COVID-19 and families with children on the Autism spectrum

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A dissertation submitted in partial fulfilment of the requirements of the

Master of Arts in Disability Studies

Department of Disability Studies

Faculty for Social Wellbeing

University of Malta

April 2021

To my husband Leonard, my daughters Martina and Louisa, who
constantly offer me love and support in everything I do.

To my late son Nicholas, although you can't be seen or heard,
your presence is felt every step of the way.

To disability activists who advocate against any discrimination
and oppression.

ACKNOWLEDGEMENTS

This thesis became a reality with the continuous support of many.

First of all, I would like to express my thanks to my supervisor Dr Anne-Marie Callus, who encouraged me to pursue this project. I am entirely indebted for her understanding, wisdom, patience, enthusiasm, and encouragement to push me farther than I thought I could go. I truly enjoyed working in a research environment that stimulates original thinking and initiative.

I want to thank the Department of Disability Studies staff and those lecturers who inspired me throughout these past years during my studies.

This study would not have been made possible without the participation of parents of children with autism. I am genuinely thankful for their time and commitment whilst sharing their family experiences.

Special thanks go to my husband and daughters for their continuous support and daily encouragement, for helping me survive the stress from this year and for not letting me give up.

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LIST OF ABBREVIATIONS

ASD	Autism Spectrum Disorder
CCP	Core Curriculum Programme
CDAU	Child Development Assessment Unit
CRPD	Convention for the Rights of Persons with Disabilities
FREC	Faculty Research Ethics Committee
IEP	Individualized Education Program
INCO	Inclusive Education Coordinator
LSE	Learning Support Educator
MEDE	Ministry for Education and Employment
MOU	Memorandum of Understanding
MUT	Malta Union of Teachers
NGO	Non-governmental Organization
SMT	Senior Management Team

ABSTRACT

This study explored the topic of COVID-19 and families of children with autism. The objective was to document and promote these families' voice during the onset of the pandemic and the partial lockdown, with a specific focus on education. The first aim was to explore how COVID-19 has affected children on the autism spectrum and their families. The second aim was to study how COVID-19 has impacted children's education on the autism spectrum in its broadest sense.

This qualitative research was carried out using online one-to-one interviews with parents of children with autism. During the interviews, the focus was on the narrative of the families' experiences and stories and their children with autism as seen through the social model's lens whilst keeping the research as emancipatory as possible. Eight parents were recruited to participate in the study. These participants accepted to be contacted again in February/March 2021 to participate in a short follow-up interview to update the circumstances. The data generated were analysed through the thematic analysis approach, where themes and subthemes were identified.

The findings were insightful as they portrayed the daily challenges the families of children with autism have experienced since the onset of COVID-19. These past months were not easy for the families. They found it hard to juggle family needs, including the shift to online schooling, the evaporation of support, reaching a work-life balance, all whilst adapting to a new normal. Contrastingly, some families managed to bond better with their children while the children developed new hobbies. Going through the parents' narratives, it is evident that some of the parents were already encountering difficulties and challenges before the onset of the pandemic, which COVID-19 compounded.

Keywords: COVID-19, Children with Autism, Disability, Education, Inclusion, New Normal

CHAPTER 1

"Inclusion is not bringing people into what already exists; it is making a new space, a better space for everyone."

George Dei

Background

For as long as I can remember, schools were always open from September till the end of June. This year marked a different scenario, as the COVID-19 pandemic reached our island at the beginning of March 2020. Since the COVID-19 cases were on the increase, the Superintendence of Public Health announced school closure on national television, and this announcement was quickly shared via social media (Government of Malta, 2020). The news travelled fast, parents were scared, and suddenly the school where I worked was inundated with panicked parents who came to pick up their children. On Thursday, 12th March 2020, the school day finished quite abruptly. Everyone at school was speechless. The educators were not given any directions. This event had never happened before, and no one was prepared. No plan was in place in the eventuality of school closure. At first, the school was only closed till the Easter holidays, which were only three weeks away. Eventually, another announcement was made that schools remained closed for the rest of the scholastic year (DOI, 2020).

Most educators tried to set up communication throughout those weeks, either with their students or through their parents or guardians. Since I am an early-years' teacher, I already had a closed Facebook group which I used to communicate daily with the caregivers before the onset of the pandemic. This group initially served to upload homework, daily photos and other notices to the caregivers. Hence, I started using this closed group to communicate with the caregivers. It was not easy getting online. All I had at home was the laptop provided by the Ministry of Education.

Furthermore, I am not tech-savvy, and hence I was putting in all my effort to get through to my students at the expense of not having enough time for my family and perusing my studies. Juggling my way through my job was not easy, as not all the caregivers were active, and some of the children just vanished as days went by. Directly contacting the young students is impossible in the early years as no tablet is provided, and the school student emails were not used at that time. The struggle was real, and as the days went by, life was getting more hectic. Days were getting longer due to work-related preparations; emails and messages were sent any time of day.

Apart from being a teacher, I am a mother of two girls. My youngest daughter and I have unilateral hearing loss. Wearing a hearing aid has benefits as it aids hearing, but the sounds in the surrounding ambience is always challenging as the aid picks up other background noises. Due to my hearing experience, I often pondered the school ambience's inclusivity and how minor adjustments can make a big difference in someone's life. Since hearing impairment is an invisible disability, it is very often overlooked. Before I embarked on my Master of Arts in Disability Studies, I always wondered how children with hidden disabilities feel at school. At that time, I was not aware of the social model of disability, but I always felt that these challenges could be mitigated with some adjustments. Throughout my teaching years, I taught various children with different needs. COVID-19 brought our daily routines to a halt, and no one was expecting this major upheaval. People found it difficult to adjust to this sudden change and adjust to new routines out of the blue. This made me reflect on children with autism and their families. Autism support practitioners always highlight the importance of establishing a daily routine accompanied by a visual activity schedule (e.g. Alderson, 2008; Knight et al., 2014; Pierce et al., 2013).

As a reflective practitioner, I wondered how this sudden change was affecting these children and their families. I wanted to know more. I tried to research to see how and if these families are adapting, any challenges they encountered, and the services they were offered in these unprecedented times. Apart from being an early-years' teacher, in this study, I position myself as a person with a hidden disability. As mentioned earlier, I have severe hearing loss, and I use a hearing aid. Hidden disabilities are less visible disabilities to outside observers. These disabilities are less visual than other physical, sensory or mobility impairments and can often lead to misunderstandings, false perceptions and conclusions (e.g. Conn, 2016; Cook & Clement, 2019; Wolf, 2001). There are several forms of hidden disabilities, and autism can be one of them (e.g. Canavan, 2014; Conn, 2016; Evans & Shanley, 2011).

Moreover, I am a mother in a household of four who has to balance work, study, and motherhood in these unprecedented times. Striving to ascertain a new routine whilst giving my full potential in different roles, I could not help but relate my situation to that of the parents of children with autism. They also had to balance work and parenthood in these difficult times. Finally, I position myself as a student reading for a Master of Arts in Disability Studies. To sum it all up, working with children with different abilities and having a hidden disability motivated me to further my studies in this field. I am now more aware of how society views disability. With the knowledge gained throughout these past years, I will do my utmost to embrace and advocate for implementing the social model of disability throughout my teaching years.

COVID-19

The COVID-19 pandemic was first identified in December 2019 in Wuhan, China. The outbreak was declared a pandemic in March 2020 (World Health Organization, 2020). To inhibit the spread of the COVID-19 pandemic, all Malta schools were closed on 13th March 2020 (Times of Malta, 2020). This was one of the many measures taken to slow down the spread. Some of the other measures taken included the cancellation of mass events, and football leagues were played behind closed doors. As the coronavirus (COVID-19) pandemic is unfolding rapidly in our lives, it is causing widespread concern, fear, stress and uncertainty, all of which are natural and normal reactions to the changing and uncertain situation that everyone is finding themselves in.

COVID-19 on Maltese Shore and its Effect on Education

Back at the beginning of March 2020, Malta experienced the first case of COVID-19. Although it was apparent what Malta was about to experience, it was oblivious that no educational plan was put in place (Grech & Grech, 2020). As mentioned in the introductory chapter, schools were suddenly closed on 12th March 2020. This closure meant that educational institutions and families had to work together so the transition to a remote online education as swiftly and quickly as possible (Farrugia & Busuttil, 2020). Apart from the school closure, various measures were being announced every day to combat the pandemic. On 28th March 2020, it was announced that all educational institutions and schools were to remain closed until the end of the academic year and that teaching was to be continued online. Throughout the lockdown period, one could read reports and social media posts about different education experiences (Busuttil & Farrugia, 2020). Some educators tried to set up platforms to connect with their students. Others just posted online material with no contact or explanation, whilst others just vanished from the system.

The Ministry of Education and Employment (MEDE) set up a working group to strengthen online teaching and learning for the third term of the academic year. This group was made from representatives of the state, church and independent schools, and the Malta Union of Teachers (MUT). They worked on several points that were agreed upon by all the stakeholders and were later published in a circular dated 6th April 2020 (DCLE, 2020b). The teachers were free to use their discretion whether to give real live online teaching or any other form of online education. The main objective was to "cover the most important aspects of the respective syllabi and render themselves best to online modes of teaching and learning" (DCLE, 2020a).

End of the First COVID-19 Wave

By the end of June 2020, the cases were decreasing substantially and eventually, the country had some days with no new positive cases. Malta was close to becoming COVID-19 free by mid-July 2020 when only single figure numbers of active cases were recorded. The restrictions imposed throughout the first weeks of the pandemic were being lifted, shops, bars, restaurants and the airport were reopened. To prevent the spread of COVID-19, the mitigation measures of social distancing, the use of masks or visors and hand sanitisers were enforced. It was effective to reduce the transmission in the community.

Protocols for the New Scholastic Year

As September 2020 approached, new protocols were drawn out for the reopening of schools. These protocols set out measures to be taken by each school to safeguard every student and educators' health. Details of the guidelines were given by the Superintendent of Public Health and the Ministry Permanent Secretary. The schools' guidelines were to keep to the social distance of 1.5 m, and children are to be held in the same bubble, use of masks, temperature checks and hand sanitisers, isolation rooms and records for contact tracing must be kept. Doors and windows should be kept open at all times. After several disputes with the MUT, an agreement with the Ministry of Education was reached. All children were back at school by 14th October 2020. On 20th October 2020, a Memorandum of Understanding (MOU) with The Malta Foundation for the Wellbeing of Society was signed. This MOU aims to support vulnerable students, students with health problems or with health concerns in their immediate family, to follow online learning from home. Moreover, it highlighted how parents or guardians should be "equipped with the necessary knowledge and means to provide a complete education for their dependents at these trying times" (The Malta Chamber, 2020).

Aims of the Study

In this study, I intend to provide insight into the effects that COVID-19 brought about in the lives of families with children with autism. Every household has routines. As mentioned above, families of children with autism find routines useful to help children adapt, participate and know what to expect. Primarily, in this study, I will delve deeply into the experiences of parents of children with autism in the current context. Secondly, it analyses the effects of the COVID-19 pandemic on the families and children with autism. Thirdly, it explores and identifies the types and quality of support these families are receiving. This study originated out of a perceived need for empirical data related to this new reality. The pandemic was unfolding, and social distancing was set to be in place for quite a while.

The Research Questions

Hence, this research aims to document and promote the voice of families of children with autism during the COVID-19 pandemic. Moreover, to offer an analysis of these families' experiences during the partial lockdown, with a specific focus on education. Education is taken in the broadest sense, including curricular and extracurricular activities.

My research questions will explore:

a) How has COVID-19 affected children on the autism spectrum and their families?
  i. How are the parents explaining the new reality to their child?
  ii. To what extent are daily routines important for the child and their family?
  iii. In what ways have family routines changed due to COVID-19?
  iv. In what ways has social distancing affected the relationship between the child and members of the extended family?

b) How has COVID-19 affected the education of children on the autism spectrum?
  i. What support are children with autism receiving to continue with their lessons with the rest of their peers?

ii. What support has the family received to be able to home-school the child with autism?

iii. What impact has COVID-19 had on extra-curricular activities in which the child with autism was involved?

Conceptual Framework

My study explores the effects of COVID-19 on families of children with autism and seeks to uncover the reality these families had to face in these unprecedented times. Through this qualitative research, I aspire to capture aspects of the social world by using methods that do not rely on numbers as the unit of analysis. King, Horrocks, and Brooks (2018) highlight that "qualitative interviewing situates the methodology and method deliberately within the qualitative domain where a broad and holistic approach is taken to the study of social phenomena" (p 7). Hence this study was conducted through one-to-one online interviews with one of the family caregivers of a child with autism. Qualitative approaches are generally founded upon theoretical perspectives rooted in interpretivism. Interpretative research allows the description of the social world by offering an account of specific social settings, processes or relationships (Thanh & Thanh, 2015). Since my focus for this research was to find out how people feel about the world and make sense of their lives from their particular vantage points, qualitative interviewing fits nicely as conversing with people enabled me to listen to their shared experiences and understanding given this pandemic. These interviews allowed me to explore and follow the interpretive paradigm where I constructed and interpreted the findings from the generated data. This method is discussed in further detail in chapter 3, the methodological framework of this qualitative study. The social model of disability was my conceptual framework. The narratives were compared, and the social, environmental and cultural barriers that families of children with autism encountered during the onset of the pandemic were elicited.

Structure of the Study

Based on the research questions defined above, the literature review in chapter 2 focuses on an overview of autism, the importance of daily routines, parent's fears, the importance of support, and the sudden change COVID-19 brought about. Chapter 3 describes the conceptual framework and research methodology used for this study, the participants, the method used for data collection and the tools used. This chapter also includes a discussion on how the data generated were analysed. Chapter 4 presents the analyses and findings of the research, followed by a discussion of the results. Chapter 5 concludes this research study with a summary of the main findings. This study's strengths and limitations are put forward, along with suggestions for improvement and recommendations for future research.

CHAPTER 2

The COVID -19 pandemic brought about a drastic change in our lifestyle, and we adapted to a new 'normality' (Penkler et al. 2020). This chapter aimed to discuss the impact COVID-19 had on families with children on the autism spectrum. This dissertation started by giving a general overview of autism, the inception of the condition, the stigma, strengths, and challenges surrounding the disability. Followed by the discussion of milestones achieved in education and inclusion, the rights, legislations, empowerment of children with autism, and the healthcare system's services in parallel with the educational sector. It continued to explore what happened after school hours, the participation in extracurricular activities. Moreover, it delved into the parents' feelings and thoughts regarding their child's unknown future. Finally, this chapter explored the effects of COVID-19 on schools and services and how it impacted the families and their children with autism.

Autism

Autism spectrum disorder (ASD) is a term that comprises a spectrum of developmental disorders (Zamani Jam et al., 2018). Autism is considered a form of neurodiversity (van den Bosch et al., 2018). It affects different aspects of psychological, neurological, fine and gross motor skills, communication, difficulty building social relationships, and challenging behaviour, interests, and activities (Wainer et al., 2017; Wigston et al., 2017). People on the spectrum have strengths and also challenges, which can vary from mild to severe. Although children may be labelled with the term autism, one must acknowledge that no two children are the same, as they think and learn differently. Also, their needs and interests may differ (van den Bosch et al., 2018). Autism is a complex term to which there is no simple answer.

A Brief History of Autism

Studies about autism can be traced back to 1943 when Kanner, one of the first researchers focusing on autism, wrote the first accepted clinical paper about his observations describing the psychological features of eleven children whom he later labelled as 'autistic'. In his study, Kanner (1943) followed these children for several years and perceived autism as a biological disorder. This condition has common characteristics that vary. These children might find it hard to establish social relationships, lack socialisation, limited language use to communicate with others and a fascination for objects. On a positive note, Kanner found that their cognitive potentialities were good, such as outstanding vocabulary, remarkable memory for names and poems, and a good recollection of patterns and sequences. Similarly, in 1944 an Austrian paediatrician Hans Asperger (Asperger & Frith, 1991), published a case series about four children. In his research, he noted similar observations to Kanner's research.

Stigma, Strengths and Challenges

Throughout the following years, various researchers explored ways to define autism. In the 1950 and 60s, autism was considered a form of childhood schizophrenia and multiple treatments such as shock therapy were carried out (Ejaz, 2020; Waterhouse, 2000). In the late 1980s, there was an increased awareness of autism (Barbaresi et al., 2005).

Many people perceive television as a reflection of reality. The way minority groups such as people with disabilities are portrayed in television programmes helps to "shape the perception and reception of real individuals with disabilities" (Ejaz, 2020, p.785). However, when misrepresentations about people with disabilities are portrayed, these impact the audience's attitudes (Connor & Bejoian, 2016). The movie *Rain Man* is centred around two brothers, one of whom has autism, who discovered one another after their father's death. Levinson (1988) depicts an adult, Raymond, as an autistic savant who resided for at least 20 years in a residential institution.

Whilst this film managed to generate awareness and interest in autism by choosing to portray Raymond as an autistic savant with extraordinary math and memory abilities, the film might give the impression that all autistic persons are savants. Prochnow (2014) draws our attention to the fact that although "being a savant is real, possible aspect of having autism, it is not the norm" (p.137). Young (2012) highlights that with the movie Rain Man, "people were intrigued to learn more about autism, what people with autism think and hence it improved awareness" (p.40). Movies commonly portray people with autism as having high functioning abilities and having some type of extraordinary savant abilities. These exceptional abilities may provide audiences with false expectations and misunderstandings about autism.

The awareness about people with disabilities in the late 1980's also led to changes in the human rights sphere which also included education provision.

Education and Inclusion

More than three decades ago, UNESCO (1990) affirmed that every human being, child, youth or adult, is entitled to benefit from educational opportunities. The Salamanca Statement (UNESCO,1994) maintained that it is the child's right to receive education in inclusive schools (Urwick & Elliott, 2010) whilst it also urged educational settings to work towards the school that are inclusive to all students. December 2006 marked the adoption of the Convention for the Rights of Persons with Disabilities (CRPD) and its Optional Protocol by the United Nations, which were later signed and ratified by Malta in 2007 and 2012, respectively (Equal opportunities persons with disabilities, 2016).

The CRPD consented that people with disabilities face barriers that are socially constructed. It advocates for human diversity and human dignity (Pillay, 2014). The aim of the CRPD is that people with disabilities enjoy "full and effective participation in society on an equal basis with others" (United Nations2006:1). In 2000, the Equal Opportunities Act (Persons with Disability) was enacted in Malta (Equal opportunities persons with disabilities, 2016). This act further safeguards and gives voice and rights to people with disabilities. Recently, in 2016, Maltese legislation was passed to empower persons within the autism spectrum. This legislation sets to enable persons on the spectrum better living conditions whilst giving control for their health and well-being in society. It will also accredit their participation and inclusion in society (Standing Committee on Social Affairs of the House of Representatives, 2016).

