RENEGOTIATING ROLES, CONNECTIONS, AND RESILIENCE: STORIES FROM FAMILIES OF YOUNG ADULTS WITH AUTISM

Frida Mangion

A dissertation submitted in part fulfilment of the degree of Master in Family Therapy and Systemic Practice

Department of Child and Family Studies

Faculty for Social Wellbeing

University of Malta

2023

Abstract

This qualitative study explores the process of renegotiating roles, connections, and resilience in families of young adults with autism. Autism is characterised by persistent impairments in social functioning and communication which significantly impact one's social, occupational, and daily functioning across the lifespan. The functioning and dynamics of families of individuals with autism are particularly affected by this condition. A narrative analysis (NA) was adopted, and eight individual semi-structured interviews were conducted with two families, comprising two young adults with autism, their parents, and their siblings. Findings were analysed and interpreted using the social model of disability, family systems theory, resilience theory, family life cycle model, and attachment theory, which also served as the theoretical frameworks for this research. This study revealed that as expected, the whole family unit was impacted by autism spectrum disorder (ASD), but the member were also affected in diverse ways, based on their position in the family, understanding of ASD and the dynamics going on within the family over time. Practical implications of supporting families of individuals with autism through family therapy and systemic interventions are discussed. Suggestions for future research are also presented.

***Keywords**:* renegotiating roles, connections, resilience, ASD, narrative analysis, family unit, family members, family therapy, systemic intervention, and sources of support

Dedication

Dedicated to you, MUM,

our guardian angel,

an embodiment of resiliency.

Your unconditional love brought me to this field.

You ignited in me the fire to hold, especially the invisible ones.

Never forgotten, and dearly missed!

Thank you for listening to my plea and sending the right soul at the right time.

It felt like you stretched your arms through her!

Acknowledgments

First and foremost, I would like to show my deepest gratitude to the participants. Looking back, I recall the exhaustion of searching for participants that fit the research criteria. However, the opportunity to interview both families emerged at the point of giving up. Their rich sharing was a testimony to the validity of this research. Despite their tight routines, I am eternally grateful for the families' commitment to the interviews. This could not have been possible without the perseverance the gatekeepers.

Special thanks go to my supervisor Ms Elaine Schembri Lia, and my co-supervisor Prof. Anne-Marie Callus for constantly believing in this research despite the ups and downs faced throughout this long journey. Their expertise was crucial for the completion of this project. I also extend my gratitude towards the guardian angels I met along the way for their compassion, wisdom and empowerment through moments of intense hardship. Heartfelt thanks to Ms Mariella Zerafa as she strongly believed that I deserved to be part of this profession, her conviction motivated me to see the light at the end of the tunnel.

This journey brought me close to amazing peers who made sure to take care of me until the completion of this project. Therefore, my warmest thanks to the course mates who became close friends beyond the scope of the course. Their ability to embrace my painful moments is a testimony to their big heart; humbly grateful!

Last but not least, my undying supporter, my brother Joseph!

Table of Contents

Chapter 1

Introduction

Preamble

The experience of working within a residential respite home for persons with disability in the last few years has allowed me to witness a diversity of unique realities encountered by families of children with disability. These include parents and couples in conflict due to the added work that caring for a child with a disability has presented them with over time, but also stories of resilience amongst families and communities. While I have encountered many individuals who have daily forged through the ‘costs’ presented by their family members' impairments for the past years, I have also witnessed family members who have been psychologically challenged by the harsh experiences resulting from their relative’s disability. This experience gave me insight into the physical and emotional exhaustion for which parents tend to seek respite. It stirred within me the desire to delve deeper into what contributes to or hinders the adjustment process within the family system as they relate to autism.

Rationale

Autism Spectrum Disorder (ASD), henceforth referred to as autism, is characterised by persistent impairments in social interaction and communication together with a restricted and repetitive pattern of behaviour, interests, or activities (American Psychiatric Association [APA], 2022). Significant impairments in daily functioning are experienced across the lifespan (APA, 2022). Recently, in the United States, the prevalence rate of autism has been estimated to be 1 in 54 (Maenner et al., 2020). The official prevalence of autism in Malta is not known, meaning that these families are unrecognised on a statistics level despite efforts to see them in the policy. However, it is estimated to be similar to the global estimate of the World Health Organisation (WHO, 2023), 1 in 100 children. The rising incidence of autism, sometimes called the ‘autism epidemic’ (Chiarotti &Venerosi, 2020, p.1), might be explained by increasing autism awareness and advanced diagnostic tools. Nonetheless, this rising incidence necessitates a multi-disciplinary research approach to understand further this phenomenon and its effects (Dillenburger et al., 2014). Unfortunately, despite an array of treatment availability and recent studies, the management of autism remains poor (Mubashir et al., 2020).

Within the Maltese context, Caruana (2020) has reported a shared feeling of social exclusion of families of children with autism, which poses a challenge to affected families. However, resilient families accepted the situation and found a positive way forward to live with it (Caruana, 2020). Indeed, abundant discussion about autism revolves around the conceptualisation of the condition as either disability or as a group of distinctive skills that are thought of as strengths (Urbanowicz et al., 2019). Whereas there is truth to each view, there is abundant proof that autism significantly impacts family life (McCafferty & MsCutcheon, 2020). It is argued that a better understanding of the challenges parents of children with autism face can help reduce parenting stress and improve their psychological well-being (Hartley & Schultz, 2015). As the incidence of autism has continued to rise, research regarding the needs of parents of children with autism has significantly increased (DePape & Lindsay, 2015; Hall et al., 2017; McCafferty & McCutcheon, 2020). However, most of the literature in the field of autism is mainly focused on discussing the negative impacts of autism on the family (Potter, 2016).

Two recent meta-syntheses have reported that mothers' inclusion in autism-related research studies is higher than fathers’ (DePape & Lindsay, 2015; McCafferty & McCutcheon, 2020). Research that includes the experience of siblings of individuals with autism is also scarce; as well as studies that consider the entire family's perspectives with a systemic approach. Indeed, Wright and Benigno (2019) argued for including all family members in future research in the autism field, particularly adopting a Family Systems approach. In Malta, a dearth of literature seems to focus on the experiences of the family living with young adults with autism from a systemic perspective.

Aim of the Study and Research Questions

Guided by the mentioned literature gaps, the current research study aimed to explore the stories of families of young adults with autism. I wanted to present the individual and joint stories of parents, siblings, and young adults with autism. Trough this study, I sought to understand better how each family member has adjusted to the autism diagnosis within the family. I explored how the family unit has negotiated its dynamics to maintain a sense of cohesion following an autism diagnosis and how this impacted their adaptability and resilience over time. This research gives voice to the young individuals with autism themselves. More specifically, this study sought to answer the following four research questions:

- What are the stories told by members of families who have a young adult with ASD?
- How did each member make sense of and adjust to the disability over time?
- How did this adjustment contribute to the family's adaptability, cohesion, and resilience over time?
- What were the sources of support and challenge for these individuals and families over time?

Theoretical Frameworks

In line with the aims and questions of this research study, the following theories and models were used to inform the research process: the social model of disability, family systems theory, resilience theory, family life cycle model, and attachment theory.

The social model of disability views disability not only within the individual but also as socially constructed (Oliver, 2004; Reindal, 2010). This acknowledges that societal barriers can hinder the individual with a disability. Research shows that societal barriers such as stigma can be a source of stress for the parents of children with autism, posing an added challenge (Kinnear et al., 2016).

Bowen’s family systems theory (1978) explains how individuals cannot be understood in isolation and defines families as complex social systems where individual members interact to influence each other. Literature increasingly suggests that the child’s diagnosis of autism has a significant impact on the other family members (DePape & Lindsay, 2015). Families of children with autism are prone to higher degrees of stress (Johnson & Piercy, 2017).

The resilience theory (Walsh, 2012) is pertinent to this research as it explains how certain individuals deal with and successfully adapt to life’s adversities, becoming stronger and more positive. Research shows resilient families experience less parental stress by finding meaning in their struggles and dealing with challenges together (Cheatham and Fernando, 2022).

Carter and McGoldrick’s (2005) family life cycle model posits that families must adapt to particular predictable life changes to avoid dysfunction. The stress families experience differs depending on the different life stages of their child with autism (Neely et al., 2012). For instance, in early infancy, throughout the child’s elementary school years, families must cope with the realisation of a problem and news of the diagnosis while making treatment decisions and developing a support system (Neely et al., 2012). Families must handle the child's physiological changes during adolescence and prepare for adulthood while dealing with financial and logistical support. Substantial financial and societal stressors continue to be experienced once the child with autism becomes an adult with autism (Neely et al., 2012).

Bowlby's (1988) attachment theory explains how the bonds formed by the child to the primary caregivers significantly impact the child's life. Hudson et al. (2017) reported that autism-related factors can pose a greater risk to developing healthy and secure relationships between parents and their children with autism.

The above theories and models guided my exploration of how families of young adults with autism have formed bonds and responded to adversities at different life stages to maintain a sense of cohesion over time.

The Local Context

Locally, the diagnosis of autism is frequently carried out within a multi-disciplinary team of professionals, mainly psychiatrists, psychologists, and paediatricians (Zammit, 2018). The diagnostic criteria used are generally those laid out in the ICD-10 by the WHO or the DSM-5 by the APA as there is no official protocol guiding the diagnostic process in Malta (Zammit, 2018). Indeed, an assessment of the exact effect of the condition and providing the latest diagnostic and treatment options to people with autism and their families in Malta is needed (Mubashir et al., 2020).

Within the Maltese context, various disability and family-based policies target the social inclusion and equality of persons with disability. For instance, the *Equal Opportunities (Persons with Disability) Act* aims to promote equality and eliminate discrimination (Laws of Malta, 2000). The *National Strategic Policy for Positive Parenting 2016-2024* aims to promote and safeguard equality, self-determination, dignity, and social inclusion, including that of persons with disability and their families (Abela & Grech Lanfranco, 2016). Recently, a more autism-specific national milestone was the launch of the *Malta National Autism Strategy* (2021-2030). This is a state support plan which aims to work in tandem with Article 11 of the *Persons within the Autism Spectrum (Empowerment) Act*. In accordance with the *United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD), it aims to provide the necessary resources and living conditions to improve the health, education, well-being, participation, and inclusion of people with autism in society (United Nations, 2008). Indeed, as is the present study's focus, a chapter of this strategy is fully dedicated to adulthood. It emphasises the need to engage the family members of adults with autism as key informants on their needs and challenges, including their siblings and their significant others.

Overview of Chapters

This first chapter has provided a brief introduction to this research. The next chapter will provide a critical review of the current literature related to families living with autism. Chapter 3 will explain the methodology used to address the research aims, followed by the results presented in Chapter 4. These results will then be critically discussed in Chapter 5. The last chapter concludes by presenting a summary of the main findings, along with both research and clinical recommendations and the limitations of the research.

Chapter 2

Literature Review

This chapter explores previous studies investigating the impact of parenting and living with individuals with ASD. To gain insight into available research I entered relevant keywords in the University of Malta online library. E-journals such as the Family Process; Disability and Society, Journal of Family Psychotherapy, and more were looked into.

The Transition from a Child to a Young Adult with Autism

Within the general population in the United States, around 500,000 young adults with autism transition to adulthood each year (Roux et al., 2017). Anderson et al. (2018) identified poor transition outcomes affecting most young adults with autism, including inadequate healthcare provisions, social connections, tertiary education, employment, and the likelihood of independent living. Earlier on, Buescher et al. (2014) stated that, to safeguard against these poor outcomes, emphasis must be placed on individualised support focused on changing aspects of the young adults’ social and physical environment, including the families. Indeed, they also argued that poor transition outcomes might result in a lack of fit between the person and the environment, unclear parental roles, and a lack of integrated service provision.

Current service provision is not adequately equipped to support this population as individuals with autism transition from childhood to adulthood (Anderson et al., 2018). Over half of the individuals with autism lack community participation and find it hard to engage in school or work endeavors (Myers et al., 2015). Even when adults with autism find employment, they tend to work fewer hours, consequently having a low income (Nord et al., 2016). Thus, a growing need for adequate services that support students with autism to transition into the workforce is evident (Wong et al., 2021).

The health and quality of life of individuals with autism are also impacted by their sexuality and intimacy (Cheak-Zamora et al., 2019). However, the area of sexual and romantic relationships among adolescents and young adults with autism is relatively unexplored. In their qualitative study, Cheak-Zamora et al. (2019) explored the sexual and relationship experiences of adolescents and young adults with autism. Just like typically developing counterparts, most study participants desired to be in a relationship. However, despite this desire, adolescents and young adults with autism had limited definitions of a relationship, possibly not understanding the complexity of sexual and romantic relationships. Moreover, only a few study participants reported having a partner who matched their ideal relationship. Thus, there is a clear need for sexual health education targeting this population to support their sexual self-development better while also reducing the likelihood of sexual abuse and exploitation (Cheak-Zamora et al., 2019; Hannah & Stag, 2016).

Parents of Individuals with Autism

Extensive studies report the challenging and stressful experience of raising a child with autism (McCafferty & McCutcheon, 2020; Padden & James, 2017; Shepherd et al., 2018; Zhang et al., 2018). Parenting a child with autism was found to impact the families' financial situation and the couple's intimacy (Johnson & Piercy, 2017). In their research investigating the stress of families with autism, Sim et al. (2018) identified four key factors associated with severe parenting stress. These include limited access to individual therapy, difficulties with socialisation, extreme expenses to cater to the child's autism needs, and negative relationships between the parents.

Johnson and Piercy (2017) reported higher stress levels among parents of children with autism compared to parents of typically developing children. This is because they deal with specific forms of autism-related behaviours by attempting to deviate their children from socially shunned soothing, stimulating, and ritualised behaviours. Studies with parents of children with autism report higher vulnerability to parenting stress and depressive symptoms among mothers than fathers (e.g., Hickey et al., 2020). This may be explained by the different roles adopted by parents, specifically, the caregiving duties often taken on by mothers and the financial responsibilities adopted by fathers (Callander & Lindsay, 2017). In a Malaysian quantitative study with parents of children with autism, parental stress was associated with caregiving tasks. In contrast, poor quality of life was associated with relational problems with the child with autism (Chu et al., 2020).

Moreover, Hickey et al. (2020) reported how the mothers' poor psychological well-being negatively impacted the parent-child relationship, specifically, with less warmth and more criticism being shown towards the child with autism. This reflects the impact of autism symptomatology, such as communication and socialisation difficulties, on family relationships and dynamics. A systematic review of the stress, coping, and resiliency among families of individuals with autism showed that fathers reported their wives' stress as the major problem affecting them from their child's autism (Ghanouni& Hood, 2021). This reflects the systemic impact of autism among the family members and their relationships and the need to explore this further, which is what the current study aimed to do.

