the system, coping was not impossible but for those who were still out of the system and coming to terms emotionally and psychologically with the impact of a person with disability in their family, they struggled a lot." (Parent 2) "[The] parent has to push for things to get done, you have to be the manager of the services." (Parent 2) "A parent needs to be proactive, but they shouldn't be the ones that have to email and phone themselves." (Parent 2) "With disability, one has to be very assertive." (Person with a visual impairment)	Concerns about the lack of awareness, empathy and inequality, as well as the constant struggle to receive support in the disability sector were raised.

In the following section, a number of evidence-based recommendations are listed to enable a more positive response to the Covid-19 pandemic for persons with disability.

Recommendations

5. RECOMMENDATIONS

1. **Provide psychological support for persons with disability**
   The pandemic has had a major impact on the mental wellbeing of society in general, including persons with disability. It is therefore imperative that specialised psychological services are provided to cater for the needs of persons with a disability.

2. **Provide emotional support for parents and family members of persons with disability**
   Parents and family members of persons with disability require additional support to give the care and support to the person with disability within their family, especially when respite services, schools and day centers cannot function due to restrictive measures.

3. **Provide training for parents and family members of persons with disability who struggle with dealing with challenging behaviour.**
   The findings presented above show that when their children are out of schooling and not receiving support community services, parents and informal carers of persons with disability struggle with dealing with challenging behaviour. This therefore calls for adequate tailor made training for such carers.

4. **Provide training to front line professionals who interact with persons with disability and their families on questioning techniques.**
   A discrepancy in communication was noted throughout the research that meant that families did not articulate their needs sufficiently to service providers and service providers did not know how to ask the right questions. Providing this training will ensure that front liner professionals have the required skills to elicit the needs of families.

5. **Enhance awareness amongst decision-makers.**
   Provide information sessions to inform politicians, policy-makers and decision-makers responsible for mainstream services, on the challenges and stereotypes faced by persons with a disability, and their rights.

6. **Ensure fair representation of persons with disability across services.**
   Enhance the representation and active participation of persons with a disability for consultation purposes focused not solely on services provided for persons with a disability, but especially mainstream services.

7. **Persons with disabilities of schooling age who are followed by LSE's to be offered a tailored program**
   Throughout the research it was noted that schools did not tailor their online teaching to cater for persons with disabilities. While creating tailored online programs will undoubtedly tax school resources, these bespoke lessons should involve the LSE that is paired with the student. Schools cannot guarantee a quality education, even during restrictive measures, if there are no tailored online lessons.

8. **Create a system that categorizes persons receiving treatments and therapies according to the urgency that these are required.**
   Throughout the restrictive measures, services were stopped completely and resumed slowly through digital channels. This was prejudicial to certain persons with disability who were at very delicate junctures. Creating a framework within which services being currently delivered are prioritized according to need and continuing to service the most severe or critical cases is of great importance.

9. **Create a structure where urgent and serious cases continue to receive treatment.**
   Based on the framework suggested in the previous recommendation, serious and urgent cases may be highly prejudiced if treatment is discontinued during restrictive

measures. To counter this harm, a list of basic and essential services ought to be set up in a manner that is compliant with social distancing but that guarantees continuous delivery of these services. This might require additional logistical preparations as well as financial compensation to frontline professionals who will be required to man these services.

10. **Carry out a complete IT overhaul of systems and operations audit.**
    Restrictive measures provided an opportunity to explore how services can be provided online as well as to assess the readiness of the IT infrastructure. Thorough operational analyses should be carried out to ensure that unnecessary bureaucracy is reduced as a matter of generic good policy but also to see what can be shifted online, and what logistical and technical setups are required to do so.

11. **Ensure adequate logistical provision of IT equipment**
    The strong demand of IT equipment throughout the restrictive measures highlighted a lack of equipment available at hand as well as the limitations of dated equipment. Given that blended service provision will be the new normal for the short to medium term, ensuring adequate supplies of quality IT equipment is imperative to ensure quality service provision.

12. **Provide training opportunities for persons with disabilities and their families to use IT communication platforms.**
    While most people have access to the internet through a mobile device or laptop, some may not have the skills or knowledge to use such devices to their full potential. Providing training will facilitate the job of professionals who will find communicating with persons with disability and their families easier.

13. **Provide training opportunities to staff and service providers on how new technologies can be incorporated into service provision.**
    While it is assumed that all professionals involved in service delivery have a basic grasp of the use of communication technologies, shifting to a new paradigm wherein some of the pre-Covid 19 face-to-face work carried out can now be done online requires additional upskilling.