In Malta, inclusive education policy is based on the Framework for the Education Strategy for Malta 2014-2024 (MEDE, 2014). The philosophy outlined in the National Inclusive Education Framework (MEDE, 2018) and the values promoted through the Respect for All Framework (MEDE, 2014b). The latter encompasses the four pillars presented by UNESCO (1996), which are of utmost importance for 21st-century learning. The four pillars are "Learning to know, Learning to do, Learning to live together and Learning to be" (MEDE, 2019, p.11).

A Culture of Inclusion, Building a Sense of Belonging

Inclusion goes beyond legislation and policies and depends on what happens in practice in educational settings. In an inclusive classroom, educators and learners are encouraged to work together and create a community of practice and foster a sense of belonging (de Boer et al., 2011). Riddick (2001) pointed out that some disabilities are evident; for example, visual impairment is usually apparent to an onlooker, while disabilities such as autism are not apparent. When disabilities are not so prominent, it might be difficult for others to recognise or acknowledge and make accommodations. Dodd (2005) states that children with autism have strengths and abilities, which must be identified. It is essential that "education and school structures, systems and learning methodologies must meet all learners' needs at various education levels and kinds of support" (Mweli, 2012, p. 6). Riddick (2001) argued that "although individuals may have impairments, these are only transformed into disabilities by the negative attitudes of the society they live in" (p.4). This highlights the importance of inclusive education in schools. Segregating children with disabilities from mainstream education would transform the impairment into a disability.

Reid (2019) maintains that, although meeting all the student's needs can be pretty challenging, educators should not view disabilities as a problem that belongs to the individual. Viewing disability as a problem endorses the idea that autism is a condition that needs to be treated. The social model of disability puts forward the notion that autism is an aspect of human diversity and that support and services should be in place to mediate the socially constructed barriers (Ejaz, 2020; van den Bosch et al., 2018). The social model of disability specifically "emphasises how individuals with a disability are disabled by society's failure to accommodate their particular need, thereby further disadvantaging them" (St John-Matthews et al., 2016, p.27). Adjusting teaching to an inclusive system will help the students reach their potential (Spiteri et al., 2005), and thus students with disabilities feel that they are keeping pace with their peers and not falling behind.

Autism is a broad term used to describe a group of neurodevelopmental disorders where adjustments need to be made to embrace inclusion in the educational system. Although a label such as 'autism' gives the right for accommodation, one must be vigilant that this label does not give way for the medical model to be adopted (Ho, 2004). Ho (2004) states that given the historical oppression of people with disabilities, some may not want to label their children as being disabled. A lot of misconceptions remain. Wadlington and Wadlington (2005) highlighted that some parents are hesitant to use this label as they feel that they are perceived as making up excuses for their children's poor performance. On paper, a title such as autism can help teachers as it provides an insight into the type of barrier the child is encountering (Payne & Turner, 1999). It may be that a label is significant for the not-so-evident disability, so it prevents inaccurate or harmful attributions. On the other hand, one has to keep in mind that no two children with autism are the same, and hence educators must uniquely plan accommodations according to their individual needs.

We might be presumptuous and think that, just because we know one child with autism, we know how it will manifest itself in the following child we meet. Crowley (2016) draws our attention that it is imperative to get to know the child and the child's unique needs and family. Some families may struggle to meet their own needs or the needs of their offsprings. Furthermore, there might be other circumstances such as domestic violence, poverty, drug abuse and other factors that may contribute to neglect or abuse. These situations will impact the children with disabilities as their lives are put at increased risk. Such families must be given adequate support to mitigate the stress that childhood disability might induce.

Schools and Services

In terms of support, there are a variety of services in Malta. The Child Development Assessment Unit (CDAU) coordinates a comprehensive multidisciplinary team's services to roll out an intervention plan for children between 0 to 16 years. There is a vast range of services offered, including behavioural, occupational and speech therapy, psychological and psychoeducational services, information and assistance, communication skills support, socialisation support, motor development, and support to parents and siblings (Bezzina, 2018, p.2). Moreover, there are respite services available to help the families of persons with disabilities. These services are provided either through non-governmental organizations (NGOs), such as Dar il-Kaptan (Dar il-Kaptan, 2021), or the private sector, such as Ħila (Ħila, 2016). The service providers have to follow the Social Regulatory Standards to ensure a high-quality service for the service user (Social Care Standards Authority, 2019).

In the education system, support and services are provided between 4 to 22 years of age by the Ministry for Education and Employment (MEDE). The services are offered through five resource centres. Ministry of Education, Culture Youth, and Sport (2009) also provides students with physical disabilities, complex communication needs and learning disabilities with an assessment service in assistive Technology and Augmentative and Alternative

Communication. Support in inclusive education is given through Learning Support Educators (LSE), learning support zones and nurture groups, and support teams for children with autism, hearing and/or visually impaired students. Furthermore, some NGOs offer further services for students with learning difficulties such as dyslexia and dyscalculia and outreach programs that help children with challenging behaviour (Bezzina, 2018).

Meeting the Needs of Every Student

These services provide support and advice to make schools more adaptive and inclusive in their teaching approaches. It is beneficial when the students' reports that health care providers generate are given to the educators to identify the barriers to learning and mediate accommodations (Rotter, 2014). These reports often provide valuable and doable suggestions and strategies that the educator can quickly implement to help the child in the classroom (Bowe, 2000; Bunch, 1999; Spiteri et al., 2005). In schools, an Individual Educational Programme (IEP) is drawn up every year to determine effective educational practices that will guide the educator to cater for the child's needs to access the curriculum and achieve the established goals. These goals are usually discussed and set by the team of stakeholders connected to the child's learning. This contradicts the recommendations drawn up by Spiteri et al. (2005) as in the policy, it is suggested that the stakeholders include the student as much as possible and the team of people working with them.

Including the child in these meetings will foster the idea of choice and control and promote autonomy at a young age, but these benefits are often overlooked. Shea et al. (2013) highlight that, in contrast to independence, when a child is controlled, there is no option other than to engage in an activity determined by outside pressures. Furthermore, to promote autonomy, the children should be encouraged to solve their challenges, are given reasonable choices, and their perspectives are taken into consideration. Both Article 12 of the UN Convention of the Rights of the Child (1989) and Article 7 of the UNCRPD (United Nations

General Assembly, 2006) highlight that it is the children's right to express their opinions about issues that affect them; moreover, they have the right to equal opportunities.

There are various strategies one can adopt to enhance the overall learning journey for the student. Reid (2019) explained that setting attainable goals is crucial in improving self-esteem, and it is also one of the critical aspects of successful learners. Collaboration and communication with parents and school staff are of utmost importance as this will help the teacher mitigate the child's challenges. Shakespeare and Watson (1996) presented three situations where children with disabilities are discussed. The first scenario is that people with disabilities are discussed by people without disabilities (Charlton, 1998). Furthermore, the participation of disabled children in decision-making requires further development (Cavet & Sloper, 2004). Mainly the child's right to express their view of their experiences and preferences or how they can be supported is often overlooked (Berman & MacArthur, 2017; Callus & Farrugia, 2016). Lastly that "disability is defined as a problem within a model which is individualistic and medicalised" (Robinson & Stalker, 1998, p.13).

Inclusion should be seen as an ongoing process reflected in the precise set up of the goals in the IEP. However, education should not be viewed as starting and ending within school time. Education should be taken holistically to include activities conducted after school hours and external to the school curriculum.

Extra-curricular Activities: Games, Sports and Physical Activities

Play and physical activity are two essential aspects of the overall development of the child. Games and sports offer a possible opportunity to increase children's physical activity. Daily physical activity helps prevent illnesses, enhance motor skills and the child's development (Hassani et al., 2020). During play activities, children are encouraged to develop their language, social competence, emotional control and other essential skills (Miltenberger &

Charlop, 2013). While neurotypical children will engage easily in play activities, children with autism tend to find it more challenging to engage in such structured activities.

Barriers to Engaging in Play

Physical activity is equally important for children with autism as it has "positive effects on mental and physical health in children and adolescents" (Hassani et al., 2020, p.1). Miltenberger and Charlop (2013) highlighted that "the play of children with autism tends to be less mature, complex and varied than the play displayed by school peers in the same physical area and neurotypical children" (p.41). Given the broad spectrum and the nature of the disability, it is at times particularly challenging for children with autism to take part in extracurricular activities. Difficulties with sensory integration can hamper participation because it would be difficult for them to understand what is expected. These unstructured settings may cause difficulty for children with autism as they have to read social cues, and in some leisure activities, they have to listen and remember instructions (O'Connor et al., 2000). This deficit may trigger some challenging behaviour, which results in them being side-lined from the rest of the group (Brewster & Coleyshaw, 2011).

Like all children, children with autism need access to sports and games. Physical activity in children with autism was less frequent than the neurotypical children in the general population (Hassani et al., 2020; Pan & Frey, 2006). McMahon et al. (2020) linked the lack of participation to various barriers such as "lack of inclusion, inequity, stigmatisation, non-accidental violence, maltreatment in multiple sports, and other organised physical activities" (p.1002). O'Connor et al. (2000) suggest that trainers may initially need to close an eye for inappropriate behaviour when children with autism join sports programmes. This will give them time to adjust to the new routines. Moran and Block (2010) point out that trainers might be afraid to accept children with disabilities because they lack training and are fearful that the child might get hurt. Many of the trainers are usually volunteers and have little or no experience teaching children with different abilities.

In Malta, some centres cater for people with disabilities' "cultural and leisure lives, general leisure and social activities for people with disabilities" (Bezzina, 2018, p.4). These activities are usually run by disabled people's organisations and are funded through fund-raising activities or private donations. Through these sports activities, the children improve their motor control, improve social deficits and self-efficacy (Hassani et al., 2020). The children's benefits include other essential skills such as creating schedules and routines (Jones et al., 2017). Recent research documents that sport and physical activity help address many of the challenges and barriers children with autism encounter(Jones et al., 2017; Zamani Jam et al., 2018).

Children with autism generally spend time in passive play and maladaptive behaviours as they find it quite challenging to spontaneously participate in physical activity (Hassani et al., 2020; Memari et al., 2015). Adjusting the activities to the individual child's need is a recommended strategy that will promote participation and play for children with autism. Moreover, physical activity is also beneficial as it combats comorbid conditions such as obesity. It is crucial to identify the barriers that children with autism encounter to mediate and enhance the interventions' efficacy to improve physical activity quality.

As can be seen from the above, taking care of a child with autism may take its toll, especially when barriers and lack of support are experienced. Some parents find it quite challenging to combine their daily activities and taking care of a child with a disability. Physical activity is only one façade of the difficulties faced by the parents. The following section focuses on parental reaction to disability. It presents how parents adjust to raising children with autism whilst discussing challenges their future might hold and highlighting their achievements.

Parenthood and Raising Children with Autism

"Parenting refers to the activity of nurturing, guiding, and caring for a child to maturity" (Chan & Leung, 2020, p.1517). Parenthood requires several adjustments from the couple or family. Figueiredo et al. (2018) draw our attention to the fact that the transition from being a couple to parenthood increases stress in parents' lives; it "amplifies differences within the couple, raises marital dissatisfaction and has the potential to place couples at risk for psychological problems" (p.1). The stress can be intensified when the child has additional needs, and hence one has to devote more time and effort. Brobst et al. (2009) highlighted some common themes, including the decrease in fathers' involvement in child care and more stress in the family environment. Despite the negative comments, Brobost (2009) accentuates that some parents feel that their relationship has been strengthened and enriched while supporting their child with a disability. Parents are often aware that, since they have to tend for children with a disability, they might neglect their marriage, and hence they work harder towards their marriage to keep it intense (Brobst et al., 2009).

The initial reaction to having a child with a disability might come as a shock and bring along grief. Adapting to unexpected circumstances might take a while until the parents come to terms and adjust to the new lifestyle. It is beneficial that the parents find help, support from family members and other services to help mitigate the new challenge. Undeniably the parents' concern for the child's wellbeing and for what the future holds is always on the top of the parents' minds. The issue of preparing for the future is returned to later on in this chapter.

Adapting to Unexpected Circumstances

Parents remember when they were told that their child has a disability (Hedderly et al., 2003). Transitioning to being a parent of a child with a disability may bring a grief reaction to the news. Many parents are stunned by such information about their child's expectations, and reality precipitates into a crisis reaction. It is imperative that professionals are "well prepared and trained in communication skills and confident to share bad news yet empathic enough to respond to the parents' needs" (Hedderly et al., 2003, p.31). Each family is different. Just as the spectrum varies, scattered emotions from the parents are expected to learn about their child's diagnoses. Some of the parents might be relieved that finally, they were given an answer to their child symptoms.

On a positive note, parenting a child with a disability may at times be rewarding, as it increases the feeling of "confidence, skill, assertiveness, awareness of what's important in life, awareness of the strength and importance of social relationships and empathy with people in a variety of life circumstances" (Green, 2007, p.160). On the other hand, the new circumstance where a different perception of family life comes into play may cause significant stress (Douglas et al., 2016). A child's upbringing with a disability will bring along new challenges such as sleeping patterns, physical requirements, for instance, type of clothing, struggles for feeding patterns and limited diets, and financial stress due to enrolment for various therapies (Ben-Sasson et al., 2013). Various researchers report that when bringing up a child with a disability, it is expected that parents have low self-esteem, a feeling of helplessness, resentment over excessive demands on time and the financial strains, poor physical and mental health. These challenges will trigger pressure on their marriage and are more likely to experience higher divorce rates (DePape & Lindsay, 2014; Sobsey, 2004). As the child grows older, the parent's concerns change from one stage to another. For example, when the children reach the adolescent stage, they might face different challenges such as peer groups and learning opportunities (DePape & Lindsay, 2014).

The parent's concern about their children is providing support in the present and the future as it makes a difference in parents' abilities to raise their children with autism.

Tackling the Challenges; Reaching Out

Undeniably, roping in additional support from extended family members or babysitters is very important. It provides practical and emotional support, especially when the family experiences some of the challenges mentioned earlier.

Wall (2009) draws our attention to that grandparents may lack knowledge and awareness about autism and feel unable to support their children and the grandchild with autism. Bloch and Weinstein (2009) highlight that there must be an open dialogue with the grandparents where their concerns might be addressed. An open dialogue between the parents and grandparents is suggested as it "can promote parental competence by providing the emotional, child care, and sometimes financial support that is needed" (Bloch & Weinstein, 2009, p 29). With support and information, they might learn about autism, and instead of 'fearing' the condition, they offer support and respite to the parents. It needs to be remembered that the grandparents might take longer to come to terms that the child has additional needs. Every household is different, and the reaction and responsiveness to the news vary.

Support services are crucial for families of children with autism. In Malta, there are various support services. The state provides some; others are privately run and or supplied by NGOs. One of the NGOs that offers support is the Inspire Foundation. This centre has a specialised program, STEP Intensive Early Intervention Programme, purposely for the early years. This program provides technical interventions for children from diagnosis till the age of five. Inspire runs various programs such as Therapeutic Horseback Riding, Multisensory Therapy, and one-To-One Tutoring (Inspire, 2018). In schools, an Autism Spectrum Support Team empowers educators and parents to meet the child's individual needs and facilitate learning whilst supporting behavioural and social development and maximising the students' abilities (Government of Malta, 2020a). Alternatively, one can opt for private services such as Hand in Hand, where a wide range of programs that support families, especially those with behavioural difficulties (Hand in hand, 2017).

The 'Unknown' Future

Because we cannot see the future, uncertainty is unavoidable. In their research, Watson et al. (2013) point to three main areas of concern for parents of children with disabilities. These are "anxieties regarding the level of independence, educational and vocational concerns, and fear of harm" (p.82). The first concern is related to the child's ability to live independently and fend for their needs once the caregivers grow older. Many parents wonder what will happen to their child once they die and what the future will hold for their child (Case, 2000). Parents need to be reassured that their child has a good quality of life, will find the necessary support, and are safe (Sosnowy et al., 2018). Furthermore, parents are also concerned about love relationships and teenage pregnancies. They fear that their peers would take advantage of their "trusting and naïve natures" (p.78).

Even though people with autism have abilities, unfortunately, employment is still very low. Whilst various abilities counterbalance the challenges, these abilities are often overshadowed by the communication and social skills difficulties associated with autism (Lee et al., 2020). There are numerous documented barriers to the transition to employment. These barriers range from lack of transition preparedness, lousy career advice, negative attitudes of co-workers' and lack of social skills (Stafford et al., 2017; Watson et al., 2013).

Support services are as essential for adults with autism as they are for children. In this section below, I focus on the services for adults.

In Malta, there are 12 Day Centres around Malta and Gozo which are managed by the government agency *Aġenzija Sapport*. These services, which include transport and meals, are free to service users aged 22 and over. During the day, the support staff assist the service users whilst they "spend their time by participating in activities such as card-making, pottery, food preparation, computer skills and literacy programmes" (p.3). Furthermore, there are other small day centres such as the one run by Fondazzjoni Nazareth (Fondazzjoni Nazareth, 2018), Spero (SPERO, 2021), Dar il-Kaptan (Dar il-Kaptan, 2021) and Ħila (Ħila, 2016). Spero is for visually impaired people, and it is a private entity but financed by public funds whilst, Fondazzjoni Nazareth is a private foundation run by the residents' pension. Dar il-Kaptan is an NGO committed to providing a professional respite service to persons with disability and their families, whilst Ħila offers a wide range of services to persons with disability that include respite and residential services and employment opportunities amongst others. Aġenzija Sapport is another government agency that aims to establish principles, values and strategies for persons with disability and their families. It strives to provide support so that the persons with disability achieve independence to the best of their ability whilst living in the community. The Lino Spiteri Foundation (Lino Spiteri Foundation, 2020) is a non-profit organisation. It is a local partnership between JobsPlus and Empower to enable greater inclusion through the employment of persons with disability.

Additionally, the Catholic church has always played an important role when it comes to respite services as well as long-term residential services. Id-Dar tal-Providenza hosts people with disabilities from the age of 14 to 80. The running of this home depends mainly on benefactors, public donations, and the residents' pensions. The services provided at their eight community homes found in various villages are funded by the government.