In his qualitative study, Camilleri (2022) explored the lived experience of fathers of children with ASD in Malta. The results showed increased social isolation arising from the challenges of dealing with autism needs. This harmed the marital relationship as the parents struggled to find quality time together, contributing to increased marital conflict. On the other hand, for some fathers in this study, parenting a child with ASD encouraged the parents' personal growth and contributed to family closeness. Earlier on, in their qualitative study examining the fathers' perspective in raising a child with autism, Lashewicz et al. (2019) also highlighted the power of a parenting partnership in dealing with the demands related to autism. When the parenting approaches of each parent were aligned and the roles were complementary, fathers reported higher energy levels to manage autism-related needs. Feeling appreciated by one’s partner also helped maintain a strong marital relationship; in turn, caring for and maintaining this marital relationship significantly facilitated the parenting experience and alleviated parental stress (Lashewicz et al., 2019).

Iannuzzi et al. (2022) voiced the worries most parents present concerning the future of their child with autism as putting an additional burden on them. Indeed, the major life transition of a youngster with autism into adulthood tends to be stressful for many families (Smith & Anderson, 2014). These parents often deal with their children’s communication difficulties, temper tantrums, and other challenging or misunderstood behaviours, well past their childhood (Ludlow et al., 2012). As a result, parents of youngsters with autism are prone to public humiliation, judgmental attitudes, and even social exclusion (Broady et al., 2017; Ludlow et al., 2012). Witnessing the social exclusion of their children with autism increases the levels of stress and frustration in parents.

Consequently, this can impact the couple's relationship and the well-being of the family unit. Indeed, numerous studies reported that social stigma is related to increased perceived parental stress (Lovell & Wetherell, 2019), increased psychological distress and poor subjective well-being of parents (Torbet et al., 2019), as well as parents’ depressive and anxiety symptoms (Chan & Leung, 2021). A qualitative study in Ireland with mothers of daughters with autism (7-18 years) reported feelings of exclusion and judgments related to the autism ‘label’ and the difficulty in managing their daughters’ challenging behaviours (Fowler & O’Connor, 2021). In an attempt to avoid the judgments and reactions of the public to autism-related aggressive tantrums, parents withdraw from society, making it harder to access potential support (Broady et al., 2017).

In contrast, family support (Lovell & Wetherell, 2019), self-compassion (Torbet et al., 2019), pride in the child’s achievements, and social support, particularly from other parents of children with autism themselves; support the parents' resilience and psychological well-being (Fowler & O'Connor, 2021). A quantitative study examining the self-perceived stigmatisation, stress, and quality of life of parents of children with autism (2-18 years) in Malaysia highlighted the effects of cultural and religious beliefs on social stigma (Chu et al., 2020). In contrast to the above studies, participants in this Malaysian research belonged to a very supportive and inclusive culture towards people with mental health disorders and did not report feeling stigmatised. Considering the predominance of the Catholic religion in Malta one would expect similar values.

A recent review exploring the coping mechanisms used by parents of children with autism showed that mothers adopt more emotion-focused coping while fathers use more problem-focused coping (Al-Oran et al., 2022). Compared to the coping mechanisms adopted by parents of typically developing children, more avoidance strategies and less social support-seeking strategies are adopted by parents of children with autism (Vernhet et al., 2019). This limits access to potential sources of support, highlighting the need for psycho-educational and systemic interventions with parents of individuals with autism.

In contrast, some studies have reported positive adaptation to parenting a child with autism, resulting in a better marital relationship (Marciano et al., 2015; Ramisch et al., 2014). Moreover, satisfaction in the marital relationship is influenced by a positive reframe of the situation coupled with an optimistic outlook toward the future and adequate social support (Ekas et al., 2016). Garcia-Lopez et al., (2016) used self-report questionnaires to examine dyadic coping, psychological adaptation, and marital satisfaction in couples of children with autism. Results showed that supportive coping between parents fostered feelings of mutual trust, intimacy, and positive perceptions about one's relationship, which supported one's psychological well-being and reduced parenting stress. Moreover, relationship satisfaction was reported to foster supportive coping and adaptation, reflecting each factor's circular impact on the couple’s relationship (Garcia-Lopez et al., 2016). Brown et al. (2020) encouraged family practitioners to support couples of children with autism to develop relationship-based coping strategies to reduce parenting stress. Yet to date, only a few qualitative studies (Al-Oran et al., 2022) have explored the coping mechanisms used by parents of children with autism and any possible interactions between them, as the present research aimed to do.

Siblings of Young Adults with Autism

As Kyrkou (2018) points out, the sibling relationship is generally the most enduring for an individual with a disability. Nurturing sibling relationships from an early age facilitate the maintenance of healthy adult sibling relationships, thus fostering a good quality of life and positive outcomes for the whole family.

Iannuzzi et al. (2022) investigated the lived experiences of parents, adolescents, and young adult siblings of individuals with autism. Results showed that neurotypical siblings were generally frustrated by their sibling’s symptomatology and tended to be hypervigilant due to the unpredictability of their sibling’s behaviour. Fearing judgment from others, neurotypical siblings were reluctant to talk to their peers about their sibling with autism. Potential expectations to assume responsibility for caring for one’s sibling with autism in the future also worried the neurotypical sibling. Despite these challenges, neurotypical siblings were able to build a unique bond with one’s siblings and develop a sense of empathy and compassion towards others. Acceptance and gratitude for the challenges and opportunities created were also expressed (Iannuzzi et al., 2022).

Burnham-Riosa et al., (2022) also explored the lived experiences of siblings aged 8 - 17 years. These siblings reported carrying out additional household responsibilities compared to their sibling with autism while also adopting the caregiving and protecting role towards the sibling with autism. Communication difficulties, different interests, and aggressive and selfinjurious behaviours of the sibling with autism hindered the connection between the siblings. Despite this, some participants reported a positive and hopeful outlook and perceived their family as unique, though not unusual. Similarly, in a qualitative study with adolescent siblings in Malaysia, an opportunity to build a close relationship with a sibling with autism was reported, despite the communication difficulties experienced (Chu et al., 2023).

A recent quantitative study compared the depression and loneliness symptoms among adult siblings of individuals with autism, adult siblings of neurotypical individuals, and adults raised as only children (Sipowicz et al., 2022). Results showed higher levels of depression and loneliness among adult siblings of individuals with autism than those of neurotypical siblings. A qualitative study carried out in Malta with siblings aged 8-12 years of children with disabilities, including autism, reported that neurotypical siblings also need the support and attention of their parents (Vella Gera et al., 2021). The importance of having peer support was highlighted, while the suggestion of providing support groups for these siblings was put forward to share similar experiences with other siblings (Vella Gera et al., 2021).

Zucker et al. (2022) investigated the effects of a support group for neurotypical siblings of individuals with autism. The support group focused on providing psycho-education about autism, creating a supportive social network, and discussing emotions, coping, and problem-solving. Self-report measures of sibling relationship quality were taken pre-and post-intervention. These were compared to another group of neurotypical siblings following a support group with no particular focus on autism. Results showed improved sibling interactions which positively influence the quality of these sibling relationships. The neurotypical siblings also reported lower self-reported anxiety and depression levels. On the other hand, reflecting the typical nature of sibling relationships, no changes in the negative affect/conflict between the siblings were reported following the support group intervention. Interestingly, parents did not report any changes in their perceived quality of sibling relationships. This reflects the importance of adopting a family systems approach where all family members are involved in the intervention, providing more comprehensive support to the entire system. The present study aimed to adopt a systemic position and give prominence to the siblings’ voices concerning their role in the family system.

Therapeutic Interventions with Families of Children and Young Adults with Autism

As Brockman et al., (2016) point out, treatment models used in managing challenging behaviour in children with autism usually focus on the child with autism. Parents and siblings are usually isolated from most professional interventions. However, the challenges experienced by each family member living with individuals with autism reflect the need for more systemic interventions involving the whole family unit. Family therapy can support family members to understand better and make sense of the autism diagnosis (Helps, 2016).

A growing body of research calls for solution-focused brief therapy models (SFBT) for working with families where there is an ASD diagnosis (Brockman et al., 2016; Smock Jordan & Turns, 2016). Through a SFBT approach, the therapist acknowledges the problem but views the family as the expert on its own life (Smock Jordan & Turns, 2016). Thus, assuming that the family is already coping with its challenges to some degree, such a strengths-based approach helps empower parents of children with ASD to work on goals that fit best with them (Smock Jordan & Turns, 2016). In contrast to individual interventions, such systemic interventions also aim to strengthen the marital relationship and support the family to enhance coping and resilience (Brockman et al., 2016; Smock Jordan & Turns, 2016). By including the whole family unit, systemic interventions target each family member affected by an autism diagnosis. The family journeys explored in the current study also aim to inform potential systemic interventions with similar families affected by autism.

Conclusion

This chapter has reviewed the current literature on families affected by autism. The methodology used to address the research aims of the current study will be delineated in the next chapter.

Chapter 3

Methodology

This chapter provides a critical discussion of the methodology chosen to address the aims and questions of this research study. Participant recruitment, data collection, and analysis will be explained. I present my reflexive experience as the researcher, the methods of verification used, and the ethical considerations of the study.

Research Questions

This study explored how families of young adults with autism systemically adjusted over time. It sought to understand how the family unit has negotiated its roles, relationships, and dynamics following an autism diagnosis. Furthermore, it aimed to understand how they have maintained a sense of cohesion through the various challenges and opportunities presented to them over time. This research also aimed to give voice to individuals with autism.

Research Methodology

A qualitative methodology was deemed best suited to address the aims and objectives of this research study. Qualitative research is a form of social inquiry that focuses on the subjective meanings people attach to their personal experiences (Willig, 2013). A post-modern, social constructionist epistemology underpinned this research. This holds that multiple realities are constructed through social interaction (McNamee, 2017). Therefore, it is acknowledged that the sub-themes presented in the next chapter reflect the participants' personal stories, which were influenced by the historical and societal contexts at the interviewing time.

A Narrative Research Design

As a researcher intrigued by the participants' stories, I deemed a narrative research design as best suited to this study. The narrative design focuses on how people tell their personal stories and the meaning attached to their story telling (Green & Thorogood, 2018). Thus, in line with narrative research, this study aimed to understand the construction of the families' identity as it explores how people make sense of their lives (Creswell, 2013). Using narratives in chronic illness and disability was cited as significant in giving people a sense of personal agency (Charmaz, 2002). It helps to capture "the detailed stories or life experiences of a single individual or the lives of a small number of individuals" (Creswell, 2013, p. 73). Therefore, it focuses on how people talk about and evaluate life events and supports them in forming a coherent life story (Riessman, 2008). Rather than following specific methodological steps, I explored the participants' narratives, examining how the participants created a sense of family through the stories they opted to share (Smith, 2016). Ths enabled the identification of identification of themes and patterns (Smith, 2016).

Narrative Analysis

The Narrative Analysis follows Liamputtong's (2009) five steps for conducting data analysis. First, I read and re-read the transcript closely, noting the primary emerging key themes and short stories within the narration (Appendix O). The stories the different family members told were broken up into key elements, such as past, present, and future, and time and place. After dealing with interpretations or discontinuities that may contradict the themes, the construction of unique meaningful family stories emerged. In fact, each family story is presented individually to highlight the uniqueness of each family and its adaptation to the autism diagnosis over time. Whereas the participants' stories were not narrated in chronological order, they were rewritten chronologically (Liamputtong, 2009); whilst open to interpretation, this enabled me to connect thematic ideas to develop the narrative within the broader literature and carry out story-by-story comparisons in the discussion chapter.

Particular attention was given to the recurrent themes and patterns that emerged during the interviews and in the stories (Willig, 2013). This reflected the co-construction of meanings as presented during the interviews between the participants and myself as the researcher (Reissman, 2008).

The narratives that emerged were discussed with my supervisors and are presented in Chapter 4 and later discussed in Chapter 5.

Semi-structured Interviews

Interviews provide a rich source for narrative analysis (Esin et al., 2014). Semi-structured interviews were carried out as this facilitated conversation and allowed participants to express themselves freely (Larkin et al., 2006). Interview guides (Appendix J) were prepared for parents, siblings, and young adults with ASD, including easy-format scripts (Appendix F and J) to make the research more inclusive and accessible. These included a short list of standard questions which elicited conversations whilst allowing an opportunity for probing and clarifying questions as needed (Mitchell & Jolley, 2010). This enabled the re-tell and understanding of various stories shred by participants.

In line with the systemic approach that guided this study, any connections and differences drawn out during interviewing were explored through circular questions (Tomm, 1988). In addition to the interviews, I took field notes about the interview experience recording relevant details for transcription (Esin et al., 2014; Reissman, 2008).

Recruitment

Criteria for Selecting Participants

The participants were recruited through purposive sampling. This ensured that a homogenous sample of information-rich participants was recruited (Creswell, 2013). To ensure the ability to engage in a conversation during the interview, the recruited individuals with autism had to be diagnosed with mild to moderate autism hence, belonging to the functional Level 1 or 2 of autism (ASD, 2022).

This study also sought the opinion of siblings of individuals with autism. Therefore, only-child families were excluded from this study. No single-parent families were recruited to gain insight into the dynamics of the family unit over time. Participation was also limited to Maltese nationals reduce potential cultural misinterpretations.

Gaining Access to the Participants

Participants were recruited by disseminating information about my research through two separate agencies working with individuals with disability and their families; one of these agencies was non-profit private entity, whereas the other agency was State-run (Appendix A). Representatives from these entities acted as gatekeepers as they forwarded details about this research study to potential members (Appendix C). This ensured that the participants recruited were unfamiliar and unknown to me as a professional working within the disability sector, to avoid researcher-practitioner dual relationships. By adopting this position, ethical boundaries were maintained in line with the Ethical Guidelines for Research in Counselling Professions (British Association for Counselling and Psychotherapy, 2019).

Recruiting the participants was a laborious endeavour for several reasons, apart from the pandemic consequences per se. A potential family was going through a marital separation but did not wish to share this delicate information with the gatekeeper for personal reasons.

The gatekeepers commented that the recruitment criteria were quite restrictive. Therefore, only a few participants fitted in.

The Participants

Table 3.1provides a brief description of the two participating family sets; Scicluna followed by Micallef. Participants have been given pseudonyms to preserve their anonymity.

