



The Impact of Covid-19 Public Health Policies on Persons with Disability and their Caregivers in Malta

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Abstract

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”. The spread of Covid-19 led to social isolation, distancing and a number of restrictive measures in Malta. The aim of this paper is to analyse the impact of Covid-19 and the subsequent restrictive measures on persons with disability and their caregivers and families in Malta. Using thematic analysis, the study found that a variety of impacts ranging from a sense of isolation, lack of essential services being provided, additional difficulties encountered at the place of work and education and measures that were not sufficiently tailored for persons with disability issued by public health authorities. Underlying the additional difficulties brought about by Covid-19, structural difficulties to access essential services as well as ignorance from policy makers and politicians and the added “vulnerable-ization” of persons with disabilities were found to be highly impacting factors that pervade the experience of persons with disabilities and their caregivers.

Keywords: Covid-19; Public Health Policies; Disability; Caregivers; Malta

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”. 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 yet taking inconsideration 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, 2021). To this date (4th March, 2021), the total number of cases added up to 23,588, with 20,135 persons recovered, and a total of 325 deaths. No official lockdown was announced in Malta, until the date of writing February 11, 2021 yet within a few days from the first cases, the Government of Malta announced a number of restrictive measures including, 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).

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 Superintendent of Public Health 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 of the pandemic will not necessarily impact different sectors of society equally or to the same degree and may affect disproportionately 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. Preliminary research indicates that persons with disability has restricted access to essential services (Armitage and Nellum, 2020), placed them at greater risk for developing more severe complications from Covid-19 (World Health Organization, 2020) and exposed them to greater stress and negative emotions (Umucu and Lee, 2020). More in-depth analysis on the impact of Covid-19 on persons with disability is required to gain further insight into their needs and create policies that cater to these evolving and complex sector (Embregts et., 2020)

The aim of this paper is to analyse the impact of Covid-19 and the subsequent restrictive measures on persons with disability and their caregivers and families in Malta. Given the ongoing near daily developments the paper will look at the impact of Covid-19 on the disability sector in the period between March 2020 and July 2019.

Method

Participants

A sample of 12 participants was used that included persons with disability (n=5), informal carers (n=3), an individual representing a non-governmental organisation (NGO (n=1)) and representatives' from entities in the disability sector (n=3). 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), the commission set up to enforce the United Nations Convention on the Rights for Persons with Disabilities; Aġenzija Support, the national service provider for persons with disability; and the Social Care Standards Authority, the authority empowered to set and maintain service provision for various social sectors.

Procedure

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. 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. Entities were contacted through email and requested to send a representative to attend the interview. Due to Covid-19 exigencies all interviews were carried out online. All participants voluntarily agreed to take part in this qualitative study and provided informed consent.

Interview

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. Participants were asked the following questions: 1. Can you describe your typical day prior to Covid-19? 2. How has this changed due to Covid-19? 3. Has there been any disruption with regards to services? 4. Are you making use of any new services/ adaptations made due to Covid-19? 5. How are you feeling because of Covid-19? 6. How can you be better supported at the moment? 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? 8. As a person with a disability, how do you want your life to be improved? 9. Any additional comments? The interview guide can be requested from the authors.

Data Analysis

Inductive thematic analysis was used to identify themes within the experiences of the various participants (Braun and Clarke 2006). This follows a constructivist approach. One of the authors (AC) coded the data and reviewed the codes with the other two authors (SPG and AA). Disagreements were discussed amongst the authors and codes that were most pertinent were kept. The first author (AC) proceeded to create themes with the codes and these were reviewed by (SPG and AA) to ensure that the themes could be easily distinguished from one another and that each theme was coherent. The themes were named and a narrative structure was provided by the first author (AC).

Results

1. Coping with Covid-19

1.1 Disruption to Routine

“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 to 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)

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).

¹ These activities have been removed for anonymization purposes

“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 home-schooling at great personal cost (Parent 3), while others chose services provided by NGOs for a short time

“Inspire [A voluntary organization that provides services to persons with disabilities] 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-19 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).

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 (Agenzija Sapport, Person with a visual impairment).

For persons with disability who did not live with their families, the separation could be heart-breaking (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 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).

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).

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-19 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 the Covid-19 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)

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)

2. Engaging with External Entities

2.1 Person's with Disability's experience with National Policies

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)

2.2 Person's with Disability's experience with National 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)

“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, 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 time constrained interventions (Person with a physical impairment).

The first issue 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 [Child Development Assessment Unit], the parent 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).

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).

3. 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.

Discussion

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 throughout the interview it transpired that certain personnel resources from Aġenzija Sapport were diverted to helplines for the elderly 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 authors is the greatest concern 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 some of the issues in this article may be mitigated and thereby shield persons with disabilities and their families from 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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