Having established an overview of the services offered for adults with disabilities, this chapter will now delve into COVID-19 and its effect on people with disabilities

COVID-19

The COVID-19 pandemic was first identified in December 2019 in Wuhan, China. The outbreak was declared a pandemic in March 2020 (World Health Organization, 2020). To inhibit the spread of the COVID-19 pandemic, all Malta schools were closed on 13th March

2020 (Times of Malta, 2020). This was one of the many measures taken to slow down the spread. Some of the other measures taken included the cancellation of mass events, and football leagues were played behind closed doors. As the coronavirus (COVID-19) pandemic is unfolding rapidly in our lives, it is causing widespread concern, fear, stress and uncertainty, all of which are natural and normal reactions to the changing and uncertain situation that everyone is finding themselves in.

COVID-19 on Maltese Shore and its Effect on Education

Back at the beginning of March 2020, Malta experienced the first case of COVID-19. Although it was apparent what Malta was about to experience, it was oblivious that no educational plan was put in place (Grech & Grech, 2020). As mentioned in the introductory chapter, schools were suddenly closed on 12th March 2020. This closure meant that educational institutions and families had to work together so the transition to a remote online education as swiftly and quickly as possible (Farrugia & Busuttil, 2020). Apart from the school closure, various measures were being announced every day to combat the pandemic. On 28th March 2020, it was announced that all educational institutions and schools were to remain closed until the end of the academic year and that teaching was to be continued online. Throughout the lockdown period, one could read reports and social media posts about different education experiences (Busuttil & Farrugia, 2020). Some educators tried to set up platforms to connect with their students. Others just posted online material with no contact or explanation, whilst others just vanished from the system.

The Ministry of Education and Employment (MEDE) set up a working group to strengthen online teaching and learning for the third term of the academic year. This group was made from representatives of the state, church and independent schools, and the Malta Union of Teachers (MUT). They worked on several points that were agreed upon by all the stakeholders and were later published in a circular dated 6th April 2020 (DCLE, 2020b). The teachers were free to use their discretion whether to give real live online teaching or any other form of online education. The main objective was to "cover the most important aspects of the respective syllabi and render themselves best to online modes of teaching and learning" (DCLE, 2020a).

End of the First COVID-19 Wave

By the end of June 2020, the cases were decreasing substantially and eventually, the country had some days with no new positive cases. Malta was close to becoming COVID-19 free by mid-July 2020 when only single figure numbers of active cases were recorded. The restrictions imposed throughout the first weeks of the pandemic were being lifted, shops, bars, restaurants and the airport were reopened. To prevent the spread of COVID-19, the mitigation measures of social distancing, the use of masks or visors and hand sanitisers were enforced. It was effective to reduce the transmission in the community.

Protocols for the New Scholastic Year

As September 2020 approached, new protocols were drawn out for the reopening of schools. These protocols set out measures to be taken by each school to safeguard every student and educators' health. Details of the guidelines were given by the Superintendent of Public Health and the Ministry Permanent Secretary. The schools' guidelines were to keep to the social distance of 1.5 m, and children are to be held in the same bubble, use of masks, temperature checks and hand sanitisers, isolation rooms and records for contact tracing must be kept. Doors and windows should be kept open at all times. After several disputes with the MUT, an agreement with the Ministry of Education was reached. All children were back at school by 14th October 2020. On 20th October 2020, a Memorandum of Understanding (MOU) with The Malta Foundation for the Wellbeing of Society was signed. This MOU aims to support vulnerable students, students with health problems or with health concerns in their immediate family, to follow online learning from home. Moreover, it highlighted how parents or guardians should be "equipped with the necessary knowledge and means to provide a complete education for their dependents at these trying times" (The Malta Chamber, 2020).

The Impact of COVID-19 and People with Disabilities

The pandemic has forced many to confront a situation they have never been faced before. The disruption to our daily routines, particularly those with school-aged children and adolescents, created a sense of confusion, uneasiness, and increased anxiety levels (Ameis et al., 2020; Grech & Grech, 2020). Routines give us the rhythm of life, and these routines are essential for children with autism, as discussed above. Tassoni and Hucker (2005) emphasise that all neurotypical children will feel more at ease when a routine is established, especially if their schedules are stable. Whitaker et al. (1998) stress that a structure is beneficial to children with autism and point out that structure is advocated in nearly every book. The new COVID-19 pandemic changed how society operates. It disrupted routines, reduced access to services, and impacted families and children with autism (Ameis et al., 2020). These disruptions affected families in various ways. For instance, it restricted access to preferred activities, potentially reduced access to specific foods for children with selective eating habits and increased screen time, a challenge that is hard to control for children with autism (Mazurek & Engelhardt, 2013; Mazurek et al. 2013). Ameis et al. (2020) further attribute these circumstances to an increase in anxiety that triggers aggression towards the caregivers. This pandemic also brought home confinement.

Moreover, people were discouraged from visiting relatives and especially elderly grandparents. All these environmental changes altered the sensory input for children with autism and increased stress and anxiety (Ameis et al., 2020). Besides, there has been insufficient focus on mental, social and emotional vulnerability in children with autism during this unprecedented period of change (Aishworiya & Kang, 2020). The changes associated with COVID-19 were not only related to the environment in which the children with autism inhabit. The pandemic also affected other services which most children find vital.

Disruption of Services

This sudden disturbance "required educational institutions and families to cooperate, communicate and work together" to transition to remote online education as rapidly as was humanly and logistically possible (Busuttil & Farrugia, 2020, p.213). Traditional face-to-face lessons and services were disrupted. Going online has led to considerable challenges for families and children with autism (Busuttil & Farrugia, 2020; Times of Malta, 2020). Remote teaching has provided the means to meet the students online; however, children with special educational needs often receive general education in the classroom and support from the LSE. Moreover, the children receive other interventions such as speech therapy, occupational therapy and behavioural support (Jeste et al., 2020). This sudden shift to online instruction "highlighted the importance of student and family engagement, use of new technologies and creative ways of assessment to ensure continuity of services" (Jeste et al., 2020, p.796).

Jeste et al. (2020) conducted a study about changes in access to education and healthcare services for individuals with intellectual and developmental disabilities during COVID-19. The restrictions and the results indicated that children with disabilities "lost a substantial number of educational and medical supports, potentially adding to caregiver burden while also compromising both the child's and caregiver's overall health and well-being" (p.830). The results highlighted how most families lost service, or in the case of some of them, they lost all of their services (Neece et al. 2020). Some families wished that their children were given "careful adaptations and modified expectations from their school" (p.830). On the other hand, Reicher (2020) highlighted how children with high functioning autism have reported that they enjoyed learning from home and prefer remote learning. During remote education, they did not need to find a buddy during lunch break or change classes frequently, something that causes anxiety, demoralization and depression. Furthermore, they felt better as they did not have to fit in with the neurotypical world whilst keeping up academically. While most of the neurotypical children missed the school social stimulation, children with high functioning autism felt more at ease at home (Reicher, 2020).

Although staying at home, they had a positive outcome for academic subjects. Gupta and Jawanda (2020) point out that social distance creates more obstacles to essential services such as education and nutrition, which might cause behavioural changes. The need to follow online education amplifies the parental constraints (Neece et al., 2020), as this entails continuous support for those who have communication and cognitive difficulties. Furthermore, parents had to serve as "their child's special educator, social skills coach, speech-language pathologist or behavioural/mental health therapist" (Neece et al., 2020, p.740). Ameis et al. (2020) established that schooling would be detrimental for children who need "one-on-one professional support in a structured, regulated environment" (p.3).

As weeks and months went by, it has become evident that COVID-19 will still be amongst us for the following months until vaccines become nationwide available. As Rolland (2020) puts it, stringent mitigation measures such as social distancing, facemasks, frequent hand washing, and avoidance of public gatherings are likely to continue in the foreseeable future. In the pandemic, children with disabilities are compounded with additional challenges and barriers society constructs in their way. Markt (2020) points out that while there are legitimate health concerns that COVID brought along, one has to be vigilant on the impact this pandemic has on people with disabilities. He goes further and highlights that just as inclusion had started to gather momentum, this pandemic might push people with disabilities to the periphery of their communities and slam the door closed once again.

Conclusion

Although the literature available is limited, it can be concluded that undoubtedly COVID-19 left an impact on the life of people with disabilities. Before the onset of the pandemic, families with autism were already finding it hard. The routine services offered to these families were disrupted for quite a while, and hence the challenges were compounded. With the new 'normality', some of the services are being restored, but evidence on the effects is still lacking. More research needs to be carried out to assess the sudden partial lockdown on the children and their families.

CHAPTER 3

The previous chapter explored the research that has been carried out by other scholars in the field of families of children with autism. The literature discussed sheds lights on the challenges and achievements these families faced before the COVID-19 pandemic. It also helped me familiarise and sharpen my research focus. This chapter will now focus on the methodology used for my research process. This study's conceptual framework was narrative analysis informed by the emancipatory disability approach, whose philosophy fits well with the study's aims.

This chapter gives an overview of the emancipatory disability principles, the purpose of choosing a qualitative methodology, why narrative analyses were considered the best approach for my research, the method used, ethical considerations, and the limitations and strengths of the study.

The Way We See the World

The "term positivism is used to describe a belief that the world is capable of objective interpretation" (Hammond & Wellington, 2013, p.120). It postulates that there is only one truth out there, and it is "observable, stable and measurable" (Merriam, 2009, p.8). Using the positivist stance, value judgements cannot be considered "valid knowledge" if they are not based on empirical knowledge (Carr & Kemmis, 2003, p. 62). Merriam notes that positivism made way to logical empiricism and post-positivism. Logical empiricism asserts that there is no fundamental methodological difference between natural and social science, whilst post-positivism denotes that knowledge is relative rather than absolute. Using empirical evidence, one can distinguish between plausible and less plausible claims.

On the other hand, the interpretive stance assumes that reality is socially constructed, and hence there is no one single reality. Life is not a lab environment where the red hue of litmus paper denotes that the solution is acidic, whilst if it is blue, it must be alkaline. Rather than there being one reality, there are multiple realities or interpretations of a single event.

After reflecting on these ontological and epistemological perspectives, I felt that implementing an interpretive approach suited my research best. This research strived to understand how the pandemic had affected the lives of families with children with autism. As discussed in chapter 2, each family of children with autism is different and has divergent narratives and faced distinct experiences. An interpretive approach allowed me to consider these multiple interpretations of these families' effect on these families by the onset of the pandemic.

Adopting a Qualitative Approach

Merriam (2009) states that "qualitative researchers are interested in understanding how people interpret their experiences, how they construct their worlds and what meaning they attribute to their experiences" (p.5). There is no simple definition for the term qualitative research. Merriam instead tries to outline four general characteristics which are crucial to understanding the nature of qualitative research:

Focus on Meaning and Understanding

Qualitative research draws on the philosophies of constructionism, phenomenology and symbolic interaction. Qualitative researchers are interested in how people interpret their experiences and the meaning they attribute to these experiences. Hence, the overall purpose is to understand and not necessarily discover the nature of a stable and unchanging truth.

Researcher as the Primary Instrument

The second characteristic, as outlined by Merriam (2009), is that "in qualitative research, the researcher herself is the primary instrument for data collection and analysis" (p.15). Since qualitative data's main objective is to understand, the human is an ideal instrument as "the instrument" can be immediately responsive and adaptive. Verbal and non-verbal communication can be used to expand the researcher's understanding, and analyse information immediately can help the researcher clarify questions to the respondent, ensuring the accuracy of interpretation and exploring unforeseen responses.

This primary relationship between the researcher and the generated data can lead to shortcomings that impact the study since the researcher can be deemed biased since subjectivity is impossible to avoid altogether. As Merriam (2009) notes, it is essential to identify and monitor the subjectivity and shape the collection and analysis of data rather than eliminating subjectivity. Hammond and Wellington (2013) note that the researchers must express their positionality in the research. My positionality was expressed in Chapter 1. As Hammond and Wellington note further, having a different position from others does not mean that we are incapable of understanding. Indeed "positionality is important as it helps us see barriers and the limits in our understanding" (Hammond & Wellington, 2013, p. 118).

An Inductive Process

A key attribute of qualitative research is that researchers generate the data to build concepts, hypotheses, and theories rather than test the hypothesis as in positivist research. Observations, pieces of information from interviews and documents are entwined together into themes as the researcher works on the data to extract knowledge. Merriam (2009) warns that this does not mean that the researcher starts with a clean slate. All investigations are informed by literature and the bag of experiences that the researcher brings to the field, leading to the subjectivity mentioned earlier.

Rich Descriptions

Qualitative inquiry results in a richly descriptive account of what the researcher has learnt from the research. The description includes the context, the participants and the themes of interest. Quotes from interviews and documents, rather than numbers, are used to support the research findings.

In this study, I strived at providing an insight into the effects that COVID-19 brought about in the lives of families with children with autism. Primarily, this study delved deeply into descriptive qualitative interviews with the parents/primary caregivers of children with autism. Secondly, it analysed the effects of the COVID-19 pandemic on families and children with autism. Thirdly, it explored and identified the types and quality of support these families are receiving.

Research Design Based on Emancipatory Disability Principles

Stemming from the social model of disability, emancipatory research shifts the idea from having the researcher in control whilst using persons with disability as subjects to putting the skills and knowledge at the disposal of people whilst passing on the control to people with disabilities (Stone & Priestley, 1996). Integrating social model thinking and emancipatory disability research promotes the disabled person as an individual and empowers the disabled person in the research as an active participant.

There are six core principles to follow for emancipatory research (Stone & Priestley, 1996). These are:-

i. Choosing an epistemology
ii. Surrendering Objectivity
iii. What is in it for Them
iv. Reversing the Social Relations of Research Production
v. Personalising the political and politicising the personal.
vi. Qualitative and quantitative.

With these core principles in mind, I wanted to keep my research as emancipatory as possible. However, due to the nature of the study, not all principles could be adopted. Parents of children with autism were informed of the research questions and what type of methodology would be used. During the interview, the narrative focused on the families' experiences and stories and their children with autism and seen through the social model's lens. Thus the research gave the participants a voice to recount their lived experiences whilst allowing me to delve deeply into their narrated stories.

Moreover, advice was provided when a parent had a dilemma regarding decisions about her daughter's education. Due attention was given when interpreting data as this could have been easily influenced by various aspects. Finally, I intend to publish my research results in a peer-reviewed journal to disseminate the research results.

Interviewing

Interviews can be defined as conversations between the researcher and the research participants (Hammond & Wellington, 2013). They allow the researcher to go deep into the participants' account while probing them to elaborate on their thoughts (King et al., 2018; Merriam, 2009). They also allow participants to articulate their thoughts, feelings and values and at the same time permit the researcher to interact with the participant. Moreover, the researcher can tap on points that need further clarifications and also prompt the participant to elaborate on unexpected themes that may arise (Merriam, 2009). Through these interviews, these participants recounted their narratives by talking about their version of reality whilst having the choice and control of what to say and how to order the events described. This qualitative research was carried out using one-to-one online interviews. Although interviews are generally carried out face-to-face, it was safer to carry out the interviews online due to the pandemic. In this context, online interviews offered a better opportunity to access the participants. Various researchers point out that online interviews mitigate the challenge of time barriers. The participants might find their home environment less intrusive, which may provide a better opportunity for reflective answers (Hammond & Wellington, 2013; King et al., 2018). These interviews allowed me to go deep and probe the participant to elaborate on their thoughts, values, feelings and perspectives. During the interviews, three of the parents were briefly interrupted. Two of the children with autism needed assistance; one could not find the iPad charger, and the other needed help while doing an activity. The third participant's daughter wanted to see who her mother was talking to.

Recruitment of Participants

Access to participants was gained through the Autism Parents Association, which acted as the gatekeeper for my research. Snowballing was used to reach the maximum target of 8 families.

Information about the research study was provided to the Autism Parents Association. Subsequently, their Facebook page administrator allowed my posted blurb about the study to show on their Facebook page. The blurb contained details about the research study and my contact details, through which parents made contact to participate in the study. After contacting, I emailed the information sheet about the research and the consent form to the participants. Some sent their consent forms signed, while others opted to send an email consenting to the study as they had no printer available. During the first interview, the participants were asked if they would like to participate in a short follow-up interview which would be held in February 2021, to give an update on the circumstances. All the participants agreed to take part in the second interview. In February 2021, all the participants were contacted via email to participate in the follow-up interview. Six of the eight participants acknowledged the email and consented to the second interview. All six interviews were conducted between the end of February 2021 and the beginning of March 2021. While the first set of interviews took between 35minutes to 1 hour, the second round of interviews took between 15 to 30 minutes.

The Research Participants

Of the eight parents that participated in the interviews, seven were mothers, and only one participant was a father. All participants were in a relationship, and all the interviews were held online. Of the eight participants, five had a son with autism, two had a daughter, and one participant had all children with autism. Five of the participants had two or more siblings. The age of the children with autism ranged from 8 years to 15 years. Whilst two of the participants were stay-at-home parents; the rest had both parents in full-time employment.

Table 1

Participant demographics

	Name of Parent	Gender of child	Age	Number of siblings	School
1.	Emma	Male	8	-	State
2.	Nora	Male	11	-	State
3.	Jack	Male	9	1	Independent
4.	Lucy	Male	10	1	State
5.	Anna	Male	13	1	State
6.	Ruby	Male	11	1	State
7.	Mary	Female	15	3	State
8.	Kate	Male	9	-	State

Procedural and Relational Ethical Considerations

Every research project needs ethical approval, where judgments are made not adopted to oversee that the research meets the ethical principles that concern the research participant's rights, dignity, and safety (Cohen et al., 2011; King et al., 2018). Cockburn and Cundill (2018) distinguish between procedural ethics and everyday ethics or ethics in practice. Since this research was conducted to fulfil my degree requirements, I followed the procedure to obtain ethical clearance from the Faculty for Social Wellbeing Research Ethics Committee (FREC). FREC ascertains that all the documents abide by the legal requirements to ensure that the University of Malta standards are met in the documents provided. Fulfilling the research's procedural ethics component is essential as it keeps both researchers and institutions accountable and responsible (King et al., 2018). To fulfil the requirements, I created a recruitment email that was sent to the Autism Parents Association to request the approval of the blurb on their Facebook page (see appendix A). Furthermore, as mentioned above, I made a blurb to introduce my research study (see appendix B) to the Autism Parents Association before disseminating my information/consent sheet to the participants (see appendix C)..

"The ethical research practice takes place outside the bounds of the procedural ethics system" (Cockburn & Cundill, 2018, p.89). It is the researcher who must bear responsibility for the ethical research decisions and must ensure that throughout the project:

- Participants are treated with respect and dignity.
- All research aspects are treated with transparency and honesty.
- The researcher acts in an accountable and responsible manner.
- The researcher upholds integrity and academic professionalism standards.