Pseudonym	Age	Nationality	Status	Relation to Young Adult with Autism
James	22	Maltese	Single	Young Adult with Autism
Martin	58	Maltese	Married	Father
Marthese	53	Maltese	Married	Mother
Mark	25	Maltese	Single	Brother
Simon	18	Maltese	Single	Young Adult with Autism
Rose	47	Maltese	Married	Mother
Charlie	48	Maltese	Married	Father

Nicholas	14	Maltese	Minor	Brother

The Interview Procedure

Two families were interviewed between May 2022 and June 2022. Each family consisted of two parents, a young adult with autism, and a sibling. Therefore, a total of eight interviews were carried out. These were carried out separately with each family member. In one case, a communication device was used by the young adult with autism, James; this seemed to support him in his communication and expression. Completing this interview took a couple of hours, and the energy invested by the young adult was admirable.

Interviews were conducted at the participants' chosen time and preferred location. All interviews were audio-recorded. Since participants were free to speak their preferred language, five interviews were conducted in Maltese and three in English.

Pilot Study

The first interview served as a pilot to assess the quality and validity of the procedures used (Creswell, 2013). It also supported me in preparing myself well for the upcoming interviews. Since no significant changes to the interview structure and procedure were required, the findings and analysis from this pilot interview were incorporated into the study (Yin, 2003). The original plan incorporated an hour of observation of the family following the interviews. As a result, an observation checklist was drafted (Appendix L). However, all the families were uncomfortable with this idea, so the observation had to be dropped.

Self-reflexivity Throughout the Study

I kept a reflective diary where I noted any observations, feelings, reflections, and curiosities emerging during this research process. This helped me to identify personal biases and beliefs potentially impacting the emerging findings (Etherington, 2007). Such notes were then discussed with my supervisors and colleagues, who supported and challenged my views.

The traumatic events shared by the participants impacted me personally, especially the ones narrated by Scicluna's family about James' behaviour of concern. The harsh realities they endured over time were vividly presented during the interviews. As a trainee therapist, I could see how these events reverberated over the family system over time. I was struck by the family members' unconditional love toward the young adult with autism. Their resilience inspired my practice and refreshed my sensitivity towards the numerous families referred to our respite services, especially those with children with autism. Resiliency resonates with my life trajectory thus, I could relate to their ability to adapt to challenging situations.

A Note on Translation

Data analysis was carried out on the original transcript version but Maltese quotations had to be translated into English. This translation process is in itself an interpretative process influenced by contextual, historical, and political decisions (Reissman, 2008). This involves a degree of meaning construction that might not reflect the participants' original stories. Thus, in an attempt to address these issues, the full English version will be presented in Chapter 4 while the original version can be found in Appendix P.

Methods of Verification

Yardley's (2000) four data verification principles were followed to achieve a good quality research study. An extensive and critical review of previous studies provided a context for this research study and created a link between current and previous research findings aiding the credibility and validity of this study (Yardley, 2000). The voluntary nature of this study and the participant's right to withdraw ensured their genuine interest in participating and enabled them to share their stories freely.

Care was taken to select a homogenous sample of participants to appropriately address the research aims and questions, ensuring rigorous research. I transcribed the interview recordings myself to facilitate data immersion and better understand the complexities of the shared stories. A detailed and exhaustive description of the data collection and analysis was presented aiding research transparency. Frequent discussions were held with my supervisors, who acted as peer reviewers to help eliminate research bias and aid reflexivity (Yardley, 2000). The results presented in the next chapter citing the participants' own narratives, attempt to bridge the literature gap and support professional and therapeutic communities to enhance the services provided to families of young adults with autism.

As part of the verification process, transcripts were disseminated amongst the participants (Appendix Q). After discussion with my supervisors, it was concluded that the stories would not be shared with the families as some emergent findings might not help the participants (Morse, 2015). The Information Letter (Appendix D, E, and F) clearly stated that despite taking all the necessary precautions, there can still be a chance that someone may recognise the participants through the unique experience they share. Their consent to this clause ensured they were comfortable with this potential (Appendix G).

Ethical Considerations

Various measures were taken to safeguard the participants' safety and anonymity (Creswell, 2013). Participant recruitment and data collection processes began after receiving approval from the Faculty Research Ethics Committee (FREC) at the University of Malta (Appendix B). The data gathered was treated with strict confidentiality. Each participant was given a pseudonym to safeguard anonymity, and any identifiable information was not divulged.

Before the interview, participants were informed about the aims and objectives of the research study, and no rewards or compensation was provided for participation. Participation was voluntary, and each had the right to withdraw at any time without explanation or incurring any negative repercussions, with the data being destroyed after that. Participants were also advised that any collected data would be stored in a locked cabinet and a password-protected computer and would only be accessible to the researcher, supervisor, and co-supervisor. All data will be destroyed after the study's publication.

Considerable attention was given to the Ethical Guidelines for Carrying Out Research with Disabled People (2018). This ensured that the specific needs for researching a potentially vulnerable group were catered for throughout the research process. Young adults with mild to moderate autism, thereby belonging to the functional level of autism (APA, 2022), were recruited to guarantee the participant's ability to provide consent.

Consent was obtained from each family member, and to make sure that the young adult with autism was comfortable that during the interview with his family, they would be asked to describe his relationship with different members of the family, third-party consent (Appendix H) from the young adult with autism, was signed. Regarding the minor siblings, when the custodial parents granted parental consent, and the minor's assent (Appendix I) was also sought to protect against coercion.

The interviews were carried out sensitively to avoid the potential risk of causing psychological distress to the participants and each participant was debriefed accordingly (Willig, 2013).The possibility of seeking further therapeutic support was also offered together with a list of support services for participants (Appendix M).

Conclusion

This chapter described the methodology used for this research. The next chapter will present the results that emerged from presenting narratives.

Chapter 4

Findings

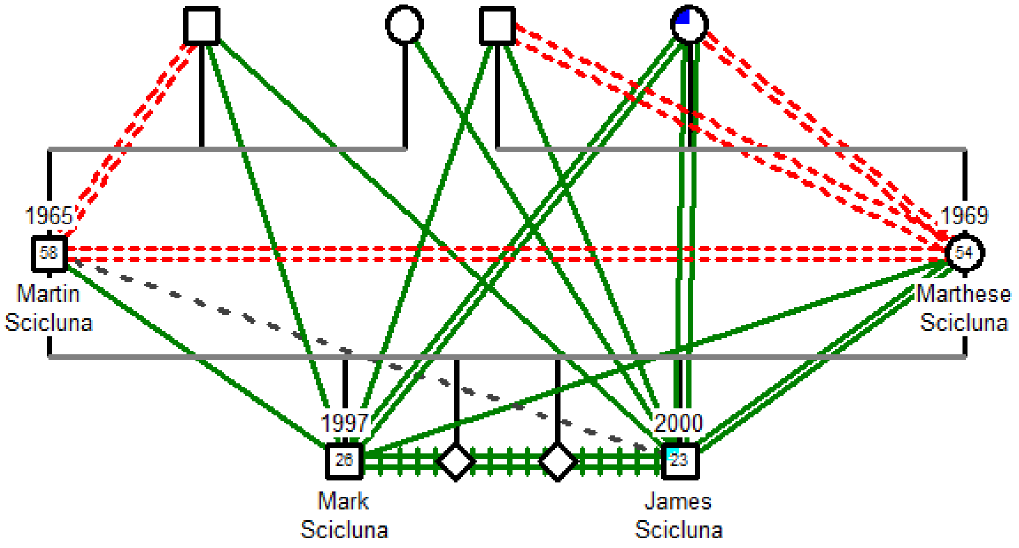
Introduction

This chapter presents multiple stories told by participants. The narration is enriched through direct quotes in bold. These results shed light on the families' ability to deal with the diagnosis through negotiating roles and connections, contributing to their resiliency.

Scicluna's Family Story

As shown in Figure 4.1, Family Scicluna consists of four members, Martin and Marthese, the parents, and their sons Mark and James with autism. James is the second-born child.

Figure 4.1
Family Scicluna's Genogram (Appendix N)



Navigating the Problem

At **the age of two years,** James' parents realised **there was a problem,** eventually, **even hearing was becoming a problem, and we went to the paediatrician,** recalled Martin. **He told us**, **it could be autism**. This was **the first time they learned about it**. **It was an enormous shock**, Martin recalled. At **the beginning, they sought support mainly from psychologists** and **CDAU.** Eventually, they engaged James in a program run by **Inspire,** and paid for it, **it stopped because of Covid, and following that, he started attending Sapport**, he explained. Martin told me that initially they were referred to a psychiatrist from school, yielding minimal positive results, so they sought the advice of another psychiatrist. **He gave him different medication and slowly, the episodes** [tantrums] **started to decrease.**

Martin explained that **at the time, they weren't convinced with the quality of answers they received** locally**. We even went to England; they gave him games to play with, asked him questions to observe his reaction; "but we think he has autism,"** the British said bluntly. **I was a bit disappointed,** said Martin, as he did not expect such a quick conclusion on such an important matter. Sadly**, 'I am not sure if we made the right decision … but at one point, you sort of give up. Once we realised that there was a problem, we took it seriously ... like when you lose someone, at first you take it seriously, but slowly, time enables us to get used to it, and we did the same.** Martin expressed that they **couldn't live a normal family life as the situation was abnormal, also on a psychological level, as you have a child with a disability**.

Mark recalled his mother's reaction **first, my mother was like; it's not a curse that** [the autism] **brought us, but it's like, why? It's like a punishment ... it took a while to get her to accept that ... she used to bottle things up and not enjoy life...**she used to see **other people's children ... and try almost to force my brother to do everyday things**.

Interestingly, when asked to describe himself, James, with a smile, said **I am autistic, and I am clever, I am handsome, and I am funny.**

Mark hinted that Marthese blames **this injection** [MMR]. Given the painful realisation, Marthese attempted to compensate for ‘the problem’ by assimilating that it could have been worse, **you can have a normal child, and suddenly something happens to him, or drugs, I try to calm myself down. It helps me to see him healthy.** This facilitated her journey to acceptance. **By nature**, James **was rather naughty**; **I remember that he was always hanging with delinquents … he escaped many times from school,** Mark sustained. Martin compares life to a **bunch of playing cards,** and he said **some have a worse bunch than them.** This reasoning keeps him sane.

Manifestation of Autism Symptoms

Marthese and Martin’s parents **supported** [them] **when they could, recalling that when he had a tantrum you could tell ...that they were shocked.** Mark shares that his grandmother **fell into a depression as she couldn't accept it... my brother’s** [diagnosis] **was her breaking point.** Unfortunately, to date, she **keeps hoping and prays that a miracle will happen.**

Ten years ago, there weren’t many services. We happened to experience autism at the very beginning, continued Martin. **They did not know how to handle him at school, although they surely meant well,** Martin added. Mark recalled that his brother **was the only one with autism** at their school, **and he used to feel very sorry for him.**

Martin recounted that at one point; **the facilitator started to report that James banged on the desks and disrupted the class,** which was uncharacteristic if him. The facilitator hinted that James was aggressive towards her; we **were surprised as he never did anything of that sort**, said Martin. **Suddenly, his behaviour changed at home as well; he became very aggressive … both my wife and I ended up with bites, bruises, and blood.**

Martin assumed his son experienced **a breakdown because as time passed, he** [James] **understood more that he was different from others … this was his way of processing the environment around him.** Likewise, Marthese narrated that James **felt different; he used to see other children, and he used to feel upset realising that he had a difficulty** believing **that triggered the depression.**

Martin recalled vividly receiving an urgent call from school. With a sad tone because James had written that **he wanted to die ... we came to a situation where I couldn't go to work** once for **two months. He became aggressive from the time he woke up until he slept. He used to bite himself and bang his head on the floor or the wall, but mostly towards us.** Martin showed me how he **pulled him onto the mattress and kept holding him until** he **got James tired.** Martin knew that if James had to have a window of opportunity, **he would bite** [him]**, pinch** [him]**, and if you were not careful, he would hurt you.**

His mood would change **suddenly.** Recounting the exhaustion, Martin explained that it used to take him **two hours to struggle with James** during a tantrum. **I used to end up worn out** and in disbelief at James' physical strength. Marthese painfully recounted that this aggressive behaviour restarted during his teenage years; James **used to throw a lot of very loud tantrums; he would give** her violent **blows.** After each of these tantrums, she **used to break down.** At that point, she showed me the area where she had **twenty stitches, and he cut off my ear.** Tremendously convinced, she added, **it's not a tantrum; it was aggressiveness; a tantrum for me is mild. I've seen big scenes, horrors, breaking, TV breaking and often I was alone.**

Mark frequented his brother's same school; he recalled that people expected **me to calm him down**. He was once him to sit next to his brother during one of his tantrums, and he attacked him. **He would rip off my skin, it's like he's lost consciousness.** Mark said it was not easy to make sense of his brother’s **loss of temper.** I could feel that she was not proud of this decision; however, Marthese admitted that **she had bought handcuffs to tie him and invented a belt to the sofa to tie the handcuffs back to the sofa so he wouldn't wake up for** [her]**.** However, he would still retaliate. Martin admitted having difficulty comprehending such **aggressiveness, I did not understand; I was angry ...** Martin feels that one of their **biggest mistakes was to speak about James' problems in front of him;** because **he understood.**

Impact of Traumatic Experiences on the Couple

When asked to speak about their relationship, Marthese confessed that her husband focuses entirely on work, meaning that she is **the one who has to keep up with everything.** Claiming that her husband was **very supportive at the beginning... he used to feel sorry … we were different. We used to complement each other**, said Martin. Martin recalled that he used to be involved **as much as his wife.**

My wife used to call me at work, and I used to hear yelling and shouting in the background … I used to go home as a madman. I used to find a massacre at home … my wife's hair on the floor, **once even her ear lobe. Terrible times,** he added. **Recently, it seems that my wife faces the problems.**

I think he fell into a depression between work and what happened to James, said Marthese. **I sometimes collapsed alone without anyone's support**. Martin describes this shift as an **aftermath** of their son’s autism; **we never recovered.** This experience **brought a bit of bitterness toward life and towards me,** said Martin. Mark also witnessed his parents’ romantic relationship changing; he said **my mother and father are no longer close.** According to Mark, **his parents accepted it at different stages of their lives … also in different ways.** He feels that his mother **sometimes projected her anger onto the**

relationship. Whereas my father, a tranquil person to deflect from the problem, looks like his escapism is at work, sustained Mark.