14. **Provide training to management on AGILE decision making.**
    Throughout the restrictive measures, it was clear that a number of services found the massive change difficult to come to terms with, even in the relatively harmless and mundane aspects of the new situation. Training in certain project management methodologies such as AGILE, will allow management to be able to deal with uncertainty and change in a quick, coherent and effective manner.

15. **Review and remove unnecessary bureaucratic processes.**
    While this recommendation should occur even without a pandemic, Covid-19 has additionally demonstrated the harm being done by unnecessarily complicated and Kafkaesque bureaucratic procedures. A thorough review of all bureaucratic procedures, to truly make human service organizations welcoming, helpful and easy to access is strongly required.

16. **Review policies in light of Covid-19 exigencies.**
    All standard operating procedures and policies require that they are analysed with a fine-tooth comb to ensure that they are valid and fit-for-purpose in the light of Covid-19 exigencies. Policies that require one to remain in hospital, even at the cost of imperiling one's life or otherwise lose access to outpatient services is a prime example of a policy that may have worked pre-pandemic but currently ensures unnecessary misery and anxiety as well as potential fatality if Covid-19 is contracted.

17. **Enforce recommendations 10 - 16 by creating a set of standards and operating procedures that service providers must orient towards during any form of restrictive measures arising from emergency situations.**
    Without external checks and balances, well-meaning services will most likely not complete the previously mentioned transition within a timely manner. Since it is being accepted that restrictive measures are part of a new norm all services must adapt to, a set of standards and criteria must be adopted for services to adhere to. This will also contribute towards ensuring that service provision is of a high level throughout instead of depending on luck of the draw of which professional is involved.

    Standards and operating procedures for emergency situations within mainstream services should also cater for the persons with disability. Planning ahead would safeguard the rights of persons with disability and a smooth transition in such emergencies.
18. **Ensure consistent service provision all throughout each service.**
    One of the issues raised by participants in this report has been that service provision by individual service providers working within the same organization or department is not consistent. Certain professionals went out of their way to provide a high quality service, even at times using their private resources to do so. Others sat back during the chaos of transitioning and did not follow up to the best of their abilities. Large changes naturally mean disruption to the quality of service that is provided, but the nature of the services provided are of such great importance that large variation in the quality can highly prejudice persons with disability and their families. Standards and additional checks are required to ensure that consistent service provision even during a time of transition is the norm not the exception.
19. **Carry out an entire review of current policies to ensure that there are no policies in place that are not in line with the principles of social distancing and the new Covid-19 realities.**
    Such policies may include hospitalization policies that in light of infective potential might need to be re-written to allow patients to leave hospitals earlier, without losing access to other services.
20. **Provide free telephony and internet services particularly to people who are further isolated during the restrictive measures such as persons with a visual disability.**
21. **Second a person well-versed in disability issues in public health.**
    Given that most decisions relating to restrictive measures an officer or representative of the disability community should be permanently stationed within public health authorities. This will ensure that decisions will be catered and nuanced at source rather than going through the burdensome and cumbersome process of providing feedback on each measure.
22. **Ensure that all health policies are nuanced enough to capture the particular needs and possibilities of persons with disabilities.**
    From wearing masks to strict lockdown rules, not all persons with disabilities have the possibility of adhering to the rules and guidelines of public health. Such guidelines need to be nuanced enough to provide adequately for exceptions and to inform stakeholders and the public-at-large of such exceptions.
23. **Issue directives specifically dealing with disability issues.**
    Instead of issuing directives on various issues and inserting a footnote at the end of the document which can easily lead to not being implemented, the issuing of standalone directives regarding disability issues by public health officials will guarantee that disability policies are not ignored.

24. **Recruit more resources and personnel to deal with periods of restrictive measures.**
Throughout the interviews it was clear that prior to Covid-19 services were already stretched. This has only been exacerbated during the restrictive measures. Ensuring that entities focus on their scope and target group, and that there are enough well-trained professionals will ensure that services can cope with shifts to the way that services are provided as well as have contingency should some of the professionals need to quarantine.Carry out further research to establish the intersectoral relationship within the welfare ecosystem in supporting persons with disability throughout the pandemic.

    An intersectoral overview would present insight on the role of mainstream services, non-governmental organisations and the private sector in supporting persons with disability during such a crisis.

25. **Provide psycho-social services to support frontliners.**
Frontliners deal with their own anxiety, frustration and fears, their families' if they have caring responsibilities and provide services to others. This can be the recipe for burnout and strong feelings of being overwhelmed. Providing frontliners with professional psycho-social support over and above supervision given in-house will allow frontliners some reprieve from the at times overwhelming burdens and responsibilities they are currently facing.