Various authors (Braun & Clarke, 2013; Cohen et al., 2002; Heath et al., 2010; Silverman, 2006) outline a series of goals that researchers need to achieve in their research to act ethically. Researchers need to ensure that participants are informed of the research's objective and what it will take to participate in the study. They need to be told that participation is voluntary and that they can opt to stop taking part in the research at any time they want. Comments made by participants and their behaviour should remain confidential. Participants should not suffer any harm by participating in the study. After reflecting on the issues highlighted by Cockburn and Cundill (2018) and Silverman (2006), I ensured that these ethical, procedural principles were followed during the study's design and implementation.

Generating the Data.

As this situation was still unfolding and creating instability in the families of children with autism, I was very cautious to ensure that the participants were feeling comfortable and not pressured. In addition to these precautions, I had already contacted a private psychologist who had agreed to support any participants referred should the need arise. Pseudonyms were used to help preserve the participants' identity and anonymity to be kept as much as possible. All personal details will remain confidential. Hard copies of interview notes were kept securely locked away. While files, including computer files and audio recordings that contained personal or identifiable data such as names, were password-protected and only accessed by myself. The data will be kept for six months after submitting my research study to the Faculty for Social Wellbeing. Every effort will be taken to ensure that the participants are not identifiable in any report or publication arising from the research. However, since the sample is small, anonymity cannot be fully guaranteed.

Analysing the findings

The transcribed data were analysed according to the narrative analysis approach. Narrative analysis is a flexible approach that focuses on individual experiences, typically on personal experiences being collected and recorded one at a time (Ollerenshaw & Creswell, 2002). This approach can be used with written and oral communications in various settings (Druckman, 2005). Within narrative research, the emphasis is that human beings are storytellers, and it is the narrator’s perspective, rather than the researcher's perspective, that drives the process. The narrative study explores how humans experience the world around them (Connelly & Clandinin, 1990). In this research, I interviewed the parents individually, focusing on their experiences from the onset of COVID-19 until the interview. All the narratives were studied chronologically from the outset to the interview. This procedure was done to identify and address questions about what was said, who said it, and to whom it was said. Then I used thematic analyses to elicit the common themes between the narratives.

A necessary precursor to the analysis of data is the transcription. (King et al., 2018) stress the importance of adopting a consistent style during transcription so that anyone reading the material can understand the features of speech the notation used indicates. They also warn about three threats to quality transcription which the research should mitigate against:

- Quality of recording - a researcher, should always ensure that the recording mechanism adopted results in audio that is clear and without a lot of background interference. Whilst ensuring that too much attention is not drawn to the recording device, the researcher should ask the participant to repeat a response if the initial response is not deemed to be clear.
- Missing context – interviews do not occur in a vacuum. Non-verbal communication and paralinguistic aspects are just as important. These aspects should be considered whilst transcribing interviews.
- “Tidying up” transcribed talk – It is not the purpose of transcription to produce a correct version of what the interviewee has said but rather an accurate one.

Braun and Clarke (2006) identify six phases in a thematic analysis approach to analysing data. Although the phases are presented as a sequential list, and each phase builds on the preceding one, Braun and Clarke (2006) note that analysis is typically recursive. The researcher will find oneself moving back and forth between different phases. The six phases as outlined by Braun and Clarke (2006) are:

- Familiarisation with the data: Transcripts are read several times so that the researcher becomes immersed with the content.
- Coding: This phase involves generating concise labels, also referred to as codes (Merriam, 2009, p.173)), that identify essential data features relevant to answering the

research question. This phase involves going through all the transcripts and coding the data. All the codes and relevant data extracts are grouped and all for later stages of analysis.

- Searching for themes: In this phase, codes are grouped to identify potential themes or broader meaning patterns. It then involves collating data relevant to each possible theme to work with the data and review each likely theme's viability.
- Reviewing themes: This phase involves checking the potential themes against the dataset to determine that they answer the research question and tell a convincing story of the data. In this phase, themes are typically refined. This might lead to themes being split, combined, or discarded.
- Defining and naming themes: This phase involves developing a detailed analysis of each theme and working out each theme's focus and scope. It also involves deciding on an informative name for each theme.
- Writing up: This final phase involves weaving together the analytic narrative and data extracts and contextualising the analysis with existing literature.

Thus, I started by listening to the recorded narratives repeatedly whilst I transcribed the data. When all the interviews were done and transcribed, I re-read the transcribed narratives to familiarise myself with the rich descriptive accounts while also taking notes on different things. These detailed descriptions were then coded under various headings as this allowed me to identify, order and organise the most meaningful and important topics mentioned by the parents. I grouped the list into sub-themes with the codes in hand whilst ensuring that all the important and relevant data were included. Consequently, I collated the sub-themes into themes whilst ensuring that the themes reflect the participants' topics. During the last phase of analyses, a title that captures the theme's real meaning was given. A diagram of the themes and sub-themes is presented in Chapter 4 (see figure 1 Themes and sub-themes and figure 2

Themes from follow up interviews). The findings with extracts from the participants and the discussion to describe the participants' situation are presented in chapter 4.

Conclusion

The narrative analysis allowed me to listen to families whilst they recounted their journey from the onset of the COVID-19 pandemic to almost a year later. Integrating social model thinking and emancipatory disability research empowered the parents of children with autism as an active research participant.

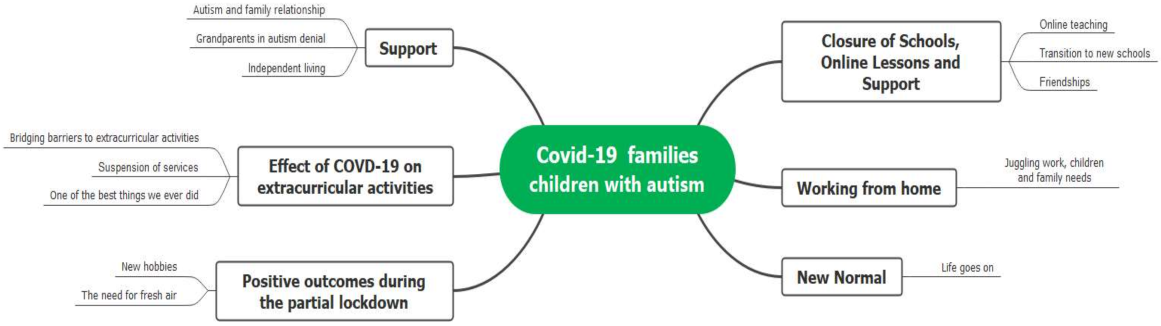
In conclusion, this chapter gives a detailed description of the methodology used to carry out this research. In the following chapter, the findings along with the analysis are presented.

CHAPTER 4

This chapter will analyse and discuss the study's findings, shedding light on families' situations and their children with autism during this COIVD-19 pandemic. I hope that these findings will be a valuable addition to local literature on the subject and provide insights for implementing actions and improvement. As I explained in the methodology chapter, the results are presented in themes and sub-themes (Figure 1). These categories were elicited from the transcripts of the eight families that were recruited for the individual online one-to-one interviews.

Figure 1

Themes and Subthemes



Support

From the data's findings, it was evident that the families had a difficult and challenging time during the partial lockdown caused by the onset of the COVID-19 pandemic. In this section, three subthemes are presented. The first subtheme is ‘autism and family relationships, where I present the narratives recounted by families of how the partial lockdown affected their family and the support provided by the grandparents and service providers. Two of the parents expressed how their grandparents are in denial over their grandchildren's diagnoses, which further impacted the support and understanding of the family needs during COVID-19. The second sub-theme focuses on the understanding of family needs. Related to this theme, the families recounted how the lack of support and understanding during the partial lockdown made them feel helpless and stressed. The last theme recounted how four parents were quite adamant about teaching independent living skills. During the partial lockdown, the parents felt that if the support had to be withdrawn again, they wanted to make sure that their children could independently carry out basic living activities. The parents were concerned for the future of their children. They also claimed that the partial lockdown made them feel that independent living is more important than any other academic subject.

Autism and family relationships

Throughout the interviews, it was noted that most of the families rely on help given by the grandparents. During the COVID-19 pandemic, three of the interviewed parents had vulnerable parents, so the helping hand was out of the question. Nora expressed that it was quite a hassle for her "heqq jien għajnuna, jiena dejjem il-mummy imma l-mummy mal-vulnerable people" [My mum always offered a helping hand, but now she was classified as vulnerable]. Lucy said that "għand in-nanniet ma bdejtx nieħdu, bdew jibżgħaw minhabba li kbar hux, biex ma noħoduhomx hdejhom, no no ma kellix support" [I could not take him to the grandparent's house, as they were afraid, given their age. I had no support]. Kate also found it difficult "ommi vulnerabbli imma kienet għada taħdem, imbagħad ħarġet bis-sick, kelna inbiddlu naqra l-affarijiet" [My mum is vulnerable, but at that time she was still working. Eventually, she had to take sick leave, and we had to change routine]. Ruby's parents are still of working age and were still working during the pandemic as they are essential workers. On the other hand, two of the participants were grateful that although the grandparents were afraid of contracting the virus and could not help with their children's care, they still provided support.

Anna was grateful that “my mum can help from an emotional standpoint but not really from a physical standpoint”. Kate was appreciative that although her mother could not give physical support, she used to “taħsilli l-ħwejjeġ u hekk jew nagħmel load u tonxora u bħala xirja timsaħha” [she used to wash and hang the clothes and she used to wipe down any shopping bought]. This was only possible since they lived in the same apartment block. As discussed in chapter 2, Bloch and Weinstein (2009) highlight the importance of keeping an open dialogue with the grandparents. This proved to be beneficial for emotional support at times of need.

Mary, a mother of three children with autism, found it very hard to cope. Before COVID-19, apart from her parents' continuous support, her children had carers who Aġenzija Support provided. These services were disrupted “dak ukoll ġie affettwana ħafna minħabba il-COVID” [that affected us a lot as well, because of COVID]. Although in the beginning, staying at home was not an issue, as time went by, “the children were missing their grandparents, and their grandparents were missing the children”. Mary said, “one of the girls, she is very close to nannu [grandad], ehm and my mother is very close with my son. So it was an issue both ways for them and for my children”. As discussed earlier, making time for oneself was an issue for Mary as her son was “challenging li jibqa jinsiti għal affarijiet li ma nistax nipprovdijomlu,[challenging and used to keep persevering with requests that were impossible to provide], he was not letting me sleep so I had to send him to my mothers, I was not coping”.

Although not to the same extent, Anna said, “I am so tired at the end of the day, I don’t feel like... I only feel like going to bed and go on Netflix, and I sleep halfway through as well”. Anna’s comments echo the observation by Ooi et al. (2016) where it is highlighted that, in some cases, parents have little time for themselves due to high demands of taking care of the child, which "results in sleep deprivation, insomnia and low energy levels" (p.752). Parenting children with autism can increase stress levels and impact their daily lives, especially if there is a sudden change in routine or the environment. Parents of children with autism experience stressors that exceed "those associated with caring for children with other disabilities and medical conditions" (Hillman & Anderson, 2018, p.260). In a study conducted by Pace Gasan et al. (2020), it was evident that people with disabilities felt an increased sense of isolation once the restrictive measures were introduced. This sense of isolation resonates with the Richmond Foundation's longitudinal study (2020), wherein it was found that in June 2020, 39.9% of the respondents felt that they were socially isolated. This feeling decreased to 22.7% in August 2020 but increased to 28.7% in December 2020. Pace Gasan et al. (2020) observed that the restrictive measures also impacted the family members differently. Some of the parents called CRPD (Aġenzija Sapport), whilst others gave in to their children's demands and allowed technology with no time restrictions.

In conclusion, the evidence points out that families of children with autism struggled to keep their families in sync during the partial lockdown. Due to the pandemic nature, the outside pressure took a toll on the family, especially when extended family members could only give limited help compared to the usual routines. With so many changes, children with autism were becoming more restless, and some exhibited challenging behaviour. Although some extended family members give regular support to their families, some grandparents still struggle to accept that their grandchildren have a hidden disability. This issue is discussed in the next section.

Grandparents in autism denial

Both Emma and Kate had to deal with contrasting family dynamics as their elderly grandparents never accepted their grandchildren's diagnoses. Emma said that both sets of grandparents are in denial. Her mother "never accepted the condition allura għaliha it-tifel imqareb mhux għax autistic" [so for her, my son is mischievous and it's not because he has autism] and same thing with the paternal grandparents where her mother in law used to say "forsi għax imqareb, iġifieri they never accepted it, aħna kelna ukoll problema b'missieru, missieru qatt ma' accetta" [perhaps because he is mischievous, and the grandfather never accepted the condition]. In chapter two, I discussed how Wall (2009) draws our attention to the fact that grandparents may lack knowledge and awareness about autism. During the partial lockdown, Emma's son was getting bored at home, and he used to get up to mischief regularly. When Emma spoke about how she felt with her parents, she narrated that her parents put pressure on her and blamed his behaviour on the way she is raising her son. Emma stated that her mother compared her son to her neurotypical niece and blamed Emma whilst she transmits a subtle message that "it-tifel imqareb, inti ma tafx x'jiġifieri trabbi is-subien"[my son is mischievous and that I don't know how to bring up boys]. Although they give a helping hand, the feeling that the upbringing is not up to their standard puts stress on Emma and on the relationship she has with her parents

Similarly, Kate's parents give a helping hand. Unfortunately, the grandparents do not confront the parents but are inflexible with the child. Kate states that her elderly parents "ċertu affarijiet tal-kundizzjoni ma jifmuiex, u it-tifel għadu lura biex jikkomunika, u ċertu affarijiet jekk ma jobdix, jibdew jiġġieldu, tibda tinqala ħafna tension" [do not understand that certain behaviour is due to the condition itself, my son still does not communicate well and when he does not comply, arguments arise which induce tension]. Kate often felt stressed during the partial lockdown as she ended up between a rock and a hard place. For some time they had to live with the grandparents as they were in the middle of house renovation, "heqq is-soltu it-television dejjem kien ikun fejn irid it-tifel, issa ma jistax għax jixxerjah man-nannu"[at home he used to watch his favourite programmes but now he has to share the television with his granddad]. Hillman (2007) highlights that when grandparents cannot understand the specific cause of their grandchild's condition, it creates anxiety and frustration. Moreover, discordant perceptions of disability between parents and grandparents may arise, and there may be disagreement over treatment and discipline (J. Hillman, 2007).

In summary, the grandparents do not accept their grandchildren's diagnoses as the cause of what they perceive as misbehaviour adds pressure to both Kate and Emma. The COVID-19 situation extenuated this frustration. Following is another prevalent theme that the parents highlighted was their worry about what will happen to the child if they are no longer able to provide support.

Independent living

Half of the parents felt the need to express that the schools emphasised only the academic aspect while daily living skills were put aside during the partial lockdown. These four parents felt that since they spent the time indoors, it was time to focus on independent living rather than academics. Mary claimed that "the priorities are not appropriate, l-iskejjel jagħtu ħafna fuq l-academics, hekk hu nemmen ukoll independent living, speċi kellhom affarijiet daily living skills l-iskola, imma imbagħad when you are at home academics biss" [the priorities are not appropriate, the schools press on academics. I believe in independent living skills, at school they practised daily living skills but when at home, only academics were taught]. They expressed how essential it is for their children to increase these skills as they believe that it is a building block that provides strategies and ideas for future adult life. Earlier in chapter 2, I highlighted how Watson et al. (2013) found that the first area of concern for parents of children with disabilities is the level of independence and the child's ability to fend for their needs once they are older. This was stated by Jack when he said, "meta immut jiena x'ser jiġri minnu? Għax ħeqq nibda nibża ngħid forsi jkun hemm min jimmaltrattah, ħadd ma ser iħobbu daqsi żgur u nifimha, imma ngħid minjaf x'ser jiġri minnu, nixtieq li jkun jista jikkomunika, imur ix-xogħol" [When I die what will happen to him? At times I am afraid that people might be nasty to him, no one will ever love him as much as I do, and I understand, but at the back of my mind, I always wonder what life he would lead. I hope that he would be able to communicate, go to work]. Jack's concern resonates with Sosnowy et al. (2018), which highlighted how parents need to feel reassured that their child will have a good quality of life.

Lucy and Jack are adamant about teaching their sons basic skills such as the value of money, reading time and the ability to do some shopping. While Lucy emphasised that "dawk l-affarijiet li għandu bżonn għal ħajtu kuljum hux biex in-nies bħal speċi ma jitmejlux bih" [he needs to learn life skills so that people will not take him for a ride], Similarly, Jack said that "imma ngħidha jiġifieri that is my target li meta niġi biex immut hu jkun għandu ċertu skills li at least is-socjeta` mhux qed ngħidlek li ma tagħmilx bih li trid imma jekk jista ikun jaf jiħħendilja ċerti basic things, li jaf imur jixtri" [but I say that my aim is that when I eventually pass away, my son will have acquired certain skills so that at least society – I'm not going to say that it rides roughshod over him but that he can handle certain basic things, like shopping].

Nora was very concerned during the interview as she felt that the first year in secondary school was of no benefit to her son. Whilst her child was progressing well in an independent primary school, the unintended move to a secondary state school due to excessive demands and financial strains has brought a drastic change in the child's life. Moreover, Nora highlights that it is useless for the school to emphasize Geography and Science since he is not good at them. She tried to raise this issue with the Inclusive Education Coordinator (INCO) that "my objective is I want to see in what he is good and go from there". She further emphasises that "if he is good at IT, I want to push him towards that area". Likewise, Jack was also giving priority to the social aspect rather than the academic subjects "issa tgħidli allura Maths u English mhux importanti, iva ħafna imma if I have to prioritise, emm nippreferi social aspect” [so you may say that Maths and English are important, yes but if I had to prioritise I prefer the social aspect].

As evident from the excerpts, these families have been challenged as they experienced evaporation of support during the partial lockdown. The lack of support ranged for various reasons. These include vulnerable family members, extended family members that are still in denial over the diagnoses of their grandchild, and other support services that had been withdrawn to limit contact because of the virus. This lack of support made the parents reflect on their situation, prioritising teaching essential tasks to their children rather than academic subjects.