Martin feels that **their family life was ruined.** The family situation seemed like **hell at one point because we were coming** [home] **to hell.** The psychiatrist was the only professional who validated Martin's feelings and used to tell me **you went through a lot, and you are still here; this is a big achievement.** Martin confessed to the psychiatrist that he was **constantly being blamed**, the psychiatrist normalised this and was the first professional to **refer** [the couple] **to a therapist**. When asked if they were ever referred to family services, Marthese explained that no family services were ever offered as **services focused on the child, mostly education.**

Renegotiating Roles

In digesting the news, the family members had to reposition their roles to deal with autism. Mark explained that despite the need to abandon certain family rituals, his parents managed to re-negotiate their roles to attend to their family needs. Mark confessed that **only one would come on his prize day because the other had to stay with James.**

Marthese affirmed that no, **the life she planned came different. I had to try to turn around and adapt, James turned my life upside down**. With a cracked voice, Marthese added, **I used to love my job... I had to stay at home, sacrifice my career, everything.**

The Sibling's Experience

Marthese recalled Mark's anger towards James when he would hit her. **I sometimes left Mark alone,** confessed Marthese, **and I didn't even shout for help so he wouldn't see those scenes.** Martin recalled that they did their best not to resort to Mark as he was still very young, but **at times, they needed Mark's help and he used to be very angry towards James; he used to react unreasonably, but I understood him as James was destroying**

us. Martin went through a similar process as he recalled episodes when he used **to shout at** James, as **he did not understand why he was being mean towards** them. **It is complex; sometimes, you feel like cursing everything and ask, why us? What did we do wrong?**

Marthese is fond of the **beautiful relationship** she shares with Mark nowadays. As Mark was growing up, she realised that her primary focus had been on James, and at one point, she reminded herself that she needed **to take care of him** [Mark] too. Mark expressed that his mum **is very overprotective of him ... when I was younger, I used to feel that she projected the aspirations she had, both mine and my brother's, on me, so it was like I had a double responsibility that used to tire me.** Growing up, Mark's form of escapism was through **travelling abroad and spending a lot of time outdoors;** like his father, he used to regret going back home.

The Impingement on the Family Dynamics

James shared that **sometimes** [the relationship with his mother] **is good but sometimes bad …** he **doesn't like that his mother fights with his family. It makes him feel upset.** However, when asked to describe his relationship with his father, James admits they **do not have a bond; this makes him feel angry as he wants a better one**. Mark shared that although his father doesn't show it, **he loves** them both **immensely.** Mark said their father **failed to do the things you usually do with your father. I used to feel like he abandoned me, but now I understand him.**

Mark admitted that, at first, **he used to say he should be ashamed he was ruining my life with these antics.** Mark explains how he was expected to care for his brother with autism**; at a young age, I used to** [hear] **'make sure you take care of your brother and stay with him.' I used to feel that I shouldn't say my problems to my parents 'We have**

enough problems with your brother; don't add yours too…' his parents used to say. To date, Mark has difficulty disclosing certain issues with his parents.

Despite this, Mark shares that his **parents gave him a very good childhood. When you grow up, you see things in a different light... I am not sorry, as if it wasn't for this, I might have been a different person.** Mark also insists that he owes a lot to his grandparents, **they've been very supportive;** they did not only compensate but also **overcompensated,** especially when his **brother was going through his worse.**

Reaching Out for Connections

James yearns for connection outside the family. He does not have friends and **would love to have autistic friends like** [him]**.** Mark mentioned that his brother is highly sociable, **enjoys company** … **and everyone loves him**.

Nowadays, Marthese enjoys spending time with James and describes him **as a forever baby.** She said **he waits for her near the television in the evening. We hug; those are beautiful things,** said Marthese fondly. **James gives me energy… if it was not for him, I am not where I am,** insists Marthese. James expressed that he likes it when his family engages in outdoor activities rather than staying indoors: **we like to swim, walk, and visit family.**

Martin said **that seeing James as a happy boy** reassures him. When asked to share how he feels when he thinks of his family, James said that he **feels happy,** although he feels that **they do not talk enough.** James explained that his **mum is always busy and doesn't want to talk to him.** Martin admits that the communication barrier hinders their relationship and, to some extent, poses dilemmas as to why James communicates with strangers, including me as the researcher, but not with family members. Equally, Mark would give anything to communicate with his brother. He **has yearned for this communication since** [he] **was a**

little boy. I was curious to know what the communication device meant for James; hearing the device **give him a voice** was fascinating.

Mark appreciates James' ability to communicate non-verbally; **I always feel that from his look and mannerisms, we know and feel what the other is feeling,** emphasised Mark. James enthusiastically said **my brother is my heart, he is fond of me, and he jokes with me.** Mark explained that they **will always be there for each other;** he tearfully added, **we are each other's best friends till death do us part.** Mark claims to be very protective towards his brother; he **feels responsible** for him; **he is my little brother,** he emphasized. **We have an unbreakable bond… whatever happens between us,** concludes Mark. Also, James added receives a lot of affection from **his grandmother, she always kisses** [him] **and makes** [him] **feel welcome.**

Societal Norms

Initially, Marthese had attempted to conform to societal norms and used to tell James **to be quiet, he would stomp his feet...** and she used to **feel uncomfortable. I hoped he would be normal.** Marthese attests that she **accepted it now... everyone has something... maybe they look at him with disgust or handsomely, but it won't affect me.** Interestingly, when asked what he understood with the word autism, without hesitation, James said, **we are clever, but people treat us as stupid and don't try to understand.**

Marthese reflected on society's judgments against what does not fit within the "normal" parameters. She firmly believes that for **society to improve**, **one must experience autism personally or have someone in the family … to become more aware of it...** otherwise, **no one is interested. It's difficult because it's a hidden disability; people can't understand autism. Because you see a normal boy or girl, and then suddenly he/ she does something, and rightly so, it shocks you,** she explained. Martin narrated that once

James **threw a tantrum outside once, and people saw him, but nobody tried to help me. And then he calmed down, and we were sitting on the fence, and the police came, and I ended up at the police station; they thought I was beating him.**

You have to continue with your life; you cannot lose yourself

In those days, if you needed an LSA, Marthese explained, **you had to pay. I ended up working at the same school,** and with the money earned; I paid for the LSA, narrated Marthese. **Then I said I want to do something better,** Marthese started studying, opened her small enterprise, and despite describing the experience as **very painful**, characterised by **a lot of confusion, as you start saying this child will not be typical, but at the same time, you must study …; it was difficult …** however, **I managed,** said Marthese. Martin exclaimed **we resisted and stood on our feet; it was our duty**. Similarly, Marthese speaks about what supported her to go on, **the way the human being finds a way to survive; you survive and try to find the beautiful things there are. You have to continue with your life; you cannot lose yourself. The positive part is that you start seeing the true happiness of life.**

What Does the Future Hold?

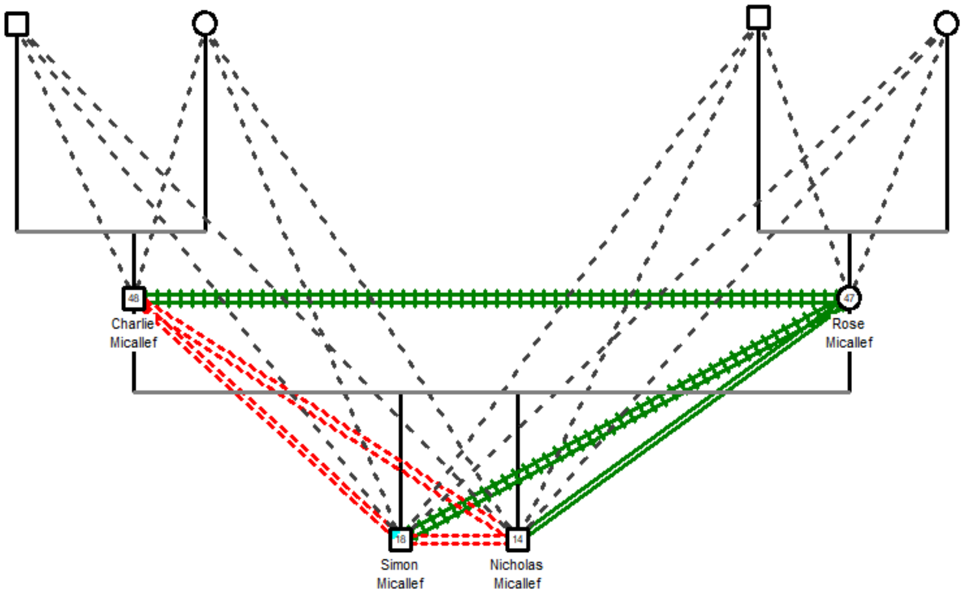
The future seems to elicit fear and hope simultaneously in James' family. Marthese and Martin are concerned about James once they pass away; **that is our fear,** exclaimed Marthese. Consequently, they would like him **to become more independent** to put their mind at rest**.** Mark wants to ensure tha his brother has **everything and the most comfortable life possible. We will have a beautiful future together,** he insisted. Mark also expressed gratitude for his parents' hard **work** and **sacrifices** and he feels it is time for them **to be happy**. **They've done enough, and they've given a lot.**

James concluded the interview by saying; **we felt happy** [to participate in the interview] **because you are trying to help autistic like me … we appreciate it.**

Micallef's Family Story

As shown in Figure 4.2, family Micallef consists of four members, Charlie and Rose, the parents, and their sons Simon with autism and Nicholas. Simon, is the first-born child.

Figure 4.2
Family Micallef's Genogram (Appendix N)



Meaning Making

After we jabbed him, exclaimed Charlie; the change happened **when we gave him the MMR,** confided Rose. **We even tried to get second opinions, and you start saying I have no one in my family like that; how can it be?** continued Charlie. **When it starts sinking in, it is like when you have a problem and see how to find a solution.** As a result, **we gave Nicholas the MMR six months later.**

The testimony of a mother who shared her story in church encouraged Rose; **God gives children with specific difficulties to those who can cope with them, not those who can't. Those words remained imprinted;** she said while touching her forehead. **There were moments when I felt like banging my head against the wall,** admitted Rose. Rose expressed her gratitude towards God, compared to the realities she comes across when she attends hospital appointments with her son; **I have seen children with ALS and ... I tell him, but mine have nothing next to this girl. Others, who have autism and full autism... ours does not have it fully,** shared Rose.

The Couple's Relationship

Rose's face lightened when asked about her relationship status, **yes, we are married,** and with a sweet laugh, she added, **we've been together for many years.** The affinity towards each other struck me; as Rose described her personality, she turned and looked at her husband; **my husband tells me I have a golden heart, but I** [also] **am hard-headed**. They teased each other after this comment, and they both laughed when Charlie sighed, **it has been like this forever.** When asked to describe their family, Simon immediately mentioned that soon his parents would **celebrate their anniversary.**

Rose explained that she **works full-time reduced … I try to keep up with family and home**. Previously, she **had to reduce to part-time to run around with her son's** appointments, **which meant less income**. **All their commitments had to focus on their children's needs**. Indeed, Charlie's dream was also impacted as he **had to abandon the idea of obtaining a Ph.D.**

The Relational Dynamics

When asked to describe their family, Rose said, **our family is united**, and Charlie instantly validated her comment. The children also shared this reflection. Simon and Nicholas had a positive view of their family; my **family is fine**; **I love my mum** [did a heart shape with his fingers], **and my father too,** said Nicholas; he even enjoys the family rituals like, for example, **eating dinner along with them or go outside to eat something.** At the same time, Simon mentioned that he **enjoys taking the car to the car wash with his father, and playing football with his father.** Simon reflected on a deeper level; he said confidently that his **family feels joyful because...** they've **been a core to me ever since I was a little kid.**

When they were young, Simon and Nicholas used to **fight; Simon is more physical,** explained Charlie; he **used to fight,** said Rose, **and the other used to get hurt,** continued Charlie. **Simon did not realise that he could hurt him since he is bigger than him; I often sent Nicholas to school with a scratch,** explained Rose. The **other extreme now** smiled at Rose as **they go very well together,** continued Charlie. Nicholas attests that **he often plays with his brother**, describing this as what he likes most about their relationship. Nicholas feels that **games connect** them; however, when asked to describe their relationship, he rated it as **50/50; sometimes, he is nice and others mean.** Simon describes his relationship with his brother as **going down; they fight a lot.**

Rose insists that her children **always tell the truth and do not hide anything; she won't be able to help them if something happens.** Despite being **eighteen and can make his decisions,** she feels Simon trusts her... and seeks her opinion. **Simon is a follower, not a leader; we sometimes fear that someone might give him a bad example,** and he takes it on board, said Charlie backed up by Rose. **We always tried to protect him from the outside world,** explained Rose.

Simon is concerned that **the course will not make** [him] **a footballer… his parents are telling him that** [he] **has to train with a club and start improving himself immediately.** Simon recalled that his **mother used to tell** [him] **that if** [he] **failed his subjects,** [he] **won't even get a job, simple as that.** Similarly, Nicholas spoke about feeling pressured to achieve good results and said **Dad is pushing me a lot, so he tells me to pay attention to this, that, …it's kind of like so tough** he admitted.

The ASD Journey

Charlie chose the word **survivors**, **and thank God we remained united,** he stated. **We went through what we went through.** The couple highlighted a **financial struggle; it was a money issue** that fuelled **arguments between them;** Rose continued saying that **loans, bills, and petrol … all needed to be paid**. And Charlie pointed out that **even professionals… You cannot use government services, there are long waiting lists, and you need the assistance now, and it would be too late** if you had to wait, argued Charlie. As a result, they even had to sacrifice family outings; the **expenses were enormous; we were like in a bubble,** remarked Rose; we **could afford a treat once a month.**

When asked to reflect on their journey around the autism diagnosis, Rose said sharply, **our son used to speak, as we went up the home stairs, he counted the numbers in English, Maltese, and even German.** I spontaneously remarked he used to communicate, and with that comment, Rose felt validated and said, **ehe, but at age two,** she looked at her husband to seek reassurance about the age; he **stopped talking**, **not entirely,** said Charlie and she agreed. **He wasn't the same; suddenly, he changed,** Rose's facial expressions became heavier.

In the beginning, it was difficult, said Rose. **Simon used to throw himself to the ground; he had a lot of tantrums. We used a lot of flashcards with him; I know he would want water when he was little; he tells me, e e mama. I tell him what do you want? I used to make him talk.** Simon exhibited difficulties related to **speech** and **communication, and expressing himself** clarified Charlie. **If you want, you can**

understand him, but the word sequence … he mixes masculine with female pronouns, elaborated Charlie. Through the interview with Simon, I could relate to this as it took quite a toll on me to understand him.