26. **Provide support to the families of frontliners.**
Families of frontliners also carry the burden of the jobs members of their family have. Providing support, psycho-socially, financially and also logistically will ensure that frontliners can perform better with less worries. Additionally, should frontliners contract Covid-19 or be required to enter into quarantine, families of frontliners should be fully supported on all fronts.

27. **Engage in talks and negotiations with employer associations and Chamber of Commerce.**
The impact of Covid-19 on the economy is undeniable, however this cannot be used as an excuse to nullify years of campaigning and advocacy by the disability community to participate in employment. Representatives of the disability community should meet with various sectors and employers to ensure that all redundancy is proportionate, required, justifiable and non-discriminatory.

28. **Provide support to persons with disability who are afraid of losing their jobs due to the Covid economy.**
Support ought to be provided to persons with disability who are currently fearing that they might lose their job. Information about employment rights, help to transition into another job if redundancy is unavoidable as well as emotional support throughout this difficult time should be provided to such persons.

29. **Carry out further research to establish the intersectoral relationship within the welfare ecosystem in supporting persons with disability throughout the pandemic.**
An intersectoral overview would present insight on the role of mainstream services, non-governmental organisations and the private sector in supporting persons with disability during such a crisis.

30. **Carry out a more comprehensive mixed-methods comparative study in a few months time to assess improvement or otherwise in the field.**
To gather feedback and ensure that standards are being adhered to, a follow-up study ought to be scheduled to monitor changes in the field.

Conclusion

The Covid-19 restrictive measures provided challenges on many fronts to all stakeholders within the disability sector. Services were stretched and had to adapt to ever-changing circumstances and directives from SCSA with caregivers required to take up the slack that closure in services caused. Persons with disability bore the brunt of the restrictive measures with impacts that ranged from psychological , educational, health, access to services as well as employment.

One could be tempted to read this report and look at the impacts and perspectives in a piece-meal approach attempting to problematize discourse and issue recommendations and actionable goals, yet this would be a missed opportunity to reflect further on systemic issues characterizing the disability sector. The lack of nuance in public health policies and mainstream services that impacted persons with disabilities and their caregivers disproportionately indicates that at best a lack of awareness and integration of disability perspectives into mainstream policymaking. At worst, they indicate a casual disregard or de-prioritization of persons with disability. A prime example of this policy in action can be seen when personnel resources from Aġenzija Sapport were diverted to helplines for another target group within the Ministry for the Family, Children's Rights and Social Solidarity. One questions whether the personnel "lent" had the required expertise to carry out such duties, given fundamental differences between the disability sector and the elderly sector. This seems to suggest that the needs, issues and subsequent expertise required to provide services for different marginalized identities are not well understood and are at times grouped together not out of a literature informed understanding and praxis but mere administrative convenience. Additionally, diverting resources from what is, an allegedly understaffed-in-normal-circumstances agency, throughout a time of crisis and great change highlights the lack of priority given to the disability sector. This is compounded by the reticence to shift services online which could benefit from such a migration, with management citing lack of IT policies as being to blame. While it would be difficult to ascribe the resistance to change and lack of agile practices as being merely the product of de-prioritization of the disability sector, the severe dependence of persons with disability on these services, have the same outcome, namely that persons with disability are severely undermined in the enjoyment of basic rights and services, thereby further contributing to their "vulnerability".

Tackling the issue of vulnerability creates a multi-faceted issue, given that as stated earlier it is not an unproblematic construct and has been used as stated earlier to justify the deaths of the elderly and the immuno-compromised. However, the callous application of the term often forces persons with disability into a relationship of dependency. On the one hand, persons with disability genuinely require the additional protection and nuanced treatment that is only possible to beneficiaries termed as vulnerable, yet on the other hand persons with disability are keenly aware that such a term is used to deny them the opportunity to be considered as the modern humanistic subject, namely as bounded, rational and capable of making their own decisions (Goodley & Runswick-Cole, 2016). Additionally, persons with disability are also cognizant that the term vulnerability could be used to normalize their infection and subsequent death. Such a choice is the very definition of a Hobson's choice and does not correspond to the commitment to social justice and equity embodied by the UNCRPD, which the Maltese state has ratified.

At the very basis of all these structural processes lies, what in the opinion of the report writers is the greatest evil of all, ignorance of disability issues. The minority status of disability ensures that it rarely features in the thoughts, considerations and knowledge of politicians and policymakers. While the recommendations made in this report can mitigate some of the worst impacts of Covid-19, discussions on the stark structural issues faced by the disability sector can only initiate when decision makers have at least a working understanding of the broad complexity of disability issues. Failure to educate and bring awareness will constrain the disability sector to cyclical processes, instead of progressing towards a strategic dismantlement of oppressive structures that are made worse when emergencies or crises such as the Covid-19 pandemic arise.

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