In conclusion, support during the partial lockdown was one of the main topics that the parents of children with autism found challenging. Throughout the previous years, the parents set up a routine to incorporate support from services provided and established help from the extended family. Once the COVID-19 pandemic disrupted these routines, the parents and the children with autism faced considerable changes. All the support services such as occupational therapy, physiotherapy, and other hospital appointments were stopped, and families were left to fend for themselves. This situation added more stress to the parents. These developments also impacted children with autism as their everyday routines and support structures were halted, and this unforeseeable change at times triggered frustration and boredom. Similar to the findings to the study of Pace Gasan et al. (2020), parents felt the need to ask for support when dealing with their children’s challenging behaviour. Another critical thing to remember is that parents might not be accustomed to deal with or manage this behaviour. Despite all the challenges the parents were encountering, it was prevalent how half of the parents became more aware of the importance of teaching independent living to their children rather than teaching academic subjects. Although the parents wished that their children reach their full potential academically, they felt that the educational settings were not catering for their children’s needs but rather adopting the one size fits all strategy.

Closure of Schools, Online Lessons and Support

Although the schools' closure took everyone by surprise and disrupted all the routines, and created various challenges in people’s lives, three of the parents felt that schools' closure was a blessing in disguise. Before the outbreak of COVID-19, they already had a rough year when their children in secondary school were not allocated an LSE due to a staff shortage. Hence, sorting out support for the child when sent back from school was dealt with when schools and teleworking were implemented. They narrated how hectic and stressful the academic year 2019/2020 had been since their children were either sent home as no LSE was available on the day or given a different LSE daily. One of the parents stated that her child was given a student LSE for several weeks when the placement came to an end; her child was sent home for the rest of the days.

This section's main themes encompass schooling, the reality of online lessons for children with autism, the challenges, struggles, and educators' commitments to include all the children. Since schools were abruptly closed, the parents were concerned with transitioning to the new teaching model as the children did not have time to acquaint themselves with it. Moreover, an overview of friendships is discussed.

Online teaching

Two of the participants were satisfied with the quality of online live lessons during the partial lockdown. Jack recounted how his child’s school were ready and adapted in no time to online live teaching. He only had words of praise for his son’s school and was happy that he had enrolled his son in this independent school. However, Jack said that, although “l-iskola kienu ippreparti u baqaw għaddejin bl-online lessons eċċetra, ipparteċipajna fi tnejn - tlieta pero he did not want to know not at all” [the school were prepared and provided online lessons, we only participated in two to three as he did not want to follow]. Jack recounted how they decided between "stress u jitgħallem xi ħaġa nippreferi not stressed and he lives a happy life" [stress or that he learns something, I prefer not stressed and he lives a happy life]. At this point, the parents chose not to follow any lessons as their child's happiness is more important. Ruby narrated how her LSE followed her daughter, who attends secondary state school. She states that "waqt il-COVID ma telqitnix ġurnata jiġifieri mhux biċ-ċajt bagħtitli email kuljum biex tistaqsini dwar it-tifla, tibatli ix-xogħol u tgħidli fejn nidħol u hekk. It-tifla qatt ma riedet tattendi lessons live"[during COVID, the LSE kept in contact every day, she used to send emails to enquire about my daughter, she sent work and used to give tips on sites to follow. My daughter did not want to follow online live lessons].

These two experiences contrast with those of the other 3 participants, who were disappointed with their respective educators' lack of contact. Mary narrated that her children were only given handouts "kieku jibgħatuli handouts email li għalija ġa inkun onesta kienet banali għax titfa' iktar pressjoni fuq l'omm" [that were sent by email to the parent, this was not adequate as it only added pressure on the mother]. On the other hand, Kate recounted how her son's teacher used to send her work, but the work sent "ma kienux daqshekk effettivi, irrid noqogħod naqta' jien, nivvinta nagħmel... fhimt" [was not suitable as I had to adapt the work]. Then again, she highlighted that other LSEs gave resources to the children in their care. This felt quite unfair, although the children are in the same school "tinduna li mhux kulħadd fuq l-istess playing field"[not everyone is on a level playing field]. Nora narrated that although some lessons were given online, her son did not want to follow lessons with his classmates. Nora recounts that the few lessons she attended with her son were too slow for him, and he got bored and distracted. Since her son refused to follow online lessons, the LSE assigned to him gave her all the files so that the mother could adapt the lessons accordingly. Nora found it quite challenging and stated that "jiena ma stajtx nagħmilhom għax dawn bdew jitfgħu kollox Form One imma jien ma nifhimx saħta, jien jekk ma jkunx hemm xi ħadd jagħmilhom adapted għalih hu ma jistax jagħmilhom u jiena ma nifhimx" [I could not do them because the work was for Form One and I couldn't understand anything if there isn't someone to adapt the work for him he cannot do it and I don't understand it].

Undoubtedly, the COVID-19 pandemic impacted the educational setting, and schools reacted in different manners. These narrations resonate with the findings of Pace Gasan et al. (2020), where it was highlighted that after a while, the educational settings offered online platforms. Still, there was a lack of adapted work for children with disabilities. This situation caused more stress for the parents, and at times the parents incurred further costs to engage professionals to provide good homeschooling for their children. This pandemic further highlighted the importance that the Seniour Management Team (SMT) and the educators need to work hand in hand with parents. As discussed in my literature review, collaboration and communication with the parents are of utmost importance, so the challenges encountered can be mitigated as soon as they arise.

In the studies conducted by various local researchers, it transpired that clear guidance from the SMT was crucial at that moment in time. While some educators were given proper guidelines and support from the SMT, others "were thrown in at the deep end" (Sciberras & Schembri, 2020, p.203) with no clear guidelines on how to tackle the online scenario (Busuttil & Farrugia, 2020; Sciberras & Schembri, 2020). On the other hand, by dishing out work that the child cannot complete and expecting the parents to adapt the work, the educator enforces the medical model of disability where the child is seen as a problem, and the problem belongs to the individual. As accentuated in the literature review, education should be seen holistically, and inclusion should be an ongoing process, whilst the goals set up in the IEP should be followed.

COVID-19 brought further challenges to children with disabilities as it also disrupted the transitioning from primary to secondary schools. This is an important life transition that can affect the children's attainment and well being as they transition from one school to another.

Transition to new schools

Two out of the eight parents narrated their experiences about transitions to a new school. Before the pandemic reached our shores, at the beginning of year 7, Nora changed school for her son. He used to attend an independent school, but as he was about to transition to secondary education, the school fees to support their child with autism skyrocketed. This made it impossible for the parents to keep up with the school fees. Hence, they were left with no other option than to change school. The transition from the independent school to a state secondary school at the beginning of the academic year 2019 did not go smoothly. Since her son had transitioned to secondary school, Nora recounted that he missed several school days since he was not provided with an LSE at the beginning of the academic year. Firstly, there was no LSE available and, since her son has been statemented as needing one-to-one support identified, he could not attend school. When an LSE was engaged, the parents were overjoyed "li ħa jerġa jibda skola, tort tiegħi din kienet l-ewwel ġurnata u ħallejtu full day, u ma kienitx full day, għax għamel tantrum ovjament miskin, new school, new environment, new people, mhux ovvja" [that he is starting school again, it's my fault because it was the first day and I left him there for a full day, and it was too much for him, because he threw a tantrum obviously, poor thing, new school, new environment, new people, it was obvious what was going to happen]. Partially blaming herself for leaving her son for an entire school day, Nora recounted how a transition program should have been put in place by the school until her son settled in smoothly, as this would have prevented the meltdown and tantrums. The transition into secondary school was quite challenging, so staying at home was quite convenient.

Lucy was feeling somewhat afraid as her son was about to transition to secondary school in September 2020. Since schools closed in March 2020 due to COVID-19, no transitioning sessions were held between the primary and secondary schools as is usually done. Up to August 2020, they were still in the dark and were not contacted by the new school to plan their son's transition program. When Lucy contacted the new school, a member of the SMT told her "jekk jiftħu, ġimgħa qabel biex nieħu lit-tifel biex jara l-iskola u nitkelmu ftit għax ma kien hemm xejn. Iġifieri lanqas video jew hekk tal-iskola l-ġdida" [if schools open, we will be asked to take our son to school a week before so he can have a tour of the premises whilst they have a chat. Until now, no transition of any kind was held, not even a video about the school]. Lucy fears are mirrored in Nora's experience, as Lucy believes that, although the COVID-19 pandemic brought disruptions to the educational sector, the schools must adapt to this new reality and provide her son with a proper transition to the new school.

As seen in Nora's experience, her son's sudden school change was quite challenging since he has communication difficulties. The lack of transition from one school to another resulted in an exacerbation of communication difficulties that triggered difficult behaviour. Makin et al. (2017) highlight that one of the challenges some children with autism face daily is communication. Meanwhile, Lucy was afraid that changing classes would also be a barrier for her son. There is an increase in the number of students in secondary schools, and the school is much bigger, and subject teaching will be introduced (Hebron, 2017). Lucy is adamant that her son needs a smooth transition from one school to another. Makin et al. (2017) highlight that this transition should include communication and collaboration between the school and the family, prior orientation tours with the secondary school environment, familiarization with the school structures and introducing the new staff to the child. If the steps suggested by Makin (2017) are adopted, the child with autism will find the transition to secondary education less stressful.

Moreover, Lucy narrated how her son was to be placed in a Core Curriculum Programme (CCP) class, and no further information from the school was provided. Since she had never heard about this class setup, Lucy felt lost and worried because she had no idea what this new setup caters for. After speaking to other parents about her worries, she narrated that, from what she could gather, the children that attend the CCP class will not need to change classrooms to attend lessons. To this news "jiena ħadt ir ruħ ħa ngħidlek, għax hemm hekk iridu imorru minn lesson għal oħra issa. Mur ġibu imur minn lesson għal lesson" [I was relieved because now they need to change class for lessons, I can't imagine him changing classes to follow the lessons]. Lucy fears were reflected by Makin et al. (2017) as transitioning to a new school may create difficulties both at the micro and macro levels, and they suggest thorough planning for a smooth transition. The COVID 19 pandemic made a difficult situation even worse, as schools drastically reduced communication with parents of children transitioning to their schools for the first time.

Friendships

Half of the participants expressed how their children do not have friends at school. They narrated that their children do not like to socialise and are withdrawn to themselves. The COVID-19 pandemic did not affect their children in this regard, as none of them missed their school mates. Anna claimed that her son "does not have a lot of friends or anything like he doesn't socialise the same way as other as other kids. My son, he was happy because we'd have an online session in the kitchen. He was able to do his drawings and stuff which he loved, and that wasn't stressful". Emma narrated that her child "lanqas biss isemmihom" [never mentions them] as at school he walks away and does not communicate with any of the children, so COVID-19 did not affect his friendships at all. Ruby claimed that her daughter says she has friends. Still, in reality, if a girl "tkellima jew tidħaqilha, dik ħabiba tiegħi, le ma joqgħodux magħha, naħseb jarawha weird jiena, għax hi taqbad tagħmel il-movimenti (flapping) jew tagħmel hekk jew toqogħod tabeż" [speaks or smiles to her, she assumes that she is her friend. She is always on her own, I think her peers feel that she is weird because she flaps or starts jumping].

Moreover, Ruby claimed that her daughter never mentioned her school friends during the lockdown and was happy to stay home. Jack said that his son "ħbieb li huma konoxxenzi iktar minn xejn, jafuh imma ma għandux dak il-ħabib, la min-naħa tiegħu u lanqas min-naħa tagħhom" [aquaintences rather than friends, he does not have that special friend. This is reciprocated from both ends]. He explained that the school took it very seriously and introduced his son to his friends through a presentation. They explained the condition and how they can help him, and what to do to avoid triggers. He said that during the partial lockdown his son "bħala ħbieb ma kien hemm immissjat xejn"[with regards to friends, he did not miss them].

Contrastingly, two parents said that their children missed their school friends and were looking forward to the schools' opening. Lucy claimed that although most of the children with autism "iħobbu joqgħodu waħidhom, imma dan le, hu jħobb ħafna il-ħbieb u ħass ħafna l-effett tas-social distancing" [enjoy being on their own, but that's not the case, my son loves friends and he felt the effects of social distance]. Throughout the partial lockdown, neither her son nor his friends made any contact. Kate also claimed that her son missed the school and is looking forward to opening its doors again. She said that he would return to school "irrankat, ifhem hu l-iskola jħobbha, l-ambjent sabiħ, it's a very healthy environment, jiġifieri bilfors jimmissjha" [eagerly, because he loves school, the ambience is nice, it's a very healthy environment, so it stands to reason that he misses school].

Rodríguez et al. (2018) draw our attention that it is pretty challenging to determine the existence of friendships in children with autism. They suggest that to determine the type of friendship, the data needs to be triangulated between their friends, teachers, and families.

Notably, the parents expressed their view from the observations outside the school premises and throughout the COVID-19 partial lockdown. A study conducted by Calder et al. (2012) suggests that children with autism perceive a different understanding of what makes friendships and highlighted how these children base the friendship on sharing company rather than sharing emotions. Moreover, it was accentuated that children with autism felt the need to play by themselves rather than engaging with other children (Calder et al., 2012). In Rodrigues and Calder's studies, although the parents think that the child did not miss their friends because the child has no friends, it might be that the child has friends but failed to communicate this to the parents. Although two of the parents claimed that their children were missing their friends, at no time during the COVID-19 partial lockdown did the children feel the need to call or meet their friends. It seems reasonable to conclude that friendship is quite tricky to analyse just from the parent's point of view. Still, additional observations and perspectives of all the stakeholders need to be taken into consideration.

In conclusion, working from home became very important during the pandemic since it helped prevent spreading the virus, even more since it allowed employees to do their job and thus get paid. Parents had contrastingly different narratives about their experiences. As highlighted in chapter 2, no two families of children with autism are the same, and hence the support needed varies from one family to another. These circumstances highlighted inequalities between the services and education provided to children with autism and their families. Furthermore, it also emerged that some of the families found time to reflect on their family situation and position their priorities for their children. Having discussed the impact of the lockdown on the children's schooling, I will now discuss the impact on activities held outside school hours.

Effect of COVID-19 on extracurricular activities

The restrictions of COVID-19 created havoc in schools and extracurricular activities carried out after school hours. Extracurricular activities are taken to their broadest sense and incorporate all the services such as Embrace Diversity Organisation, speech therapy, other physical activities, and leisure activities. In this section, I present how Nora and Emma mitigated the challenge of their child's physical activity before COVID-19 whilst they recounted how the pandemic created new challenges. Jack, Lucy, Ruby and Kate recounted how all their services were suspended during the partial lockdown. On the other hand, Anna recounts a new positive experience that COVID-19 brought on her family.

Bridging barriers to extracurricular activities

Nora and Emma recounted how difficult it was to enrol their child in physical activity outside school hours. Nora narrated how before COVID-19, she struggled to find a sport where her son would fit in. She explained that "Special Olympics kont ilni xi erbgħa snin fil-waiting list it-tifel leħaq kiber" [he had been on a four-year waiting list with Special Olympics] and when he finally started attending it was not suitable for him, as the gym echoed and it bothered him and to top it all up he had a different trainer every session. Just before the COVID-19 outbreak, Nora had managed to find a personal basketball trainer for her son. Her son loved the basketball training sessions. When the restrictions started, these sessions had to stop, but since they had bought the basketball stand, her son was still practising at home.

Similarly to Nora, Emma expressed how she gave up trying to enrol her son in extracurricular activities "għax tant ippruvajna extracurricular activities, u dejjem jitfgħuh il-barra għax iħarbat lil kulhadd" [since we tried so many extracurricular activities and he always end up being chucked out as he disrupts the whole group]. Finally, Emma started taking her son to inspire, and both of them used to swim four times a week. During COVID-

19, it was hard for her son to understand why his mother is home and could no go swimming. Similarly to Emma, Ruby said that before COVID-19, she used to take her daughter swimming at r-Razzet tal-Ħbiberja but unfortunately, it was getting out of hand every time they go. She recounted how “kont noħoda swimming pero kienet qed tkun iebsa ħafna għalija għaliex kienet qed ittini kedda meta titla’ mill-pool, emm ma kellhomx instructor għalija, emm kienet qed tkun ta’ kedda għalija” [I used to take her swimming but it was very difficult for me because she gave me a lot of trouble when she came out of the pool, there wasn’t an instructor for her, it was a lot of trouble for me every time.] Ruby felt relieved when COVID-19 hit our shores since the service was stopped, and so did her struggle with her daughter.

Reflecting on these three narratives, one can note that Nora, Emma and Ruby tried hard to enrol their children in physical activity. Chapter 2 highlighted that physical activity is significant in various aspects of child development yet, it is evident that there are still barriers to group activities. While Nora mitigated the challenge by engaging a private basketball personal trainer, Emma took the challenge upon herself to start swimming with her son, and Ruby committed herself to take her daughter swimming. I feel that children with autism are still missing out on other aspects. During play, the children are encouraged to develop their language, social competence, emotional control and other essential skills (Miltenberger & Charlop, 2013), which can be acquired and developed in a group setting.

Suspension of services

Six of the families had their services affected during the partial lockdown. Jack, Emma, Lucy and Kate had all their services suspended and were left to fend for themselves whilst Nora benefited only from the foreign service. On the other hand, Ruby was relieved with the closure of the pool. These families had a different outlook on the situations, as they all availed themselves of various services according to their children’s needs. Thus, each narrative has its picture, making it essential to present each narrative separately.

Lucy’s son used to attend football sessions. He used to love the sessions as the coaches used to train them for agility and gross motor skills, but once COVID-19, hit all these sessions were cancelled, and the sessions could not be held online. Furthermore, Lucy’s son attended the Autism Parents' Association (Malta) which also had to close its doors. She was delighted with the sessions they hold “hemmhekk jgħallmuhom fuq social life” [there they teach them about social life]. For instance, they are taken to a restaurant and taught etiquette, how to catch a bus and lately, they also organised barbeques. Her son used to love these sessions and was always looking forward to them. Unfortunately, during the partial lockdown, her son did not contact any friends, neither from the autism centre nor the football nursery. Jack expressed his concern as his son spent three months idle with no services whatsoever. Before COVID-19, his son attended various services such as ABA, Padovan and speech therapy. During the partial lockdown, all the services were stopped, his son would not sit in front of a computer. His parents felt that sitting in front of the computer was not beneficial for the child, creating more stress and anxiety.

Nora’s case was different to a certain extent as her son was attending local and foreign sessions. The local foundation, Embrace Diversity, provided holistic learning for children with various disabilities. This organisation had closed its doors at that time, and no services were being provided whilst the service of the private speech therapist residing abroad continued as if nothing happened. This foreign speech therapist used to conduct online, interactive live sessions. Nora explained that her son was immersed throughout the session, and he used to sit and follow the forty-minute online session alone. Emma, Kate and Jack’s narratives contrast with Nora’s experience and the foreign speech therapist's service. Emma explained how Speech therapy for her son was suspended, and no service had been provided, whilst Kate’s son used to attend speech and occupational therapy, both services were suspended. After some time, they were offered online speech therapy sessions. Kate narrated that she could not take the offer because “kienet qisa iktar ħin fuqi ridt indaħħal il-homework, ix-xogħol u ħa nerġaw nagħmlu siegħa oħra, bażikament tagħtik l-instructions u terġa tagħmel is-session inti u għalhekk waqqafnih” [it entailed more time from my end, I had to squeeze in homework, work and then spend another hour to repeat the instructions that were given during the session, so we had to stop the service]. These daunting experiences contrast primarily with Anna’s positive online experience.