After Covid, Simon kept insisting that he wanted to play football, and I searched until I found him a club; thank God he clicked with his friends. Charlie said **they were open-minded and welcomed him into the group**; this **meant a lot. Over the years, they struggle, and we struggle for them to have friends** declared Charlie. The players are mainly foreigners, enabling him to **integrate better.** Simon happily shared; I **have friends, and my relationship with them is top level… my friends love me so much that sometimes, when I go to training, they support me; they always ask me to go out with them, and I feel happy.** The parents narrated that this group gave Simon more opportunities than just football; **he goes out with them even to Paceville,** added Charlie. **Simon even takes the bus,** said Rose fondly, thanks to his friend's mum that Simon as she introduced him to the bus system; she **could understand as her son has autism,** explained Charlie. **They went along well together,** added Rose.

Rose painfully recalled that **Simon used to get bullied a lot**; for his sixth birthday, they organised a party, and the boys did not turn up except his best friend. **They used to pull his pants down,** she confessed later on. Charlie feels that **children to other children are even crueller... the children are innocent, but if they see him differently, they push him away. The bullying reality is enormous,** Rose emphasised. Charlie adds that **children with autism are targets for bullying; and easy prey as they lack communication...** Simon was also **cyber bullied at the government school,** and to Charlie's disappointment, the school's and even the police's reaction to this was a **letdown.** Thankfully today, Simon has **confidence in himself, which is a good thing, people try to tease him; he doesn't give**

them attention; he has courage ... and in particular things, he is stubborn, which is a good thing. He has his opinion and expresses it, Charlie sighed with relief.

It was difficult to see my husband’s siblings' children and him, for example, Rose expressed, **and you see the difference with your own eyes. You try to teach him so that gradually he reaches a certain point, and I think we managed... not that he’s 100% independent, but we reached 70 – 75%** said Rose confidently. **Simon never gave up through it; he has that resilience in him; he keeps going; he is brave and self-confident,** said Charlie.

Charlie wishes **to find Simon a summer job;** it’s **a pity he sent a lot of CVs, but he only had one interview …** Rose **tells him to send a CV** whenever she comes across an advert; **I wish him to enter the world of work although he is scared** added Rose disappointed. Simon i**s very helpful and emotional,** described Charlie, **ideally somewhere he can be socially helpful.** Simon stated that **when his mother got sick,** [he] **took care of her.**

Simon shared that his **relationship with his father is going tough,** recalling a memory of last summer when **his father screamed at** [him] **and yelled at** [him] **all the time to find a job. I tried everything I could, but I couldn’t work it out. I am trying to be a man and find the right job … I want my father to be patient,** ‘Simon explained. Nicholas wishes that **his brother would get a job so he starts earning his own money.**

Simon is not different from others; we never told him he has autism, said Rose boldly, but on the other hand, Charlie explained that when he speaks to the boys, **he does not go into detail about what autism is; I don’t want them to have low self-esteem … or blame themselves.** Rose is adamant that **children with autism are normal, with some difficulties.** Not surprisingly, when I asked Simon what he understands with the word ‘autism’, he got confused; **I have to ask; I do not know what autism is. I never heard that**

word, he innocently explained. Likewise, when Nicholas was asked if he had ever mentioned his brother to his friends, he said yes. **I told them I have a brother but didn't tell them he has autism,** confusing the term with **optimism because I didn't know until now.**

Rose said **Simon is mature; he wants to save money; I have my stipend; the clothes are in my hands',** Simon told her. Simon wishes to leave the house and **move on;** his friends are asking him to move close to the club; **I thought I would buy an apartment ten minutes away from the stadium; because they** [football teammates/friends] **mean so much to me that I enjoy this community/club.**

Rose feels proud that the values they instilled in their children are reaping the fruits. Rose patiently explains to Simon the value of money to enable him to make an informed decision; she confessed that it **is not always easy. It was difficult; there was a time when it was difficult to communicate with him. To calm him down, you try to explain to him, but he couldn't understand me; on the other hand, I couldn't understand him,** Rose exclaimed, a time when she felt **the children were a punishment on her, it was difficult!** she repeated.

Sources of Support or the Lack Thereof

Touched by the enormous constraints the couple had to endure, I wondered whether any support for the couple or family was ever suggested, but Rose said **no.** When asked how autism impacted their relationship, the couple looked at each other and laughed; Charlie said it did, but **positively as they always supported each other,** insisted Rose, **especially communication concerning the logistics part of it**. Charlie described their family as **bubbly, we do not fight, we discuss a lot as everyone has their opinion … and unique character** continued Charlie. **We always understood each other,** insisted Rose, **and made it a point that our children sleep by nine o'clock so they enjoy quality time together**.

However, when she was too exhausted after a demanding day with the boys, Charlie understood her.

When asked if they encountered any sources of support, they explained that, unfortunately, what the services lacked was added as extra pressure on the parent, **do this, do the other, no one gave us a manual of what to do if you have a child with autism,** asserted Charlie, with his wife nodding in approval. Further, mentioning that there are no **pathways, no map, there is the shock, and you don't have a safety net … you are diagnosed with autism, and now what? What will happen? What are we going to do?** argued Charlie passionately.

Charlie spoke highly about a tutor their son was in contact with as she saw a window of opportunity. **She saw right; Simon always wished to play football, and we kept him back, as his communication level is weak,** but she encouraged us to take him to **football friends, which is not on the competitive,** narrated Charlie. **He really enjoyed himself there,** sustained Rose. Simon said enthusiastically, **I chose football because sports football is my passion, it's my life, and I want to keep going until the end...** Simon also did a **diploma in Sports, got a pass in all subjects, and got the certificate.**

At one point, the parents tried to recall all the professionals they'd been to. They feel that one particular **educational psychologist** helped them immensely; **he didn't let us on our own, and I appreciated it immensely,** adds Charlie. His input was crucial as he supported them in understanding that Simon did not fit in the government school. Charlie narrated that **the educational psychologists were the light at the end of the tunnel; they were the people who sort of gave us answers for the future.** As other sources of support, Rose firmly stated that they **always coped; we found equilibrium between us, but it was only when she was working, and the children were younger, that the grandparents**

would keep them until they started school. When asked to speak about the extended family**,** Simon rated their **relationship as medium… normal.**

The couple recalled the most challenging moments; **he was an intelligent boy … they didn't know how to deal with him,** explained Rose. What hurts her most is that Simon grew up when there was no sufficient knowledge of autism, **it was taboo, and he was isolated.** She had to compensate for the lack of learning at school and **act as Simon's teacher** at home. **At that time, they had to sit down and learn how to write to be prepared for Year 1. Unlike today, where they learn by playing, I remember in Kinder 2, Simon wrote Simon Micallef against the wall. He was already on the autism spectrum then, and he wrote his name in full and clear. Kind of it was a big deal,** narrated Rose passionately.

Charlie mentioned that the **LSAs were still in their initial stages,** and Rose recalled that they went on strike during that time. **He had spent two and a half months without an LSA …I studied with him for half-yearly exams, but did not write anything on the paper, and got a zero … academia was always hard,** admitted Rose. Rose explained that they even tried sending him to private lessons, but it was hard to find someone one to one during that time. **Something else Charlie and I may have done is we were never angry with him,** although **academia was never good,** continued Rose. However, **the concern remains,** admitted Charlie, **as nowadays, without results, you do nothing,** added Rose.

The new church school offered a positive experience; **a blessing in disguise**; Rose said he was **overprotected** there, but apart from Simon, as parents, they felt supported too, which meant a lot for them. Rose and Charlie were convinced that from then on, **Simon started to improve.** Charlie says he met **many people with a golden heart** along this journey**. You see the true colours of many people ... 'Listen, don't take it like that, look,**

don't do that'... they tell you, 'Listen, did you hear about this one? Check this out'. I refer to them as guardian angels, Charlie remarked.

Societal Barriers and the Healing of its Exception

Charlie stated feels **their parents count in that category of ignorants; they don't even look at what the word means. 'There you see, the child has nothing,'** his parents tell them**… lack of acceptance,** he added**.** Charlie strongly believes that if **you don't experience autism, you have no interest in checking about it... Admitting that the ignorance that everyone has is the same ignorance that he had,** he never heard the word autism until they had their children diagnosed. **Once I got hurt, we were in church, and my son wouldn't sit still. My aunt came after mass and told me if you can't, don't bring him... people are too quick to judge ... it is a cruel life.**

Rose had a different experience; she recounted that when they attended **mass, Simon would not sit still;** thankfully, the archpriest knew about their reality. Once **Simon started running in church, the archpriest doing the sermon from the pulpit told her to let him run because he doesn't bother him.** Charlie narrated that before they **got married, they were active** in church**; that is, in the community, one of the regrets. You marginalize yourself once you are no longer active in the community.**

Future Aspirations and Recommendations

Rose strongly wishes that they **save up some money to travel alone to rediscover their relationship as a couple.** Similarly, Charlie wishes that they **start living again and travel; and we will experience freedom again,** said Charlie enthusiastically. **Maybe one day, we will also become active again in the community,** Charlie said, hopeful. **The children are growing, we have to give them space to find their way too, both in terms of**

jobs and in personal lives, to be independent, to know what they want, and to eventually find a job they like and then see for themselves from there onwards.

Rose wishes **for Simon to be fully independent yet happy, as her biggest worry is when they pass away, or something happens to them.** Rose shared that thanks to Simon, she **learned that it is not worth worrying too much in life.** She feels that **when you have children like hers, they come first, and you come last.**

Rose advocates for **more awareness of autism.** At the end of the interview, she strongly proposes; **a service either run by an NGO or else subsidised by the government where children with autism can stay during the evening until, for example, their parents go for a coffee or to have a word with each other, or to go for a pizza so that the** couple can enjoy a few hours of quality time together, knowing that the children are cared for by trained personnel. She firmly believes that the **CDAU is the fulcrum** to bring awareness or promote services, as every family has to start from there. Charlie adds that **more services like CDAU are necessary**, as with the current service, **you have to wait six to nine months to start a programme, and the child will grow older another year.** He believes that **those who are dependent entirely on government services are going to fall behind.** As a result, Charlie feels that families of children with autism require financial family planning support as there are a lot of out-of-pocket expenses, especially for **young couples bearing a loan**. He also mentioned the need for a **pathway** that guides families throughout the journey of ASD.

Conclusion

Following the presentation of these stories, the following chapter explores the processes experienced by the participating families.

Chapter 5

Discussion of Findings

Introduction

This chapter discusses the salient findings that emerged from the participants' narratives. Through the lens of different family members within the same system, I attempt to capture what supported and hindered their journey through the different phases of ASD. The analysis will be discussed in light of relevant literature and theoretical frameworks guiding this research.

Coming to Terms with the ‘Problem’

Through their son’s diagnosis, both parents heard the word autism for the first time. Despite being unfamiliar with the term, these parents had to accept their son’s condition and were expected to independently deal with the uncertainties related to it. It is felt that the support offered to these families following the diagnosis was scarce. Therefore, this fuelled parents to forge money to seek other professional opinions as they struggled to make sense of the information given. Indeed, research shows that individuals and families impacted by autism benefit from psycho education as it helps them find meaning in the diagnosis (Spain et al., 2017). This is an important observation for professionals to remain curious; if not, they risk assuming that parents are knowledgeable of autism. The National Autism Strategy (2021-2023) states that students with autism and their parents must be given ongoing autism awareness training. Such recommendations are vital for professionals to keep in mind as they venture on journeys with families who have just been given a diagnosis of autism.

In Search of Meaning

In line with the family resilience framework (Walsh, 2012), each family experienced their journey toward acceptance differently. The mothers compared their son’s disorder to other conditions or addictions perceived as less fortunate or severe. Mark undertook a similar process as he narrated episodes showing that his brother engaged in deviant behaviour, hinting that if it wasn’t autism, it could have been worse. This allowed each family to find meaning in their adversity, regain control, and enhance their self-esteem to establish themselves once the challenge was overcome (Walsh, 2012). The parent’s process of acceptance seemed to reflect a grieving process (Kubler-Ross, 1969). Martin made a direct association between experiencing the loss of a loved one and being told about his son's autism. The parents spoke about the shock, confusion and recounted moments of despair and helplessness.

Paradoxically, Simon is not aware of his autism, nor is his brother. This implies that the parents hardly mention the subject at home. As a result, the narration by Micallef’s family gives prominence to the parental perspective, as Simon’s and Nicholas’ contributions lacked autism awareness. This made it hard to construct the story from the young adult and sibling’s points of view as opposed to Scicluna’s narration. Charlie assumes that if Simon knew about autism, he would likely label himself and potentially develops low self-esteem or, even worse, blame himself; Rose insists that Simon is not different from others. Charlie’s assumption potentially reflects how he made sense of his son’s autism. However, literature shows that the difficulties experienced in interacting with neurotypical individuals that may impact the individual with autism’s mental health and self-esteem (Crompton et al., 2020).

On the other hand, although the findings indicate that James does not communicate with his parents at home, their openness about his condition seems to have supported James’ confidence to speak about it. The dynamic process of identity formation for individuals with autism involves an acceptance of the autism diagnosis itself and an assimilation of its meaning within the individual’s identity (Goff & Springer, 2017). Previous research reports their desire to be accepted by society (Ghanouni & Quirke, 2023). James also longs for better societal understanding of autism.

Interestingly, in the process of accepting his son’s diagnosis, Charlie even questioned potential hereditary contributions. The parental authority exercised by Charlie in hiding the autism diagnosis from his son, might impact Simon’s ability for a coherent narrative. The family therapist's role in supporting family members in understanding the impact of their decisions on others is crucial. A core characteristic of family therapy is to support families as they make sense of challenging situations by helping them to think outside the box in mitigating these hurdles together (Spain et al., 2017). Therefore, family therapists working with families impacted by autism must embrace each family's different story without judgment while respecting their timing in addressing the elephant in the room. It is fascinating to hear that despite her contribution to her son’s lack of awareness, Rose advocates for more societal awareness of autism. As previously claimed, this builds on the lack of societal openness towards neuro-diverse individuals.

Adjusting to Autism as a Family Unit

These stories highlight the distinctive account of how each family unit experienced the uniqueness of autism. Patrini (2021) highlights that the stress from caregiving demands on family members can potentially enhance or diminish challenging behaviour due to bidirectional transactions between members. Research suggests that the disruptive behaviours of a child with autism impact the whole family system, potentially more concerning to the parents than the core symptoms of autism (McStay et al., 2014).

Nonetheless, to a certain extent, both family units have validated the benefits of sharing the burden of care between the couple, especially when navigating the son’s aggressive tantrums. Despite the differences, both family units were impacted by autism. They had to adjust, adapt and re-negotiate their role within the system in unique ways depending on their family's perceived needs and the parents' understanding of autism. Clinicians working with families impacted by autism must remain curious (Cecchin, 1987), about these processes to understand the families' inbuilt resources better.