One of the best things we ever did

Anna’s experience was quite a breath of fresh air. Her son used to attend Hand In Hand services before COVID-19, and when the partial lockdown started, they switched to online services. Although at first she was “filled with dread, this is not going to work out”, she was delighted, and she said that “it turned out to be one of the best things we ever did”. She felt that having the therapist on WhatsApp with the headphones, whilst the therapist could see her child on Skype, the sessions were carried out smoothly. They continued working on the same things they used to do before, but “it was carried at home on the kitchen table, and I would be conducting it”. Anna felt comfortable and confident as she had the therapist “in my ear with the headphone telling me what to do”. This way, the therapist could correct her or tell her that she was doing well. Anna was pleased with the service and felt that they “ended up tackling many home issues like brushing teeth, life skills, more reading and literacy skills” throughout these sessions.

From the data presented above, it is evident that before the COVID-19 pandemic, parents of children with autism faced various barriers in obtaining high-quality care for their children during extracurricular activities. The pandemic exacerbated these pressures even more, as four parents reported losing all the services their children had benefited from before COVID-19. Understandably, COVID-19 brought about significantly limited access to in-person healthcare and educational services to all service users due to fear of increasing the spread.

During the initial weeks of the lockdown and post-lockdown period, these services were rendered inexistent as the service providers did not attempt to contact the service users. These participants lost a substantial number of benefits, ranging from physical activity to medical support such as speech therapy and occupational therapy. As highlighted in chapter 2, taking care of a child with autism may take its toll, especially when barriers and lack of support are experienced. This lack of support is what some of the parents have experienced during the past months. Although some of the parents felt that the lockdown was beneficial as they did not have to face the problems they encountered with different providers, I believe this is only a temporary solution. As discussed in chapter 2, keeping the children home will create more barriers to valuable services such as education. It will impose more stress on the parents as the situation will create a collision of roles. Moreover, the parents will surrender the social model of disability and endorse the medical model where the children are seen as subjects to be fixed rather than fixing the barriers created by society due to the attitudes which exclude people with autism.

Finding the right balance between taking care of the family and working from home can be a challenge. For some families, the COVID-19 pandemic had amplified this challenge into a logistical nightmare for working parents. In the next section, I discuss the challenges the parents faced when working from home and caring for a child with autism.

Working from home during COVID-19

The COVID-19 crises pushed employers to implement working from home as an alternative measure to combat the pandemic. While the action taken was to mitigate the virus's spread, work from home proved quite challenging for people living in tiny houses (Vyas & Butakhieo, 2020). Moreover, some parents had to juggle working from home and managing their children’s schedule and, as seen earlier in this chapter, also taking the full role of being a teacher and a therapist.

Juggling work, children and family needs

The COVID-19 pandemic has been a period of upheaval for family members. As mentioned above, since every family experienced the situation differently, it is essential to present each of their narratives. Out of the eight participants, two of the parents were stay-at home-mums, while the other six were in full-time employment.

Unlike her husband, Mary's job permitted her to work from home during the partial lockdown while she could tend to her children. On the other hand, taking care of the children while working and reading for a degree was very hectic. She often gave in to the children's demands and would let them play on the computer. Kate also managed to work from home whilst her husband continued working as pre-COVID-19. Kate was inundated with work and found it very hard to support and follow lessons with her son during the day. Jack, the only male participant, managed to work from home. He narrated how his son "iħobb jitfissed per eżempju jiġi ħdejja jġib is-siġġu, u jpoġġi ħdejja jħallini naħdem fehem li papa is working allura ma nistgħux noqogħdu nilagħbu" [loves to cuddle, for example, he brings a chair and sits next to me, but does not interrupt, he understood that daddy needs to work and we cannot play]. Ruby was also teaching online while her husband is a policeman and had to leave the house daily during the pandemic. She recounted that since her daughter was refusing to follow online lessons, it was not stressful when she was teaching online. Ruby narrated that she would conduct her lessons in the morning while her children would watch television or do crafts and then work with them in the afternoon. She found it very tiring and stressful that she had to prepare the lessons for the following day at night.

Similarly to Ruby, Nora was teleworking as well while her husband was still working at the office. She used to work with her son for an hour a day since they had no online lessons and then start her work. She found telework quite convenient as before she had to take leave to pick up her son from school at noon every day. With the partial lockdown, the problem of school pick up was solved. Nora said that she was more relaxed, "għax iffrankajt il-hassle kollu u anke speċi ta' jekk jien ma laħħaqtx nagħmel ix-xogħol kollu filgħodu minħabba fih stjat nagħmlu iktar tard" [as all the hassle was sorted and if need be I could finish all the work later]. In this way, both Nora and Ruby could meet their employment requirements while catering for their children's needs. Although they had to make adjustments, they both felt relieved that they could manage their workload and their children's homeschooling.

Working from home and taking care of the children was quite stressful for the parents. Despite this stressful situation, Mary, Kate, Jack, Ruby and Nora managed to keep up with their work demands whilst also tending to their children's needs. At times the parents gave in to the children's request, such as watching or playing on iPad. Contrastingly, Emma was also working from home whilst her husband was working at the office. She found working from home a nightmare and also expensive. Her job required her to attend online meetings, and these meetings ended up as a "nightmare għax il-ħin kollu jrid ibabas, il-ħin kollu irid jaqtali, irid ikellimhom, emm lill-kollegi tax-xoghol, kelli waħda kienet tghidli 'għandek il-kwiet, mur iċċekkja ara fejn hu it-tifel'" [nightmare situation as during her online meetings, he continually wanted to mess around with my computer, he wanted to end the meeting, he wanted to speak to them, my colleagues, one of them used to tell me "it's very quiet, go and check where your son is"]. She also recounted how once "ħareġ naked behind me bil-camera on, għax kien qed jgħum u iddeċieda li jiġi jittawwal, minn kollox kien jagħmel" [he appeared naked behind me on the camera, because he was swimming and decided to came and have a look, he did all sorts of things]. Emma felt "it was a never-ending saga". To top it all, at one point her boss changed her working hours, and her son had to adapt to a new routine. He found that quite challenging, and he started getting up to mischief while experimenting, such as "kisser il-viti tal-kamra tal-banju, għerreq id-dar, traumatic it was. Darba għidtlu 'stennieni ħa niġi, issa insajru pizza', insib id-dqieq ġol-kċina miftuħ u imxerred, jiġifieri that is the way he rebels|" [he broke the bathroom water taps, flooded the room with water, it was traumatic. One day I told him "wait for me and we'll bake a pizza" and I found the flour open and spread all over the kitchen, so this is the way he rebels]. She recounted how her husband suggested that they should try and teach their son how to use the tools appropriately rather than forbidding him as evidently it was not working anyway. During this period, Emma was quite stressed out and wished that she could engage a person to help her out with her son during the day, but due to the pandemic, it was impossible.

Looking closely at the narratives, it can be said that the majority of the parents combined care for their children and a paid job. Out of the eight participants, five mothers were in employment and opted to work from home; only one father worked from home whilst taking care of his son. Two mothers were not in employment. Lucy, one of the two stay-at-home mums, hoped that one day she would find employment. She recounted that at the moment, it is tough for her to find work since most of her son's health appointments are during working hours.

Furthermore, since her son has a one to one LSE, he is often sent home due to a lack of relievers. Although Lucy wishes to find a job to help the household financially, it is impossible to commit herself to a job, as she must be available when the need arises to take care of her son. This was further highlighted in a recent study conducted by Caruana (2020), where it was observed that the working hours collided with the schedule of services. Sharpe and Baker (2007) highlight that, commonly, one of the parents reduces word hours or steps out of a job to take care of the child

Working from home during the partial lockdown was not easy as one had to tend to the children's needs such as lessons or therapies while working regular hours. Children needed support to complete given tasks from the school, while other therapy sessions required them to be present. Some of the therapists were giving instructions to the parents while the parents conduct the session with their child. The parents found it hard to cope, especially when the employers were inflexible or unsupportive. Emma was exhausted and tense with everything that was going on, but she had to look as she was coping while her son was experiencing stress and anxiety during her online work meetings. Goldberg et al. (2021) highlight how working mothers often experienced stress as juggling caregiving, domestic work, and work often leads to less time for themselves. Indeed, teleworking during COVID-19 presented various challenges. Working from home was not easy for most of the parents. These parents experienced a collision of roles - parent, employee, siblings, teacher, therapist and so on for days, weeks and months.

Moreover, they had to see how to keep their children with autism, siblings and spouses safe while managing this clash of roles (Coyne et al., 2020). Since working from home is still being used by parents who have vulnerable children, guidance and strategies must balance their work demands and assist children with school work (Goldberg et al., 2021). The COVID-19 pandemic has caused a massive change in our daily lives, and these factors affected the experience of staying home while juggling work, homeschooling and parental pressures. These changes happened so abruptly that life adjustments had to happen suddenly, and the transition brought a range of emotions and experiences. These experiences had both positive aspects, such as getting to know the children better whilst enjoying more quality time on, the other hand a negative aspect was the pressure of coping with multitude of tasks and taking care of all the children’s and family needs increased stress and anxiety amongst the parents. As days and weeks passed by the families were slowing adapting to a new way of life which was mostly indoors. During these days families discovered new hobbies and consolidated their family bond, as can be seen in the next section.

Positive outcomes during the partial lockdown

Every cloud has a silver lining. During the partial lockdown, some families had more together time, although it was stressful and the children's demands were reaching new heights. In this section, I first discuss how four families found the time spent together to be beneficial, as they got to know each other better and some of the children learnt new things. In the second sub-theme, I highlight how three parents adjusted their routines to include some physical activity. These parents sensed the need that their children needed to go out and about to let off steam or enjoy the sunshine. They highlighted how they managed to adapt to the situation whilst adhering to social distance.

New hobbies

Emma recounted how during the lockdown, her son developed an interest in cars, and since he had a lot of time on his hands, he used to research car emblems and memorise the specifications. The mother claimed that he used to do the research "all by himself from YouTube". Emma was impressed with her son's love for cars and how he immersed in this new hobby. Nora had a similar experience when her son started swimming unaided in their home swimming pool. She said that it was thanks to the partial lockdown that her son "tgħallem waħdu jgħum għax issa skoprejt kemm jaf, naħseb minn YouTube kollox tgħallem" [learned to swim on his own because now I've realised how much he knows, I think he learnt through watching YouTube videos]. Nora was so pleased and felt more at ease that her son could now swim on his own. Another parent, Kate, narrated how her son found it entertaining to learn prayers and mass in different languages. She recounted that her son used to ask for prayers in a particular language and would then spend the whole morning memorising the prayers from YouTube. During this time, he mastered prayers in Latin, German and Spanish. Jack narrated how their COVID-19 experience drew them closer as a family. They got to know their son better, and their bond grew. Jack was working from home, and they spent three months together. They watched the news, and his son started to be more attentive to his parents, something that was never done before. Moreover, his son started talking more spontaneously, such as "ikun hemm l-aħbarijiet għaddejjin, inħobbu naraw it-Taljan, u jkun hemm xi tnejn jitkellmu bit-Taljan, u jinduna u jgħidilna 'look like going with the plane', għax jaf li morna l-Italja" [when the news is on, we like watching Italian television, and two people are talking in Italian and he realises and tells us "look like going with the plan" because he knows we went to Italy].

Engaging in activities that are fun and enjoyable adds to the feel-good factor in life. Children with autism might find it quite challenging to develop these skills and interests because these activities are not formally learnt. As discussed in chapter 2, some parents might find it quite challenging to combine their daily activities and taking care of a child with disabilities. At times, people with autism do not discuss their particular interests as they fear that they might be ridiculed (Jordan et al., 2012). Moreover, society dictates what is best for the child with a disability (Shakespeare, 2006). Spending time at home allowed these children to feel comfortable in their safe zone while their parents could reach out and tap into their interest. This allowed the child to be more independent and equal in society whilst it allowed choice and control over their interests. This simple example highlights how different barriers hinder children with a disability from taking part in society. Removing barriers and allowing choice and control, persons with a disability can have the same opportunity as someone without a disability to determine their interests and develop new hobbies.

The need for fresh air

During the interviews, some parents highlighted the importance of fresh air and physical activity. Three of the participants recounted that they could sense when their children needed to go out and about.

After some days stuck inside, Anna narrated how she used to feel that her son 'gets cabin fever' and starts to misbehave. During the pandemic, Anna mitigated this challenge by setting up a rooftop garden where they spent nearly every day. She believed that "they needed that sunshine", and up there, they could play with their toys while keeping safe'. Kate reported that she gives "mental health top priority" and used to go out just the same. She explained to her son that "ma immorrux fejn hemm ħafna nies, ngħidu aħna ħa mmorru nieħdu l-arja, ħa nagħmlu l-eżerċizzju" [we couldn't go where there was a lot of people, for example, we are going to have some fresh air, to do exercise]. In March and April 2020, weather permitting, they used to go for picnics by the beach. After spending five months inside, Emma also recounted how her son needed to go out for some fresh air as his behaviour was getting out of hand. She decided that "dan it-tifel irid joħroġ minn hawn ġew u kont literally insiblu x'imkien ġol-kampanja u jagħmel siegħa jiġri, ġol-għelieqi" ['this boy wants to get out of here and I would literally find somewhere in the countryside and let him run around for an hour, in the fields'].

At the beginning of the pandemic, people hoped that COVID-19 would only last weeks, maybe a few months. Sadly this pandemic is lasting much longer. The partial lockdown brought home confinement for the majority of families and their children with autism. Some children with autism felt the need to be physically active, and staying indoors for an extended period, at times triggered challenging behaviour. The importance of physical exercise was accentuated earlier in chapter two. As weeks and months passed, the parents tried to establish a new way of getting out and about for that much needed fresh air whilst adhering to social distance and the Maltese Public Health Authorities protocols.

As summer 2020 drew to an end, it seemed that things were at a standstill. Parents were still confused about the many unknowns, and this uncertainty created more stress and anxiety as they could not plan an exit strategy to the new normality. It became clear that this new kind of life will continue to look different for quite a while. Parents started slowly adjusting to new routines as they tried to create new normality for their families.

New Normal

Many people are daunted by the prospect of adjusting to the new normality (Rab et al., 2020). When the partial lockdown was eased, the new normality meant that people had to wear masks or visors to enter shops. Eventually, sanitisers were put in every entrance, shops admit only a certain amount of people, and when out in public areas, one had to abide by health authority regulations where only limited sized groups were allowed. The list of guidelines was presented earlier in chapter two. In this section, I discuss how the families and their children with autism started adjusting to a new way of life, including how the parents introduced the masks to their children and the teaching mechanisms they adopted. The parents also discussed their fear of keeping social distance. The children are still with them at home, but they were concerned that their children would not keep the distance required when school reopens.

Life goes on

Seven out of the eight participants narrated how their children got into the routine of wearing the mask and applying sanitiser, whilst only one parent stated that her son was finding it hard to keep the mask on. Nora was concerned that her son "la maskra u anqas visor ma jrid irid iżomm f'rasu hawn itajjaromli jiġri l'hemm" [was refusing to wear a mask or a visor, he tore them off and ran away]. She was concerned that now her son has to keep social distance and cannot hug anyone. She was finding it difficult to teach him to keep at a safe distance and was worried that if schools had to reopen, it would be an issue for her son to keep the mask on and a safe distance from other students and educators. The other seven participants narrated how their children adjusted to wearing masks and applying sanitisers. Emma recounted how it was challenging to teach her son to wear a mask, but then he understood that he has to put it on. He got used to the routine "jaf li intih il-mask, imur jaħsel idejh u jaf li irid intih it-temperature, jaf kif jagħmilha" [he puts on the mask, washes his hands and also waits for the temperature check, he is also able to check it our all by himself]. She was pleased that her son adapted to the new routine in little time.

Lucy still tries to leave her son at home as much as possible, and she prefers to do the errands on her own but narrated that "meta kellu bżonn libisha, ma jiddejjaqx" [when there was the need, he put it on with no hesitation]. Anna recounted how her son wanted books and when the partial lockdown was lifted, the first shop they visited was the bookshop. She stated that "they kept telling him and telling him and he understands now". Her son now understood that he needs to put on the mask and sanitiser. Mary recounted that her daughters only put on the mask for a brief amount of time. They just put it on to buy basic stuff and avoided going to the hairdresser as they had to put the mask on for a longer period. Jack's son associated the mask with his favourite cartoon "hu iħobb jara PJ mask, darba darbtejn qagħdna nilagħbu taparsi PJ mask u issa jaf li kif jidħol irid jilbes il-mask u jżommha" [he loves the PJ mask. We play being PJ a could of times and now he got into the routine of wearing the mask, and he keeps it on]. Jack believes that teaching his son in a fun way and with things he relates to helps him associate and assimilate the routine required.

Similarly to Jack, Kate recounted how they introduced the masks as a game "meta l-affarijiet nagħmluhom bħala logħba mexa" [when we turn things into he understands better] and through the game, her son adjusted to the wearing of the mask with no difficulties. Both parents highlighted the importance of introducing the mask as a game. In this way, their children adapted to the change in no time and with no resistance. Six out of the eight parents expressed their concern when it came to social distance. The most challenging part of the whole situation was explaining the social distance measure as the concept is quite abstract for the child. They are all weary that their children will not keep the distance suggested by the health authorities. Although they try to emphasise that hugging and touching people is not recommended, both Nora and Lucy said that their children could not understand the concept of social distance. Nora said that this will be quite a challenge for her son to understand as before they used to encourage hugging, but now it is the opposite.

COVID-19 pandemic has changed our lives entirely whilst it affected people in different ways. Amaral and Vries (2020) accentuate that children with disabilities may find it harder to adhere to frequent handwashing practices and consistent wearing of masks. Significantly, these findings mirror the parents' fears along with the issue of keeping social distance. Children with autism may “lack the instructional control to adhere to hand washing, refrain from face touching” (Sivaraman et al. 2020, p.71). Although most participants recounted how their children adapted to wearing masks, little is known on how it is worn, the steps of taking it off and washing or sanitising hands. Moreover, it is still early to evaluate if the concept of social distance is maintained as the children were still safeguarded within the family bubble.

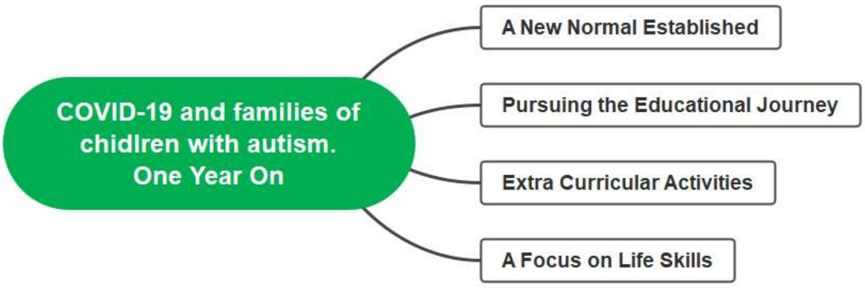
This ever-changing situation required parents to adapt to new circumstances in no time. The parents had to adjust to new routines and adjust the learning to teach new situations to their children, such as playing games to help the child adapt to the wearing of a mask. Parents also celebrated the child’s achievements with rewards, such as when Anna’s took her son to the bookshop. In the next section, I will present the second set of interviews held in February 2021, nearly a year after the pandemic onset.

One year on

The eight participants were contacted again in February 2021 to take part in a short interview. The parents were asked if they wished to give an update about their experience of COVID-19 and their children with autism. Out of the eight participants, six participants replied to the email and eventually took part in the second interview.

Figure 2

Themes from follow up interviews



A New Normal Established

During the interview, the six participants stated that now a new routine has been established. All of the participants were feeling better now than at the onset of the pandemic. In autumn 2020, Ruby recounted that the family was so stressed with the circumstances that they were on the verge of a marriage breakup. She felt that all the restrictions and taking care of the family were the disgruntlement's central issue. Ruby, Emma and Anna stated that they had got used to the new normal and got on with their lives. They are all meeting other people, used indoor pools and also went shopping with their children. As discussed earlier in this chapter, this new routine contrasts with the disease's initial fear when they spent most of the time indoors or exercising in remote areas. Also, Anna had words of praise for the speech therapist as she resumed her sessions on a one-to-one basis. Jack, Lucy and Nora are still afraid of meeting and mixing with other bubbles. The three parents keep the shopping trips to a minimum, and the children are left at home to avoid unnecessary exposure. Lucy is still very attentive, and they only meet the grandparents in a field that they own whilst Jack and Nora are still not meeting the grandparents at all. All the families take the necessary precautions such as frequent hand washing and the proper wearing of a mask. Undoubtedly, these parents are still afraid of unnecessary interactions with people other than their immediate family. Their decision to hold back on interactions with others decreases the infection risk, as asymptomatic people can spread the virus (Lund et al., 2020).

Pursuing the Educational Journey

Jack, Anna, Ruby, Nora and Emma said that the children were very happy at school. Lucy, Anna and Ruby's children settled well at school. Ruby and Nora recounted that their children were given the same LSE they had the previous academic year, so they felt comfortable as they knew their LSE. This contrasts with the previous year's experience where the children found it hard to build attachment with their supporting LSE. Anna and Lucy had two contrasting experiences. In summer 2020, when I conducted the first interview, both parents were concerned about their child's transition from one school to another. This time around, Anna was full of words of praise for the secondary school transition. She said that the transition was held at the new school. It took about 20 mins, the child was introduced to his LSE, and they also showed them around and eventually his classroom. The school organised a proper handover from the middle school to the secondary school, and the parent felt reassured and happy. She also said that the LSE was chosen purposely for her son, as she had experience with children with autism. The LSE and her son immediately got on well, and he was doing great at school.

On the contrary, Lucy had no handover whatsoever. Although she was promised a meeting, no transition was held. She also sent various emails to which she got no reply. At the beginning of the academic year, she was reluctant to send her son to school, but she felt it was not right to keep him at home as he would lose out on his education. The first weeks were not easy. Her son could not explain what was going on at school, and his mother kept receiving negative points on an online platform that the class teacher used. The importance of a smooth transition was discussed earlier in chapter 2. It is evident that when a proper transition is carried out, both the parents and the child feel secure and settle better at school whilst stress and anxiety take over parents who feel lost and overwhelmed with the transition.

Although Emma did not have a transition issue and, despite being told several times that her son is one of the best students in year 4, the LSE and her son have ongoing communication issues. At the beginning of the year, Emma had explained to his LSE that her son gets the schoolwork done very quickly. Emma suggested that to keep him busy, they should have other material readily available as he is never bored of doing extra work. Notwithstanding this, no additional work or activities are provided for the child, and he ends up getting bored when he is done with his work. When boredom takes over, the child gets into a mischievous mood, such as pouring glue into the LSE’s handbag. Because of this behaviour, Emma was getting 5 to 6 messages a day regarding her son’s behaviour. These calls were causing stress to the mother. To end this stressful situation, Emma had no other option than to engage a private behaviour specialist, so the school's behaviour is dealt with through the specialist. As discussed in chapter 2, these episodes highlight that it is pretty challenging to meet all the students' needs. Despite this, the educators mustn't view the disability as belonging to the child, but a human diversity. Individualised support and services should be put in place to mediate the socially constructed barrier.

Nora and Jack’s second interview took place after the second school lockdown. The second month-long school closure was announced on the 11th March 2021 (Times of Malta, 2021). The schools' premises were to remain closed till the 12th April 2021, just after the Easter holidays. Hence schools migrated to online daily live lessons for more than two whole weeks.

Nora’s son was doing well at school, despite the mother’s fears that he would not keep his mask on, which she had mentioned during the first interview. She recounted how her son adjusted to the new school and got used to the school’s morning routine, including putting on his mask, waiting for the temperature check, and sanitising his hands upon entrance. He is happier at school and, as mentioned before, he has last year’s LSE. Nora stated that, despite his behaviour changing drastically for the better, they are still required to drop their son later in the morning and pick their son up at 12.30 pm. This time around, her son is following the lessons with the help of an adult. Both parents are still working. Although online schooling and working out adaptations add pressure, they are pretty happy with online schooling as their son can follow the first and last lessons, which he usually misses. Nora had words of praise for most teachers as they do their utmost to include her son in the online classes. This contrasts sharply with last year’s experience, discussed earlier in this chapter.

Jack’s son had settled well in October 2020 when schools reopened, so much so that in his half-yearly exams, he did very well, and his parents were pleased with his achievement. Unfortunately, in January 2021, Jack’s son was sick for the first week, and then all his classmates went into quarantine. Jack recounted how once again, his son refused to follow online live lessons. After quarantine, it took him two weeks to settle down and adjust to the routine. Sadly, just after a couple of weeks from settling down, the schools were closed for a month. Jack narrated how his teacher and LSE have tried hard to include his son in online live lessons, but his son refuses. Implementing these lockdown measures became quite challenging for the parents and stressful for the child who missed his education. It is a pity that, once again, the one size fits all measure was adopted. Furthermore, this narrative resonates with an article published on a local news portal where some Maltese parents voiced their concerns about how their children are missing out when online live lessons are the only option (Vassallo, Sam., 2021).

Extracurricular Activities

Lucy and Nora are still reluctant to let their children engage in any extracurricular activities – before the pandemic, they attended sports sessions. Nora's son still practices sport with her at home and attends online speech therapy sessions. Jack is still vigilant and recounted that a private therapist was following his son but, due to the increase of daily active cases, they decided to stop the sessions for the time being. Lucy's fears contrast with Emma, Anna and Ruby's point of view. They narrated that they felt that it was important for their children to get back into a routine and participate in after school activities. They claimed that their children are aware of the virus and keep their masks on. Anna's son is attending private speech therapy. The sessions are held on a one-to-one basis in a private clinic. Furthermore, he is still following the piano lessons he had started during the pandemic. Emma and her son have restarted their swimming lessons. They are attending Inspire six times a week. On Saturdays, her son has lessons with a teacher he loves and is proficient with children with different needs. Ruby's daughter started attending speech therapy at the Health Centre, but her speech therapist got pregnant and is now giving online sessions.

Historically children with disabilities were marginalised from an inclusive school setting. While it is understandable that some of the parents were hesitant to send their children to school because they were concerned about their children's wellbeing, parents need to take care that through their actions, they are not perpetuating the marginalisation once again. According to the parent's narrations, the children have managed to adapt to the new normal, notwithstanding the parents' concerns during the first interviews.

A Focus On Life Skills

Both Lucy and Emma had narrated how their children spent time researching toys and games on the internet. As mentioned earlier, this habit was developed during the first weeks of the pandemic. Six months on, the children were still pursuing this trend. Both parents tapped on the children's interest and took the opportunity to teach the value of money to their sons. Through this interest shown by their children, both Lucy and Emma encourage their children to save up by doing chores around the house. When the boys misbehave, the parents give their children a fine, and the child has to pay back a fee. The parents said that the boys are adding the money they are earning, counting how much more they need for the toy and understanding that they have to work hard to earn money. Emma stated that her son’s behaviour improved as he does not like it when he is made to pay a fine. Moreover, when they enter a shop, and he requests a new toy, she reminds him that he will be spending from the money he was saving, and in this way, the tantrums for toys have drastically diminished.

In these follow-up interviews, it was evident that some of the parents have adapted to the situation and have developed new strategies to teach essential skills to their children through play. Although the parents perceived the wearing of the mask as onerous (Pace Gasan et al.,) all the children adapted to masks wearing and were back at school. While some of the children settled down with their LSE, there are some cases where the parents still struggle for their child’s rights. Additionally, Nora’s case where the drop-off and pick up times of her son differs from his peers is still a concern. Evaluating the circumstances, it is evident that some of these uncomfortable situations are created by society and were compounded by COVID-19.

Conclusion

This study explored the effects of the COVID-19 pandemic on families of children with autism. COVID-19 pandemic created a whole set of new challenges in various aspects of our daily lives. Allowing the parents of children with autism to take control while narrating their COVID-19 experience allowed me to understand how these families perceived the experience of living during the pandemic. Most of the families highlighted how, in this challenging time, they were left to fend for themselves. Since schools and services were all shut, the families and their children with autism were confined at home. This triggered various challenges as routines were disrupted, contributing to more stress on the parents and the children alike. As discussed in chapter 2, it is the child's right to have good quality and inclusive education. The narratives transpired that not all the children were given this opportunity even before the onset of COVID-19. Still, instead, the child was often seen as a problem in various extra-curricular activities. The impact of COVID-19 restrictions exacerbated the parents' challenges before the partial lockdown was set in place. This contrasts mainly with the social model of disability, where the aim is to remove the barriers so that everyone has the same opportunity.

Another aspect that is creating problems is the assumption that these children have limited capabilities. As narrated by the parents, some of the children could engage in new hobbies such as learning how to swim or learning prayers in different languages. Kok and Gan (2012) highlight that we should not ‘assume limits to what they are capable of but admit that our knowledge of their capabilities is limited’ (p.193). Providing choice and control to children with autism might be an effective intervention for active participation. Although challenging, parents can play an essential role by advocating for their children’s views to be heard. There are various child-friendly ways in which the children can be involved in decision making. When children are involved in decisions that affect them, it instils a sense of self-advocacy whilst promoting the idea of choice and control that fosters autonomy at a young age. As discussed in chapter 2, the UNCRPD highlights that it is the child's right to express their opinions about issues that affect them and the right to equal opportunities. Having all the stakeholders on board will provide a clear direction of the child’s educational journey in a more inclusive and equitable learning environment.

In the next chapter, I revisit the themes discussed in light of the research questions outlined in chapter one and reflect on the outcomes to develop further research and policy and practice suggestions.

CHAPTER 5

This final chapter presents the main findings elicited in this study and a comprehensive answer to the research questions. Following that, the research implications for current practice and policy are discussed along with recommendations about practice issues, policy matters, changes to existing services, and advocating for new services. The strengths and limitations of the research are discussed whilst suggestions for further research are provided. A plan for disseminating the research results and a personal reflection about this research process and along with my personal growth, conclude this dissertation.

Main findings of the study

This study aims to document and promote the voice of families of children with autism during the COVID-19 pandemic. At the same time, I offer an analysis of these families' experiences during the partial lockdown and its aftermath, with a specific focus on education. Education is taken in the broadest sense, including curricular and extracurricular activities. In chapter 1, I present the following research questions:

How has COVID-19 affected children on the autism spectrum and their families?

How has COVID-19 affected the education of children on the autism spectrum?

In the next section, I present the main findings through the lens of these research questions.

COVID-19 and its effects on families of children with autism

This study found that most families who participated in the research rely on extended family support. With the pandemic's onset, the families found it very hard to cope with the new strenuous situation. While before the pandemic, they had a daily routine; the pandemic disrupted their daily rhythm in various ways, as discussed in chapter 4. Some parents said that support services evaporated, and the children and their parents were left to fend for themselves for days. While some of the participants found emotional support from their extended families and a helping hand in chores, others struggled to cope independently. The social distancing measures impacted the families so much that they had to give in to their children’s demands. Families tried hard to adjust to the new routine with little help from the extended family, whilst the pandemic brought new fears and concerns. This situation further accentuated how at times, grandparents found it hard to accept that their grandchildren have autism. Occasionally, this denial increased pressure and rifts within the extended family as the parents felt coerce. Induced by the lack of help and understanding, the parents felt the need to teach independent living skills to their children with autism as they felt that these skills are essential for their future. Although the situation was quite challenging, most of the families settled into a new routine. Several parents highlighted that it was necessary to establish a new routine for the children and their parents alike. These routines played an essential part in the daily structure as most parents were working from home. As explained in chapter 4, working from home and taking care of the children concurrently was not an easy task for the parents as they were juggling several roles at a time. Staying at home for an extended period also created a sense of cabin fever. The parents mitigated this challenge by finding remote areas where they could exercise whilst keeping safe. Later on in the year, the wearing of masks in public places was set in place. Most parents managed to turn this practice into a game, and the children adapted well to the situation. As time passed, some parents maintained that the children got used to wearing the mask but were still concerned if their children would adhere to social distancing. Parents stated that they were finding it hard to teach their children to keep social distancing as it is somewhat an abstract thing to teach, and it was turning out to be quite challenging.

COVID-19 and its effects on the education of children on the autism spectrum

There was a range of effects on education; while some of the schools provided online live lessons, others only provided Powerpoint presentations or handouts. Most children with autism found it hard to follow online live lessons as they did not feel engaged. The parents felt pressured and stressed to cope with their child’s education and work simultaneously. Most of the parents maintained that the work given to their children was not adequately adapted to their child’s needs. Moreover, printing the educational material added to the pressure since not everyone has a printer at home. While some of the educators kept contact with the children, others just handed over documents to the parents, and no further support was provided. It was also maintained that some of the children with autism do not have friends but rather acquaintances. None of the children in this research asked to meet or speak to their friends during the partial lockdown. The parents also highlighted how the transition to new schools is subjective and varies from one state college to another. As discussed in chapter 2, these transitions are significant for the child as it helps them adapt and know what to expect from the new school and staff.

Extra-curricular activities were also suspended. The only services given to two of the children were private online live sessions for speech therapy, one of which was conducted by a practitioner based in another country. Both parents of the child participating in this activity maintained that they were engaged in the session and felt satisfied with the quality of service . All other services were halted, and no service was provided to the children. When the partial lockdown measures were eased at the end of June 2020, some of the services were restored. Although all health protocols were in place, not all parents felt comfortable sending their children to extracurricular activities. During this time at home, some parents claimed that they built a better bond with their children; others maintained that the children with autism fostered new hobbies. Some parents turned the situation into an opportunity to instil the value of money by asking them to do chores while the child saves for the objects requested.

Implications and recommendations

This research highlights the implications that families of children with autism have gone through the first partial lockdown. These are valuable findings that give an insight into the daily challenges these families have experienced. Some of these implications are socially constructed barriers that, with willingness and thought, can be overcome. One of the highlighted implications was that the children found it very hard to follow online lessons. On the other hand, on two separate occasions, children could follow online live speech therapy sessions. Maybe it is about time that all LSEs are trained to conduct online or face-to-face sessions on a one-to-one basis with the child they are supporting. It isnoted that children with autism found it hard to follow online class lessons. Alternative measures such as schools' opening to offer one-to-one contact sessions for children with disabilities will help them access education and keep abreast with their peers.

Another important implication is the transition from one school to another. The school transitions is another point that raised concerns and fear among the parents in the first round of interviews. In the second interview, two contrasting transition experiences were narrated where one of the participants stated that it was a well-organised transition. The child was shown around the school, and he was introduced to the LSE that would be supporting him throughout the year, whilst the other parent claimed that no transition was organised and her emails were left unanswered. The transition is usually left in every school's hands; there needs to be a policy where the colleges guide how the transition should be done. In this manner, the right to proper transition is given to all children with disabilities, and their parents can put their mind at rest.

Undeniably COVID-19 affects the help from extended families, carers and other services. Whilst it is understandable that the sudden onset of the pandemic created fear, and the services were suspended, a plan to mitigate these challenges needs to be put in place so that the families can be alleviated should the need arise again. It is pretty discouraging to discover that parents claimed that most of the services are not back to a new normal a year on from the onset of the pandemic. It is something that should be given thought, and ways to ease these challenges should be sought. One way to mitigate this challenge is by keeping the support services open, either by rotation or by appointment, while adhering to all preventive precautions. This should help alleviate the stress on the families whilst also coping with working from home, and most importantly, children with autism are given the much-needed service.

Limitations and strengths of the study

Few – if any – people remember a pandemic outbreak to this scale, let alone having the possibility to conduct research related to these unprecedented times. This study contributes further to the research carried out by CRPD (Pace Gasan et al., 2020) as it gives a voice to Maltese families of children with autism at the onset and during the COVID-19 pandemic.

Strengths

Amongst the strengths of this study, the most notable is its size. Having only eight participants allowed me to delve deeply in detail and in-depth into the narratives whilst tapping on important points that emerged during the discussion. This was possible since this research framework allowed me to revise the direction of the interview. These family narratives were rich in data and provided an insight into the family life during the onset of the pandemic and adapting to the new normal as time went by. Since no two families are the same and each family has its particular needs and dynamics, the generated data differed as no two families go through the same process. Additionally, to have the latest version of events, the parents were again contacted in February and March 2021. These insights from the research are valuable and can be used in the eventuality of another prevailing situation. Furthermore, these intuitions can be used even once we emerge from the pandemic.

Moreover, these insights will be valuable to plan and mitigate the challenges and barriers encountered during this challenging period.