These accounts demonstrate that the family experienced disruptions to their routines and social life and had to self-sacrifice. These processes fostered their resilience as they managed to withstand the hardships encountered and still be together and fond of each other. According to Halstead et al. (2018), resilience is in itself a form of protective factor. The core competence of resiliency is to strike a balance between protective and risk factors in the face of adversity (Ghanouni1 & Hood, 2021).

In line with family systems theory (Kerr & Bowen, 1988), these families experienced a difficult aftermath impacting the whole system, demanding significant adjustments from each other. Sim et al. (2017), postulate that the couple's relationship is integral to the family's adjustment to autism reflecting the complexities stemming from the interconnectedness between members. In line with previous research (Keenan et al., 2016), Marthese and Martin reported that caring for James brought significant emotional distress. The challenge to understand their son's needs, intentions, and reasoning behind such disruptive behaviours, hindered the parents emotional attuned and appropriate responses. Research shows that the inability to consolidate attunement toward their son's emotional needs, negatively impacts the parents' emotional states and leads to more attachment-related anxiety (Keenan et al., 2016).

Irrespective of what might have potentially triggered James's challenging behaviour, we need to acknowledge the physical and psychological pain that the parents endured until they learnt ways to contain such behaviour. As Marthese exclaimed, there were instances when she had to purchase a pair of handcuffs to tie James to the sofa. These crude narrations make us wonder how the parents' roles are challenged in such situations, devastatingly impacting their lives as individuals, and as a family. Notwithstanding this, her eyes glow when she speaks of James. Despite the painful experience, Marthese had an important role to fulfil, being a mother to James. Interestingly, the parents showed pride in their son's significant improvements, which kept them motivated and hopeful. These stories indicate the continuous processes of experiencing pain and moving on through the disability. Resorting to these restraint mechanisms demonstrates the parents' desperation to stop the aggression. The intensity of the experience does not provide space for reflection; often, these families are left to fend on their own. Services must offer caregivers safe educational sessions to equip them with appropriate skills for tantrum containment measures to avoid maltreatment. If not, this will push the family to close off, fearing legal repercussions based on abuse, a dominant discourse in our society.

The primary caregivers were not the only members that had to adapt to autism. Its effects have reverberated through their families of origin too. As Mark and Charlie explained, grandparents lacked the necessary skills, knowledge, and ability to deal positively with autism. This hints to the potential lack of support from family members resulting from their lack of autism-related knowledge. Simon's family comes across as more self-sufficient, relying on each other for support. This reflects the need for family therapists to consider the multiple sociocultural variables involved in the family's dynamics to better support them in expanding their social network (Gaur et.al, 2023).

In line with previous studies, the impacts of autism also reverberated through the siblings who usually report a sense of responsibility toward the sibling with autism (Burnham-Riosa et al., 2022). This reflects the need for multidisciplinary teams to include these secondary caregivers following the news break up. Mark's narration is a testimony of this; he not only took on added responsibilities in supporting his parents to care for James but was side-lined as his brother’s needs took priority. Mark speaks of an unbreakable bond with his brother but feels confused that James refuses to use the communication device at home; thus limiting their interactions. Hence, therapists need to find means of communication to include this population in therapy, as their contribution is equally important. Unfortunately, the wider systems, including service providers, often forget siblings of individuals with a disability. Thus, professionals are responsible for linking siblings to support groups such as Super Sibs, offered freely by Aġenzija Sapport and the Autism Parents Association.

Other family members play an important role in the siblings’ life. For example, Mark’s grandparents compensated for his parent's absence. This coping strategy enabled him to view his family system positively despite the hardships of sharing the care-giving responsibilities of a sibling with autism. This is in line with previous research highlighting the positive coping abilities of neurotypical siblings in preserving their relationships with their siblings with autism and their parents (Burnham-Riosa et al., 2022). When working with families impacted by autism, systemic therapists must explore the family’s supportive network as the experience varies for each system, keeping an open mind as some families might not have any. The repercussions on families who lack emotional and social support are significant, considering that social support is a major protective factor enhancing the family’s resilience (Ghanouni1 & Hood, 2021). Therefore, service providers must compensate for the lack of support, by linking these families to other families undergoing similar experiences or a trusted neighbour or friend.

It is fascinating to hear that Nicholas, a fourteen-year-old, knows his brother's future goals by heart. In contrast to Mark and James, Nicholas’ and Simon’s narration reflects that autism is unknown to them. Previous research reports a cohesive relationship between siblings considered friends, highlighting an acceptance of the sibling with autism (Burnham-

Riosa et al., 2022). Therapeutic spaces should allow siblings to safely express their experience around autism as they might be carrying traumas from childhood; such as Mark who witnessed his brother's tantrums. Family therapy offers the right atmosphere for siblings to express their concerns and voice questions about their possible future role as carers (Spain et al., 2017).

Transitioning to Adulthood

The core characteristics of autism do not cease as the individual becomes an adult perpetuate in adulthood (Ghanouni & Quirke, 2023). Indeed, research shows that more young adults with autism are being referred to family therapy due to family dysfunction (Burton & Fox, 2022). Moreover Lai et al., (2019) report a higher prevalence of experiencing mental health conditions among the autism population compared to the general one. Indeed, Marthese remembered being more concerned about James' depression than the autism itself. In contrast to the general population, individuals with autism seem to experience higher levels of stress related to change, anticipation, sensory stimuli, and unpleasant events, triggering anxiety and hindering one's coping ability (Gillot & Standen, 2007).

In contrast to Simon, James relies more on his family to meet his basic needs. Interestingly, during his childhood, James' parents could mediate for the lack of learning support assistants at school by hiring one, themselves. However, in his adulthood, they feel at a loss as the only service they managed to access is the adult training centre. Other services might be available; however, they seem to have lost the initiative to search such opportunities, possibly due to a lack of awareness or exhaustion. On the other hand, Simon is determined and hopeful to find a job, earn money, and buy his own place, reflecting his resilient abilities (Walsh, 2012). However, despite his efforts he is still unemployed. This is in line with previous research reporting the desire of young adults with autism to be independent and autonomous but facing challenges to reach adult milestones including employment (Sosnowy et al., 2018). Greater awareness about available inclusive employment services needs to be communicated to job seekers with autism and their families as gainful employment enhances one's well-being (Sosnowy et al., 2018).

The high prevalence of children with autism implies a high number of adults with autism accessing already inundated national mental health services. The current findings suggest that as one ventures into the adult world, fewer state-support services exist for these individuals and their families. Thus, the shortage of specialised services for such a population must be urgently addressed. Availability of flexible and individualised services beyond teh childhood years and into adulthood is crucial both for the adult with autism and one's family (Anderson et al., 2018; Howlin, 2021).

In both scenarios, the parents self-sacrificed drastically during their sons' childhood y; however, as their sons reached adulthood, the energy of James' parents seemed to deplete itself. At this point, a trusting network of services should compensate for this in a way that allows these families to breathe. Mark insists that his parents deserve happiness after their sacrifices. Similarly, Rose and Charlie aspire to refocus on their couple hood. The parents are concerned about their sons' future, particularly when they can no longer support them. The solution identified by both parents' dyads to compensate for this is for their sons to become more independent.

In Search of Friendship

The National Autistic Society in the UK (n.d.), reports a higher prevalence of lonliness among individuals with autism compared to their counterparts without autism. The curret findings reflect an inner need for both James and Simon to belong and a desire for friendships. Charlie spoke about supporting his son to avoid social isolation by seeking and maintaining friendships. Such concerns put additional pressure on caregivers, impacting family dynamics and their major family life cycle (Carter & Mc Goldrick, 2005). Making friends should be a natural process for each individual, a critical endeavour, especially during adolescence, to develop a sense of identity outside the family. It should not be an added responsibility for parents of children with autism. This notion provides important insights into the extent of responsibilities parents of children with autism shoulder beyond childhood.

As each of us, young adults with autism have a right to choose their friends. This resonates with previous literature reporting the preference of individuals with autism to form friendships with others on the spectrum (Crompton et al., 2020). Individuals with autism seem to find it easier to connect with and feel better understood by other individuals with autism, around whom they can be themselves (Cromptom et al., 2020). In Cromptom et al., (2020) study, individuals with autism also reported feeling pressured to conform to societal norms when interacting with neurotypical individuals leading to feelings of frustration and the experience of autism as something negative. Therefore, family therapists working with individuals with autism need to explore the individual's preferences around friendships to eventually link them to relevant social groups.

A Need to Foster a Sensitive Society

As the saying in the autism community goes, "If you've met one person with autism, you've met one person with autism" (McClellan, 2021). Understanding a hidden disability such as autism can prove challenging, especially for the community. In Charlie's own words, society is "quick to judge". Society tends to misunderstand autism symptoms without appreciating the triggers behind this behaviour (Ghanouni & Quirke, 2023). Moreover, society tends to hold negative perceptions of adults with autism and incorrectly assumes poor functional abilities across all life areas (Ghanouni & Quirke, 2023). This reflects societal barriers to effective barriers to effective functioning and inclusion. In line with the social model of disability, negative attitudes toward amilies dealing with autism can be difficult and significantly hinder social inclusion (Dirth & Branscombe, 2017).

The stories told by Martin and Rose speak volumes. Although the period these took place should not be overlooked, it is a pity that both families experienced secondary marginalisation. Martin was reported for acting promptly to contain his son's aggressive tantrum, and a family member asked Rose to consider not bringing her son to church. Charlie and Rose used to volunteer at the same church before they became parents to Simon. Similar to past research, parents have reported feelings of isolation and exclusion from friends and family, which adds to the difficulty of raising a child with autism (Kinnear et al., 2016).

These stories reflect the aims of the National Autism Strategy (2021-2030) to foster a more inclusive society by raising awareness amongst the general public who might be less knowledgeable about the condition. The parents feel that the only way to motivate a shift in mentality is to experience autism first-hand. Considering such a belief, I wonder whether the parents are potentially contributing even unconsciously, to their marginalisation from society. Though not generalisable, this reflection is pertinent in clinical practice, Family therapists need to be mindful of this possible assumption inherent in parents of children with autism, potentially impacting the therapeutic alliance.

A Dire Need for Family-Oriented Services

These stories revealed how state-run services in the autism sector are centered on the needs of the child with autism, particularly one’s educational needs. However, prior literature has reported how family therapists can be integrated within a comprehensive treatment plan for families with children with autism (Solomon & Chung, 2012). Spain et al. (2017) sustain that family therapy is more inclusive than other approaches as the latter fail to address important matters about the families’ coping strategies or identify resilient factors or issues between family members. Govind (2018) affirms that family therapy is purposeful in facilitating communication between family members, especially on difficult topics such as the effect of the symptomology of autism on the whole system. This elicits mechanisms for collective strategies to thrive through these challenges.

While the stories presented give a glimpse of the hardships and pains these family members went through over time, these families received minimal information about therapy. Therefore, even the professionals working individually with James and Simon might have needed more awareness, knowledge, and courage to speak openly about this subject. To date, from experience, very few families who access respite services speak about accessing family therapy services as a supportive means to make sense of and adjust to the demands of the disability. Then again, services are either inundated with a waiting list or not freely available. Therefore, the lack of awareness coupled with the lack of accessibility poses a significant barrier.

Even if these services had to be offered promptly, parents might struggle with prioritisation unless there is cohesiveness between the services offered. At the same time, parents are required to be personally invested in caring for their children. This creates an obvious paradox where the burden on the family increases, but the opportunity to sustain it is dramatically reduced due to caregiving demands. Creating a state-run multidisciplinary specialised service for families of children with autism that includes systemic therapists would alleviate the current services and offer timely interventions post-diagnosis. This would ensure that current family therapy services are not overstretched in balancing autism and non-autism caseloads (Burton and Fox (2022). Indeed, the National Institute for Health Care Excellence (2017) advocate for adequate family support post-diagnosis. Patrini (2021) also believes that family therapy is appropriate for individuals with autism and their families as it enhances relationships, communication, and family functioning.

Conclusion

This discussion of narratives attempted to highlight the challenges faced and resources that families in the process of working through the diagnosis over time. The next chapter will present the concluding remarks and practical implications based on the findings.

Chapter 6

Conclusion

Introduction

This last chapter summarises the major results of this study and presents important practical implications. The limitations of the study and recommendations for future studies are also presented.

Summary of Salient Results

This research has presented the experiences of two-family units as they made sense of and adjusted to autism over time. The findings added to the limited research available in around the experience of autism by family members. Their unique journey taught me how each family member contributes to adaptability, cohesion, and resiliency over time. Despite the services available, these families depend mainly on their inbuilt resources to digest, react and readjust their sails to cope with the symptomatology of ASD, developing a self-reliant personality. They did this in silence, through trial and error, and with incredible learned mastery.

The families relied on out-of-pocket payments to access the necessary educational and psychological services, their main sources of support. This led to financial constraints. As adults, individuals impacted by autism and their families still require support. The family members wish a meaningful life for their loved one with autism, engaged in society through work, friends, and social activities. Yet, locally such support is regrettably minimal.

A lot was said about how these families navigate autism, but what is most striking is their capability to adjust through challenging situations. They were incredibly resilient in constructing their meaning around their son's diagnosis. I felt that both families did their utmost to lead a 'normal' family life by taking control of past traumatic experiences.

While considering the historical context during which the diagnosis was given, we cannot ignore the pain experienced by both parents throughout the process, given the lack of services and poor understanding. Their accounts demonstrate that society dared to point fingers while providing minimal empathy and support. The same society owes impacted families great compassion, unconditional positive regard, and timely support.

Practical Implications

The stories presented indicate that an important target for intervention revolves around the family's attitude towards their situation and their perception of their child with autism. Therefore, the family members themselves must empathise with each other in the process of working together through the autism journey. On the other hand, professionals must also elicit positive insights to facilitate adaptive family functioning. Supportive family services should be able to identify at-risk families; unfortunately, those who fall behind are often linked to services later in life as they experience a crisis. This puts an enormous strain on services, making it harder for professionals to offer timely interventions.

Service providers must train their professionals about autism and its implications through the different life stages. The current figures suggest that these services will likely experience an influx of individuals with comorbid psychiatric disorders. Therefore, a need for systemic and integrative services is highlighted. These services must explore the context of these families to better understand what is happening, both within and outside the family. The need for more peer support and multidisciplinary intervention is highlighted as clinicians are vital in linking these families to available supportive services such as parents' and siblings' support groups and autism-positive parenting courses.

Not only is autism a dynamic reality, but whether the families adapt or not to it is and individual journey. Despite the reverberations of autism through the family system, family-oriented services were not offered to the participants. This is an identified gap in the provision of services. Effective training incorporating the effects of autism on the whole system needs to be offered to frontliners but also to families and society at large. A pathway should inform professionals working in this field of current evidence-based recommendations. However, this needs to cater for the different manifestations of autism and their families.

The more people are open to understanding autism, the more those impacted by the condition feel included. The key to overcoming this invisible limitation is understanding, accepting, and embracing diversities, even within autism. As a professional in the field, it saddens me to hear from participants that unless one is personally effected, one struggles to empathise with those impacted.

For those severely impacted by the symptomatology of autism, less focus on academia is beneficial, and more important themes should be explored with the individual, such as personal well-being and cultivating self-awareness and acceptance of the diagnosis. Some families would benefit from practical financial planning advice as the financial burden is evident. Lastly, ad hoc hourly respite services would support the couple to nurture their quality time amidst intense periods of autism symptoms.

Limitations of the Study and Recommendations for Future Research

Though every effort was made to present a rich and trustworthy account (Yardley, 2000), as a researcher, I acknowledge the limitations of this study. In line with the narrative methodological framework guiding this research, some experiences were undoubtedly not shared, while the construction of the shared stories may have been affected in some way.

Through this research, I was keen to give voice to young adults with autism. Therefore, young adults with severe autism with an inability to communicate were not recruited. The key demographic data of both family units were similar; white Western

European, Maltese, married, form part of heterosexual long-term relationships, and come across as financially stable despite the struggles mentioned. The resources available to these families have likely contributed to their ability to adapt to autism. Future research might explore the narratives of families coming from different backgrounds for example, females with autism and female siblings are not represented in this study, or families with an only child with autism. Single-parent households, homosexual couples, and adoptive and fostered family units were also not explored. It would also be interesting to explore how autism impacts multi-stressed and low-income families and possibly younger parents with a diverse cultural background within the Maltese context.

The recruited family units were the ones willing to participate in the research. Potentially they were the ones who successfully managed to deal with the presented challenges and, therefore, were willing to share their stories with others. It would be interesting to know whether the same family units would have been interested in participating during the toughest periods when autism disruptive behaviour was manifested. It would also be interesting to examine the family stories unfolding over the family life cycle through a longitudinal study.

Conclusion

Through their participation, these families hoped to make a difference in the lives of other impacted families. Findings yielded significant information, hopefully aiding professionals, especially systemic family therapists working within this dynamic field. The participants' rich narrations humbled me as a professional but more so as a human being. Their experiences will inform my practice, positioning, and understanding of autism. These results urge more cohesive services addressing the family’s needs as a whole. Genuinely touched by the participants' resiliency, openness, and trust, the short free-verse poem

(Appendix R) was constructed from the participants' verbatim. By representing the poem at the end, I attempt to represent how the family narrative continues to be built over time.

References

Abela, A., & Grech Lanfranco, I. (2016). *Positive parenting: National strategic policy 2016-2024*. https://doi.org/10.13140/RG.2.2.11787.08482

Al-Oran, H., Khuan, L., Poh Ying, L., & Hassoune, O. (2022). Coping mechanism among parents of children with autism spectrum disorder: A review. *Iranian Journal of Child Neurology, 16*(1), 9-17. https://doi.org/10.22037/ijcn.v16i2.31518

American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders* (5th ed., text revision). American Psychiatric Association Publishing.

Anderson, C., Lupfer, A., & Shattuck, P.T. (2018). Barriers to receipt of services for young adults with autism. *Pediatrics, 141*(4), s301–s305. https://doi.org/10.1542/peds.2016-4300G

Bowlby, J. (1988). *A secure base: Parent-child attachment and healthy human development*. Basic Books.

British Association for Counselling and Psychotherapy. (2019). *Ethical guidelines for research in counselling professions*. BACP.

Broady, T. R., Stoyles, G.J., & Morse, C. (2017). Understanding carers' lived experience of stigma: The voice of families with a child on the autism spectrum. *Health and Social Care in the Community, 25*(1),224–233.

Brockman, M., Hussain, K., Sanchez, B., & Turns, B. (2016). Managing child behavior problems in children with autism spectrum disorders: Utilizing structural and solution focused therapy with primary caregivers. *The American Journal of Family Therapy, 44*(1), 1-10.https://doi.org/10.1080/01926187.2015.1099414

Brown, D.M., Arbour-Nicitopoulos, K.P., Kelly, P., Martin Ginis, K.A., & Latimer-Cheung, A.E., & Bassett-Gunter, R.L. (2020). Examining the relationship between parent physical activity support behaviour and physical activity among children and youth with autism spectrum disorder. *Autism:The International Journal of Research and Practice, 24*(7), 1783-794. https://doi-org.ejournals.um.edu.mt/10.1177/136236132092265

Buescher, A.V.S., Cidav, Z., & Knapp, M. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA Pediatrics, 168*(8), 721-728.https://doi.org/10.1001/jamapediatrics.2014.210

Burnham-Riosa, P., Ensor, R., Jichici, B., & Davy, B. (2022). How my life is unique: Sibling perspectives of autism. *Autism*, 1-13. https://doi.org/10.1177/13623613221142385

Burton, L., & Fox, C. (2022). Are families supported to come to terms with an autism diagnosis? A service evaluation of referrals to family therapy for young people with autism in one NHS trust. *Journal of Family Therapy, 45,*154-166. https://doi.org/10.1111/1467-6427.12419

Callander, E.J., & Lindsay, D.B. (2017). The impact of childhood autism spectrum disorder on parent’s labour force participation: Can parents be expected to be able to re-join the labour force? *Autism,22*, 542–548. https://doi.org/10.1177/1362361316688331.

Camilleri, L. J. (2022). Exploring the lived experiences of fathers of children on the autism spectrum: A narrative inquiry. *SAGE Open, 12*(2), 1-13. https://doi.org/10.1177/21582440221089927

Carter, B., & McGoldrick, M. (2005). Overview: The expanded family life cycle. Individual, family, and social perspectives. In M. McGoldrick, & B. Carter, (Eds.), *The expanded family life cycle: Individual, family, and social perspectives* (3rd ed.,pp. 1-26). Pearson Allyn Bacon.

Caruana, C. (2020). Does autism come with a manual? The lived experience of families with autism, across time, in Malta[Unpublished master’s thesis]. University of Malta.

Cecchin, G. (1987). Hypothesising, circularity, and neutrality revisited: An invitation to curiosity. *Family Process, 26*(4),405-413.

Chan, K. K.S., & Leung, D.C.K. (2021). Linking child autism to parental depression and anxiety: The mediating roles of enacted and felt stigma. *Journal of Autism and Developmental Disorders, 51,* 527–537. https://doi.org/10.1007/s10803-020-04557-6

Charmaz, K. (2002). Stories and silences: Disclosures and self in chronic illness. *Qualitative Inquiry, 8*(3), 302-328.

Cheak-Zamora, N.C., Teti, M., Maurer-Batjer, A., O'Connor, K.V., & Randolph, J.K. (2019). Sexual and relationship interest, knowledge, and experiences among adolescents and young adults with autism spectrum disorder. *Archives of Sexual Behavior, 48*, 2605–2615. https://doi.org/10.1007/s10508-019-1445-2

Cheatham, K. L., & Fernando, D.M. (2022). Family resilience and parental stress in families of children with autism. *The Family Journal: Counseling and Therapy for Couples and Families, 30*(3), 419-426.https://doi.org/10.1177/10664807211052494

Chiarotti, F. & Venerosi, A. (2020). Epidemiology of Autism Spectrum Disorders: A review of worldwide prevalence estimates since 2014. *Brain Sciences, 10*(5), 1-21.https://doi.org/10.3390/brainsci10050274

Chu, S. Y., Park, H., Lee, J., Shaharuddin, K.K.B., & Gan, C.H. (2020). Self-stigma and its associations with stress and quality of life among Malaysian parents of children with autism. *Child-Care, Health, & Development, 46*(4), 485–494. https://doi.org/10. 1111/ cch.12771

Chu, S. Y., Zafirah binti Kassim, S. N., Gan, C.H., Fierro, V., Hsien Chan, C.M., & Hersh, D. (2023). "Sometimes I feel grateful…": Experiences of the adolescent siblings of children with autism spectrum disorder in Malaysia. *Journal of Autism and Developmental Disorders, 53*, 795–807.https://doi.org/10.1007/s10803-021-05184-5

Creswell, J. W. (2013). *Qualitative inquiry & research design:Choosing among five approaches* (3rd Ed.). Sage Publications.

Crompton, C.J., Hallett, S., Ropar, D., Flynn, E., & Fletcher-Watson, S. (2020). ‘I never realised everybody felt as happy as I do when I am around autistic people’: A thematic analysis of autistic adults’ relationships with autistic and neurotypical friends and family. *Autism, 24*(6), 1438–1448. https://doi.org/10.1177/1362361320908976

DePape, A.M., & Lindsay, S. (2015). Parents’ experiences of caring for a child with autism spectrum disorder. *Qualitative Health Research, 25*(4), 569–583. https://doi.org/10.1177/1049732314552455

Dillenburger, K., Rottgers, H-R., Dounavi, K., Sparkman, C., Keenan, M., Thyer, B., & Nikopoulos,C. (2014). Multidisciplinary teamwork in autism: Can one size fit all? *The Australian Educational and Developmental Psychologist, 31*(2), 97–112.https://doi.org/10.1017/edp.2014.13

Dirth, T. P., & Branscombe, N. R. (2017). Disability models affect disability policy support through awareness of structural discrimination. *Journal of Social Issues, 73*(2), 413–442. https://doi.org/10.1111/josi.12224

Ekas, N. V., Pruitt, M. M., & McKay, E. (2016). Hope, social relations, and depressive symptoms in mothers of children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 29*, 8–18. https://doi.org/10.1016/j.rasd.2016.05.006

Esin, C., Fathi, M., & Squire, C. (2014). Narrative analysis: The constructionist approach. In U. Flick (Ed.), *The Sage handbook of qualitative data analysis* (pp. 203-216). SAGE Publications Ltd.

Etherington, K. (2007). Ethical research in reflexive relationships. *Qualitative Inquiry, 13*(5), 599-616.

Fowler, K., & O'Connor, C. (2021). 'I just rolled up my sleeves': Mothers' perspectives on raising girls on the autism spectrum. *Autism, 25*(1), 275–287. https://doi.org/10.1177/1362361320956876

Garcia-Lopez, C., Sarria, E., Pozo, P., & Recio, P. (2016). Supportive dyadic coping and psychological adaptation in couples parenting children with autism spectrum disorder: The role of relationship satisfaction. *Journal of Autism Developmental Disorder, 46,* 3434–3447. https://doi.org/10.1007/s10803-016-2883-5

Gaur, B.K, Warrier ,U., & Barman, P. (2023). Examining the resilience of families of autistic children in a sociocultural lens. *Journal of ReAttach Therapy and Developmental Diversities, 6(*9), 135-144.

Ghanouni, P., & Hood, G. (2021). Stress, coping, and resiliency among families of individuals with autism: A systematic review. *Review Journal of Autism and Developmental Disorders, 8,* 389–402.https://doi.org/10.1007/s40489-021-00245-y

Ghanouni, P., & Quirke, S. (2023). Resilience and coping strategies in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 53,* 456–467. https://doi.org/10.1007/s10803-022-05436-y

Gillott, A., & Standen, P. J. (2007). Levels of anxiety and sources of stress in adults with autism. *Journal of Intellectual Disabilities, 11*(4), 359-370. https://doi.org/10.1177/1744629507083585

Goff, B. S., & Springer, N. P. (Eds.). (2017). *Intellectual and developmental disabilities: A roadmap for families and professionals* (1st ed.). Routledge.

Government of Malta. (n.d.). *Respecting diversity safeguarding equality - Malta's 2021-2030 national autism strategy.* https://meae.gov.mt/en/Public_Consultations/MISW/PublishingImages/Pages/Consultat ions/MaltaNationalAutismStrategy20212030/National%20Autism%20Strategy%20ENG.pdf

Govind, N. (2018). Family therapy for autism spectrum disorders. *Issues in Mental Health Nursing, 39*(10), 908-909. https://doi.org/10.1080/01612840.2018.1507597

Green, J., & Thorogood, N. (2018). *Qualitative methods for health research*. Sage Publications.

Hall, H. R., Fruh, S., Zlomke, K., & Swingle, H. (2017). A qualitative analysis of the experiences of minority parents of children with autism spectrum disorder. *Advances in Neurodevelopmental Disorders, 1*(2), 79–88.

Halstead, E., Ekas, N., Hastings, R.P., & Griffith, G.M. (2018). Associations between resilience and the well-being of mothers of children with autism spectrum disorder and other developmental disabilities. *Journal of Autism Developmental Disorders, 48*(4), 1108-1121. https://doi.org/10.1007/s10803-017-3447-z.

Hannah, L.A., & Stagg, S.D. (2016). Experiences of sex education and sexual awareness in young adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*(12), 3678–3687. https://doi.org/10.1007/s1080 3-016-2906-2.

Hartley, S. L., & Schultz, H. M. (2015). Support needs of fathers and mothers of children and adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 45*(6), 1636–1648.

Helps, S. (2016). Systemic psychotherapy with families where someone has an autism spectrum condition. *NeuroRehabilitation, 38*, 223–230. https://doi.org/10.3233/NRE-161314

Hickey, E. J., Hartley, S. L., & Papp, L. (2020). Psychological well-being and parent-child relationship quality in relation to child autism: An actor-partner modeling approach. *Family Process, 59*(2), 636-650. https://doi.org/10.1111/famp.12432

Howlin, P. (2021). Adults with autism: Changes in understanding since DSM-111. *Journal of Autism and Developmental Disorders*, *51*(12), 4291-4308. https://doi.org/10.1007/s10803-020-04847-z

Hudson, M., Dallos, R., & McKenzie, R. (2017). Systemic-attachment formulation for families of children with autism. *Advances in Autism, 3*(3), 142-153.

Iannuzzi, D., Fell, L., Luberto, C., Goshe, B. M., Perez, G., Park, E., Crute, S., Kuhlthau, K., & Traeger, L. (2022). Challenges and growth: Lived experience of adolescents and young adults (AYA) with a sibling with ASD. *Journal of Autism and Developmental Disorders, 52*, 2430–2437. https://doi.org/10.1007/s10803-021-05135-0

Johnson, J, & Piercy, F.P. (2017). Exploring partner intimacy among couples raising children on the autism spectrum: A grounded theory investigation. *Journal of Marital Family Therapy, 43*(4),644-661. https://doi.org/10.1111/jmft.12247. Epub 2017 Jun 13. PMID: 28612384.