Limitations

Whilst every effort was made to keep the researcher's influence, biases and idiosyncrasies at bay, my influence cannot be removed entirely. Additionally, since the situation is continually evolving, the families' situations can continue to change for better or worse. Moreover, given the nature of the autism spectrum, and the particular difficulties each family faces, one must keep in mind that no two families go through the same process.

Further research

This research is topical as it was carried out relatively soon after the start of the pandemic. This study's findings might engender further research, including issues that are not directly linked with the pandemic but emerged in this research. Below I put forward three suggestions:

This study has confirmed that schools' transitions are not congruent but are left for the SMT to decide if and how they are carried out. It is quite puzzling to see that some schools take transitions very seriously whilst others not so much. It would be interesting to explore the key aspects of transitions from primary to middle schools and secondary schools for children with disabilities.

Another exciting research would be to explore friendships between children with autism and their peers. Some of the parents claimed that their children do not have friends, but they are instead acquaintances. It would be interesting to explore what children with autism consider friendship whilst triangulating this research with educators and parents.

Lastly, during the partial lockdown, children with autism developed new hobbies. Some children had time to research and learn new things from the internet. It would be interesting to see if these hobbies were pursued and if these hobbies led to new learning areas.

Potential dissemination of the findings

Although this was a small-scale study, several noteworthy findings contribute to the field of disability. While these findings might be pertinent for future research, the dissemination of the research findings might also be relevant to practitioners working in the field of disability, especially in the area of autism, such as educators, therapists and policymakers. Due to this, I intend to publish a paper with the findings of this study in suitable fora.

Additionally, since I am an educator and work in a junior school, I intend to present these findings to my Head of School and the SMT to influence my school's policy and practice. Sharing these findings might encourage the SMT to develop preventive measures while seeking that the measures are abided by all the educators concerned. This might enhance the children's well-being with autism whilst mitigating unnecessary stress and anxiety for both parents and children alike. Should the ongoing pandemic persist for a more extended period, or a new pandemic or other emergency presents itself.

Personal reflection

The idea for this study originated just as the COVID-19 pandemic reached our shores in February 2020. At that time, I was about to embark on a different research journey. Since some restrictions had just been put in place, I decided to change my study as the previous research was not viable anymore.

Carrying out this study was not an easy journey, especially since all the procedural requirements had to be carried out quickly to acquire the ethical clearance for this study. Once the journey started, it was an emotional roller coaster ride. At times, I felt happy with the progress made, while sometimes I felt disappointed as work took over and my research had to be put aside. Once I started listening to the families' stories to gather the data, it became evident that this study was needed to shed light on the challenges the families were facing. Throughout my studies in these past three years, I feel that I have grown holistically. I am a teacher by profession, a mother and a person with a hearing impairment. I now feel much more confident to promote and advocate for the rights of people with disabilities. Reflecting on my practice, the social model of disability fits in nicely within my line of work. The chosen design fitted my research like a glove as it allowed me to listen to the families' narrations, and their voices and hardships could be heard. The first set of participants poured in, but there was a slight decrease in participation in the second interview. The decrease was expected since the first set of interviews was held in summer 2020. The second set of interviews was held when the number of positive cases was on the rise again, there was a feeling of uncertainty, and schools eventually went online for the second time. I wonder how these families were coping. Yet, the data was so rich that I still feel that overall, the interviews were an accomplishment and that the data generated was valuable and significant for my research.

My initial thoughts for this research were to listen to the views and stories of families of children with autism and put forward their narratives about how COVID-19 has affected their family lives. Although most families confirmed this assumption, further exciting points were mentioned throughout the narratives, such as how the parents bonded better with their children and new hobbies were developed. This study is valuable because, although all the families interviewed had a child with autism, all the family circumstances are unique. They are a direct reflection of what the participant deemed significant. Going through the parents' narrations, it is evident that some of the parents were already encountering difficulties and challenges before the onset of the pandemic. Still, in some cases, the COIVD-19 pandemic compounded these problems. This study helped me understand that the one-size-fits-all approach for children with autism creates a hardship on the child and the family.

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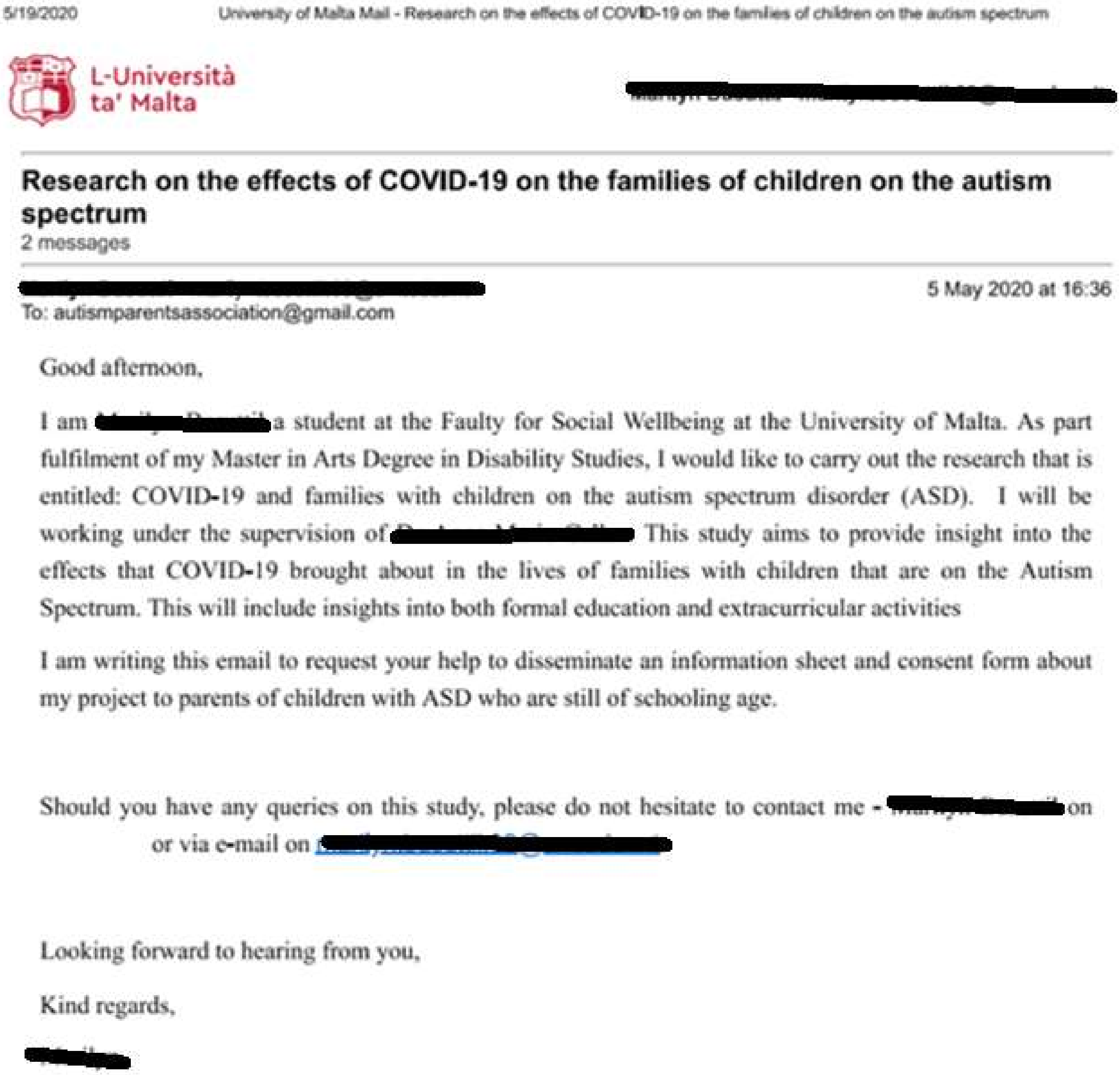
APPENDIX A: RECRUITMENT EMAIL



L-Università
ta' Malta

[redacted]

Research on the effects of COVID-19 on the families of children on the autism spectrum

2 messages

[redacted] 5 May 2020 at 16:36
To: autismparentsassociation@gmail.com

Good afternoon,

I am [redacted] a student at the Faulty for Social Wellbeing at the University of Malta. As part fulfilment of my Master in Arts Degree in Disability Studies, I would like to carry out the research that is entitled: COVID-19 and families with children on the autism spectrum disorder (ASD). I will be working under the supervision of [redacted] This study aims to provide insight into the effects that COVID-19 brought about in the lives of families with children that are on the Autism Spectrum. This will include insights into both formal education and extracurricular activities

I am writing this email to request your help to disseminate an information sheet and consent form about my project to parents of children with ASD who are still of schooling age.

Should you have any queries on this study, please do not hesitate to contact me - [redacted] on
or via e-mail on [redacted]

Looking forward to hearing from you,

Kind regards,

[redacted]

APPENDIX B: BLURBS ENGLISH AND MALTESE

Hi,

My name is Marilyn Busuttil, and I am a student reading for a Master of Arts in Disability Studies at the University of Malta. I am presently researching as part of my dissertation titled COVID-19 and families with children on the Autism spectrum. This is being supervised by Dr Anne-Marie Callus email: [redacted] The aim of my study is to provide insight into the effects that COVID-19 brought about in the lives of families with children with autism.

Do you wish to narrate the experience of COVID-19 and its effects on your family life? If yes, you can either text me on ******** or email: [redacted] and I will get in touch with you.

Thank you for your time.

Marilyn

Hi,

Jiena Marilyn Busuttil studenta li qiegħda nsegwi kors ta’ *Masters of Arts* fuq Studji tad-Diżabilità fl-Università ta’ Malta. F’dan il-kors jiena qiegħda nagħmel riċerka bit-titlu COVID-19 and families with children on the Autism Spectrum. Din ir-riċerka qiegħda sseħħ taħt is-superviżjoni ta’ Dr Anne-Marie Callus (Lettur fid-Dipartiment tal-Istudji tad-Diżabilità, fil-Fakultà għat-Tisħiħ tas-Soċjetà) email: [redacted]. L-għan ta’ din ir-riċerka hija li tipprovdi ħarsa fuq l-effett li COVD-19 ġabet magħha fuq il-familji li għandhom tfal bl-Awtiżmu.

Tixtieq taqsam l-esperjenza tiegħek dwar l-effett li COVID-19 ħalliet fuq il-familja tiegħek? Jekk iva, tista’ tibatli messaġġ fuq ******** jew email fuq [redacted] u jien nagħmel kuntatt miegħek.

Grazzi tal-ħin tiegħek,

Marilyn

APPENDIX C: COMBINED INFORMATION LETTER AND CONSENT FORM IN ENGLISH AND MALTESE

7th May 2020

Information about the study

My name is Marilyn Busuttil, and I am a student reading for a Master of Arts in Disability Studies at the University of Malta. I am presently researching as part of my dissertation titled COVID-19 and families with children on the Autism spectrum. This is being supervised by Dr Anne-Marie Callus email: [redacted]. My study aims to provide insight into the effects that COVID-19 brought about in the lives of families with children on the Autism spectrum.

Your Participation

Any data collected from this research will be used solely for the purposes of this study.

Should you choose to participate, you will be asked to participate in an hour-long, one-to-one online interview. The interview will be undertaken at any time convenient to you.

Data collected will be generated through the use of audio recording during the online one-to-one hour interview.

Participation in this study is entirely voluntary; in other words, you are free to accept or refuse to participate without needing to give a reason.

You are also free to withdraw from the study at any time and up to three weeks after the interview, without needing to provide any explanation and without any negative repercussions for you. Should you choose to withdraw, any data collected from your interview will be deleted.

If you choose to participate, please note that there are no direct benefits to you. This research will help support providers to plan and mitigate problems should the eventuality arise in the future.

Your participation does not entail any known or anticipated risks. All precautions to minimise vulnerability will be taken. Should the need arise, the participant will be referred to the school phycologist.

Data Management

The data generated will be treated confidentially. A pseudonym will be given to the participants to help preserve anonymity, and within the limitations of the law, confidentiality will be respected at all times. Rest assured that personal details will remain confidential. Every effort will be taken to ensure that you are not identifiable. However, since the sample is small, anonymity cannot be fully guaranteed. Hard copies of interview notes will be kept securely locked away. While files - including computer files and audio recordings - containing personal or identifiable data (such as names) will be encrypted and password-protected and only accessed by myself.

Please also note that, as a participant, you have the right under the General Data Protection Regulation (GDPR) and national legislation to access, rectify and, where applicable, ask for the data concerning you to be erased.

All data collected will be erased following the publication of the result.

Your identity will be revealed/attributed only with your consent.

Participant's consent

☐ I hereby declare to have read the information about the study's nature, my involvement and data management.

☐ I have had the opportunity to ask questions about the study, and my questions have been satisfactorily answered.

☐ I declare that I am 18 years or older.

☐ I understand that should I have any further queries, I can contact Marilyn Busuttil on ******** or email: [redacted] or Dr Anne-Marie Callus on [redacted]

☐ I agree to participate in this research study.

MARK ONLY IF APPLICABLE

☐ I agree to be identified in the research records.

☐ I agree to be identified in the research publications.

Thank you for accepting and finding the time to participate in this study.

_______________________	_____________________
Participant's name (in block)	Researcher's name (in block)
______________________________	_______________________
Participant' signature	Researcher's signature

Date: _________________________

7 ta'Mejju 2020

Ittra ta' informazzjoni dwar l-istudju

Jiena Marilyn Busuttil studenta li qiegħda nsegwi kors ta' *Masters of Arts* fuq Studji tad-Diżabilità fl-Università ta' Malta. F'dan il-kors jiena qiegħda nagħmel riċerka bit-titlu *COVID-19 and families with children on the Autism Spectrum*. Din ir-riċerka qiegħda sseħħ taħt is-superviżjoni ta' Dr Anne-Marie Callus (Lettur fid-Dipartiment tal-Istudji tad-Diżabilità, fil-Fakultà għat-Tisħiħ tas-Soċjetà) emejl: [redacted]. L-għan ta' din ir-riċerka hija li tipprovdi ħarsa fuq l-effett li COVD-19 ġabet magħha fuq il-familji li għandhom tfal bl-Awtiżmu.

Il-parteċipazzjoni tiegħek

Kull informazzjoni miġbura minn dan l-istudju ser ikun użata biss għal dan l-istudju.

Jekk inti tagħżel li tieħu sehem, ser tiġi mitlub biex tipparteċipa f'intervista ta' madwar siegħa. Din l-intervista ser issir online f'ħin komdu għalikom.

L-informazzjoni miġbura ser tiġi r-rekordjata waqt is-sezzjoni ta' siegħa online.

Il-parteċipazzjoni f'din ir-riċerka hija volontarja, kull parteċipant għandu dritt li ma jieħux sehem fir-riċerka jew jieqaf mill-istudju mingħajr ma jagħti l-ebda raġuni, u ma jbati l-ebda konsegwenza.

Tista' twaqqaf il-kunsens tiegħek milli tipparteċipa f'kull stadju tar-riċerka sa anke tliet ġimgħat wara s-sessjoni individwali mingħajr ma tagħti l-ebda raġuni għalfejn ser tieqaf. Kull informazzjoni li tkun inġabret mingħand parteċipanti li jieqfu mill-istħarriġ tiġi mħassra.

Mhux ser jingħata l-ebda ħlas jekk inti tagħżel li tieħu sehem f'dan l-istudju. Però dan l-istudju jista' ikun utli għall-entitajiet li jipprovdu servizzi biex ikunu jistgħu jaħsbu kif jistgħu jilqgħu għal sitwazzjonijiet simili.

Mhux maħsub li l-parteċipazzjoni tiegħek f'dan l-istudju, ser tpoġġik f'riskju. Kull prekawzjoni biex tħares dan ser tiġi meħuda. F'kas ta' bżonn il-parteċipant ser jiġi riferut lil-psikologu tal-iskola.

Informazzjoni miġbura

Kull parteċipant ser jingħata isem fittizju biex il-kunfidenzjalità tinżamm kontinwa matul ir-riċerka u d-dettalji tiegħek mhux ser ikunu ppublikati. Filwaqt li ser nagħmel dak kollu possibbli biex il-parteċipant ma jkunx identifikat fl-ebda rapport jew pubblikazzjoni li joħroġ minn din ir-riċerka, minħabba n-natura tar-riċerka u li l-grupp huwa żgħir, xorta waħda jibqa' riskju żgħir li xi ħadd jagħrfek. Kopji tan-noti waqt l-intervisti u anke traskrizzjonijiet ser ikunu miżmuma f'post sigur u msakkra. Filwaqt li informazzjoni oħra miżmuma fil-kompjuter ser tkun protetta b' *password* li nkun naf jien biss.

Kull parteċipant għandu d-dritt li jaċċessa, jirrevedi, jimmodifika jew jagħżel li ma jssemmix xi informazzjoni li ma jixtieqx li jaqsam ma' ħaddieħor, skont il-liġi tal-*General Data Protection Regulation (GDPR)* u l-liġi dwar il-*Malta Data Protection Act 2018*.

L-informazzjoni miġbura ser tiġi mħassra hekk kif joħroġ ir-riżultat tal-istudju.

L-identità tiegħek tista' tiġi ippubblikata biss bil-kunsens tiegħek.

Kunsens tal-parteċipant

☐ Jien niddikjara li qrajt l-informazzjoni dwar dan l-istudju, l-involviment tiegħi u il-ġbir ta' informazzjoni.

☐ Kelli l-opportunita li nistaqsi mistoqsijiet dwar dan l-istudju u ingħatajt tweġibiet ċari.

☐ Jien għandi aktar minn tmintax-il sena.

☐ Nifhem li jekk ikolli iktar mistoqsijiet nista nagħmel kuntatt ma Marilyn Busuttil fuq ********; emejl: [redacted] jew lil Dr Anne-Marie Callus emejl: [redacted].

☐ Jien naqbel li nieħu sehem f'dan l-istudju.

Immarka biss jekk jgħodd għalik

☐ Jien naqbel li nkun identifikata fl-informazzjoni miġbura.

☐ Jien naqbel li nkun identifikata meta jiġi ippublikat l-istudju.

Napprezza ħafna li tieħu sehem f'din ir-riċerka u nirringrazzjak bil-quddiem tal-kowoperazzjoni u l-ħin tiegħek.

______________________________ ______________________________

Isem il-parteċipant(ittri kapitali) Isem ir-riċerkatriċi (ittri kapitali)

______________________________ ______________________________

Firma tal-parteċipant Firma tar-riċerkatriċi

Data:____________