Keenan, B.M., Newman, L.K., Gray, K.M., & Rinehart, N.J. (2016). Parents of children with ASD experience more psychological distress, parenting stress, and attachment-related anxiety. *Journal of Autism Developmental Disorders, 46*(9), 2979-91. https://doi.org/10.1007/s10803-016-2836-z

Kerr, M. E., & Bowen, M. (1988). *Family evaluation*. W. W. Norton and Company.

Kinnear, S. H., Link, B. G., Ballan, M. S., Fischbach, R. L. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of Autism and Developmental Disorders, 46*(3), 942-953. https://doi.org/10.1007/s10803-015-2637-9

Kubler-Ross, E. (1969). *On death and dying*. Macmillan.

Kyrkou, N. (2018). Family quality of life and nurturing the sibling relationship. *International Journal of Child, Youth and Family Studies*, *9*(4), 75-87. https://doi.org/10.18357/ijcyfs94201818641

Lai, M. C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S.H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis. *The Lancet Psychiatry, 6*(10), 819-829. https://doi.org/10.1016/S2215-0366(19)30289-5

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*(2), 102-120.

Lashewicz, B. M., Shipton, L., & Lien, K. (2019). Meta-synthesis of fathers' experiences raising children on the autism spectrum. *Journal of Intellectual Disabilities, 23*(1), 117–131.

Laws of Malta. (2000). *Equal Opportunities (Persons with Disability) Act.* https://legislation.mt/eli/cap/413/eng/pdf

Liamputtong, P. (2009). Qualitative data analysis: Conceptual and practical considerations. *Health Promotion Journal of Australia, 20*(2), 133-139. https://doi.org/10.1071/HE09133

Lovell, B., & Whetherell, M.A. (2019). Affiliate stigma, perceived social support and perceived stress in caregivers of children with autism spectrum disorder: A multiple mediation study. *Archives of Psychiatric Nursing, 33,* 31-35. https://doi.org/10.1016/j.apnu.2019.08.012

Ludlow, A., Skelly, C., & Rohleder, P. (2011). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health Psychology, 17(5),* 702–711. https://doi.org/10.1177/1359105311422955

Maenner, M.J., Shaw, K.A., Baio, J., Washington, A., Patrick, M., DiRienzo, M., Christensen, D. L., Wiggins, L.D., Pettygrove, S., Andrews, J.G., Lopez, M., Hudson, A., Baroud, T., Schwenk, Y., White, T., Rosenberg, C.R., Lee, L.-C., Harrington, R.A., Huston, M., . . .Dietz, P.M. (2020). Prevalence of autism spectrum disorder among children aged 8 years. Autism and developmental disabilities monitoring network, 11 sites, United States, 2016. *MMWR Surveill Summ, 69*(4), 1–12.

Marciano, S.T., Drasgow, E., & Carlson, R.G. (2015). The marital experiences of couples who include a child with autism. *The Family Journal: Counseling and Therapy for Couples and Families, 23*(2), 132-140. https://doi.org/10.1177/1066480714564315

McCafferty, P., & McCutcheon, J. (2020). Parenting a child with autism: Considering the stresses, supports and implications for social work practice. *Child Care in Practice, 27*(4), 389–405.

McClellan, M. (2021*). If you've met one person with autism, you've met one person with autism*. https://autismpensacola.org/if-youve-met-one-person-with-autism-youve-met-one-person-with-autism/

McNamee, S. (2017). Social constructionism in couple and family therapy. *Encyclopedia of Couple and Family Therapy*, 1-4. https://doi.org/10.1007/978-3-319-15877-8_820-1

McStay, R.L., Dissanayake, C., Scheeren, A., Koot, H.M., & Begeer, S. (2014) Parenting stress and autism: The role of age, autism severity, quality of life and problem behaviour of children and adolescents with autism. *Autism, 18*(5), 502-10. https://doi.org/10.1177/1362361313485163

Mitchell, M. L., & Jolley, J. M. (2010). *Research design explained*. Wadsworth Cengage Learning.

Morse, J.M. (2015). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research, 25(*9), 1212-1222.

Mubashir, S., Farrugia, M., Coretti, L., Pessia, M., & D’Adamo, M.C. (2020). Autism spectrum disorder. *Malta Medical Journal*, 32(3), 56-66. http://mmsjournals.org/index.php/mmj

Myers, E., Davis, B. E., Stobbe, G., & Bjornson, K. (2015). Community and social participation among individuals with autism spectrum disorder transitioning to adulthood. *Journal of Autism Developmental Disorders, 45*(8), 2373-2381. https://doi.org/10.1007/s10803-015-2403-z

National Autistic Society (n.d.). *Loneliness*. https://www.autism.org.uk/advice-and-guidance/topics/loneliness#Autistic%20people's%20experience%20of%20loneliness

National Institute for Health and Care Excellence. (2017). *Autism spectrum disorder in under 19s: recognition, referral and diagnosis*. https://www.nice.org.uk/guidance/cg128/chapter/Recommendations#information-and-support-for-families-and-carers

Neely, J., Amatea, E.S., Echevarria-Doan, S., & Tannen, T. (2012). Working with families living with autism: Potential contributions of marriage and family therapists. *Journal of Marital and Family Therapy, 38*(1), 211-226.

Nord, D.K., Stanclife, R.J., Nye-Lengerman, K., & Hewitt, A.S. (2016). Employment in the community for people with and without autism: A comparative analysis. *Research in Autism Spectrum Disorders, 24,* 11–16. https://doi.org/10.1016/j.rasd.2015.12.013

Padden, C., & James, J. (2017). Stress among parents of children with and without autism spectrum disorder: A comparison involving physiological indicators and parent self-reports. *Journal of Developmental & Physical Disabilities, 29*(4), 567–586. https://doi.org/10.1007/s10882-017-9547-z

Patrini, M. (2021). Is family therapy effective for people with autism spectrum disorder and their families? A Cochrane review summary with commentary. *Developmental Medicine & Child Neurology, 63,* 133–134. https://doi.org/10.1111/dmcn.14757

Potter, C.A. (2016). “I accept my son for who he is-He has incredible character and personality”: Fathers’ positive experiences of parenting children with autism. *Disability and Society, 31*(7), 948–965.

Ramisch, J. L., Onaga, E., & Oh, S. M. (2014). Keeping a sound marriage: How couple with children with ASD maintain their marriages. *Journal of Child Family Studies*, *23*, 975–988. https://doi.org/10.1007/s10826-013-9753-y.

Reindal, S. (2010) Redefining disability: A rejoinder to a critique. *Nordic Journal of Applied Ethics, 4*(1), 125–135. https://doi.org/10.5324/eip.v4i1.1744

Riessman, C.K. (2008). *Narrative methods for the human sciences*. Sage Publications.

Roux, A.M., Rast, J.E., Anderson, K.A., & Shattuck, P.T. (2017). *National autism indicators report: Developmental disability services and outcomes in adulthood*. A.J. Drexel Autism Institute, Drexel University.

Shepherd, D., Landon, J., Taylor, S., & Goedeke, S. (2018). Coping and care-related stress in parents of a child with autism spectrum disorder. *Anxiety, Stress, & Coping, 31(*3), 277-290. https://doi.org/10.1080/10615806.2018.1442614

Sim, A., Vaz, S., Cordier, R., Joosten, A., Parsons, D., Smith, C., & Falkmer, T. (2018). Factors associated with stress in families of children with autism spectrum disorder. *Developmental Neurorehabilitation, 21*(3), 155-165. https://doi.org/10.1080/17518423.2017.1326185

Sim, A., Cordier, R., Vaz, S., Parsons, R., & Falkmer, T. (2017). Relationship satisfaction and dyadic coping in couples with a child with autism spectrum disorder. *Journal of*

Autism & Developmental Disorders, 47, 3562–3573. https://doi.org/10.1007/s10803-017-3275-1

Sipowicz, K, Podlecka, M., Mokros, L., Pietras, T., & Luczynska, K. (2022). Being an adult sibling of an individual with autism spectrum disorder may be a predictor of loneliness and depression – Preliminary findings from a cross-sectional study. *Frontiers in Psychology,* 01-08. https://doi.org/10.3389/fpsyg.2022.915915

Smith, B. (2016). Narrative analysis. In E. Lyons & A. Coyle (Eds.). *Analysing qualitative data in psychology* (2nd Ed.) (pp. 202-221). Sage.

Smith, L.E., & Anderson, K.A. (2014). The roles and needs of families of adolescents with ASD. *Remedial and Special Education, 35*(2), 114–122. https://doi-org.ejournals.um.edu.mt/10.1177/0741932513514616

Smock Jordan, S., & Turns, B. (2016). Utilizing solution-focused brief therapy with families living with autism spectrum disorder. *Journal of Family Psychotherapy, 27*(3), 155-170. https://doi.org/10.1080/08975353.2016.1199766

Solomon, A.H., & Chung, B. (2012). Understanding autism: How family therapists can support parents of children with autism spectrum disorders. *Family Process, 51*(2), 250-64. https://doi.org/10.1111/j.1545-5300.2012.01399.x

Sosnowy, C., Silverman, C., & Shattuck, P. (2018). Parents’ and young adults’ perspectives on transition outcomes for young adults with autism. *Autism ,22(*1), 29-39. https://doi-org.ejournals.um.edu.mt/10.1177/1362361317699585

Spain, D., Sin, J., Paliokosta, E., Furuta, M., Prunty, J.E., Chalder, T., Murphy, D.G., & Happé, F.G. (2017). Family therapy for autism spectrum disorders. *Cochrane Database of Systematic Reviews,* 5, 1-31. https://doi.org/10.1002/14651858.CD011894.pub2

Tomm, K. (1988). Interventive interviewing: Part III. Intending to ask lineal, circular, strategic, or reflexive questions? *Family Process, 27*(1), 1-15.

Torbet, S., Proeve, M., & Roberts, R. (2019). Self-compassion: A protective factor for parents of children with autism spectrum disorder. *Mindfulness, 10,* 2492–2506. https://doi.org/10.1007/s12671-019-01224-5

United Nations. (2008). *Convention on the Rights of Persons with Disabilities*. https://www.ohchr.org/sites/default/files/Documents/Publications/AdvocacyTool_en.pdf

University of Malta (2018). *Ethical guidelines for carrying out research with disabled people.* https://www.um.edu.mt/media/um/docs/research/urec/DisabilityGuidelines.pdf

Urbanowicz, A., Parkin, T., vanDooren, K., Girdler, S., Ciccarelli, M., & Lennox, N. (2019). The experiences, views, and needs of health professionals who provide care to adults on the autism spectrum. *Research and Practice in Intellectual and Developmental Disabilities, 7(*2), 179-192.https://doi-org.ejournals.um.edu.mt/10.1080/23297018.2020.1735943

Vella Gera, J., Martin, G., & Camilleri Zahra, A. J. (2021). An insight into the lives of young siblings of disabled children in Malta. *Disability & Society, 36*(1), 58-80. https://doi.org/10.1080/09687599.2020.1712188

Vernhet, C., Dellapiazza, F., Blanc, N., Cousson-Gelie, F., Miot, S., Roeyers, H., & Baghdadli, A. (2019). Coping strategies of parents of children with autism spectrum disorder: A systematic review. *European Child & Adolescent Psychiatry, 28,* 747–758. https://doi.org/10.1007/s00787-018-1183-3

Walsh, F. (2012). Normal family processes: Growing diversity and complexity. In F. Walsh (Ed.), *Family resilience: Strengths forged through adversity* (pp. 399-427). The Guilford Press.

Willig, C. (2013). *Introducing qualitative research in psychology*. McGraw-Hill Education.

Wong, J., Coster, W.J., Cohn, E.S., & Orsmond, G.I. (2021). Identifying school-based factors that predict Employment outcomes for transition-age youth with autism spectrum disorder. *Journal of Autism & Developmental Disorders, 51*, 60-74. https://doi.org/10.1007/s10803-020-04515-2

World Health Organization (2023). *Autism*. https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders

Wright, B. M., & Benigno, J. P. (2019). Autism spectrum disorder and sibling relationships: Exploring implications for intervention using a family systems framework. *American Journal of Speech-Language Pathology*, *28*(2), 759–767.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, *15*, 215– 228.

Yin, R.K. (2003). Designing case studies. *Qualitative Research Methods, 5*(14), 359-386.

Zammit, A. (2018). The role of screen-based media in the development and maintenance of peer relationships in adolescents with and without autism spectrum conditions in Malta. Doctoral thesis. University College London.

Zhang, Y., Mythily, S., Lee, S.P., Edimansyah, A., Vathsala, S., Anitha, J., Chang, S., Shafie, S B., Rahman, R.F.A., Vaingankar, J.A., & Chong, S.A. (2018). Affiliate stigma and its association with quality of life among caregivers of relatives with mental illness in Singapore. *Psychiatry Research, 265*, 55–61. https://doi.org/10.1016/j.psychres.2018.04.044

Zucker, A., Chang, Y., Maharaj, R., Wang, W., Fiani, T., McHugh, S., Feinup, D. M., & Jones, E. A. (2022). Quality of the sibling relationship when one sibling has autism spectrum disorder: A randomized controlled trial of a sibling support group. *Autism, 26*(5), 1137–1152. https://doi.org/10.1177/13623613211042135

Appendices

Appendix A

Gatekeepers' Agreements

5/27/23, 12:59 PM University of Malta Mail - Your Research Request ref: RR2022.01 - Approved

L-Università ta' Malta

Frida Mangion <frida.mangion.06@um.edu.mt>

Your Research Request ref: RR2022.01 - Approved

2 messages

Research at Sapport <research.sapport@gov.mt> 30 March 2022 at 10:32

To: Frida Mangion <frida.mangion.06@um.edu.mt>

Cc: Research at Sapport <research.sapport@gov.mt>

Dear Ms Mangion,

Thank you for submitting all required, complete documentation. I am pleased to inform you that your Research Request (*ref*: RR2022.01) is now ***Approved***.

Your research participation invitation will accordingly be disseminated to service users of Aġenzija Sapport and their relatives who meet your study's eligibility criteria for participation.

As a consideration, in your observation notes, transcripts, findings chapter, discussion chapter, any participant quotes included in your dissertation, etc., please consider the word 'Agency' (for any references that participants may make to Aġenzija Sapport) as identifying information, in line with disseminating your research participation invitation through more than one organisation, for the purpose of safeguarding participants' anonymity. Thus, kindly redact any such references (to 'Aġenzija Sapport', 'Agency'/'Aġenzija', 'the Agency'/'l-Aġenzija', etc.) replacing them instead with the generic word 'entity' or 'organisation'.

May I please remind you to submit a copy of the dissertation once it is finalised and a grade has been allocated.

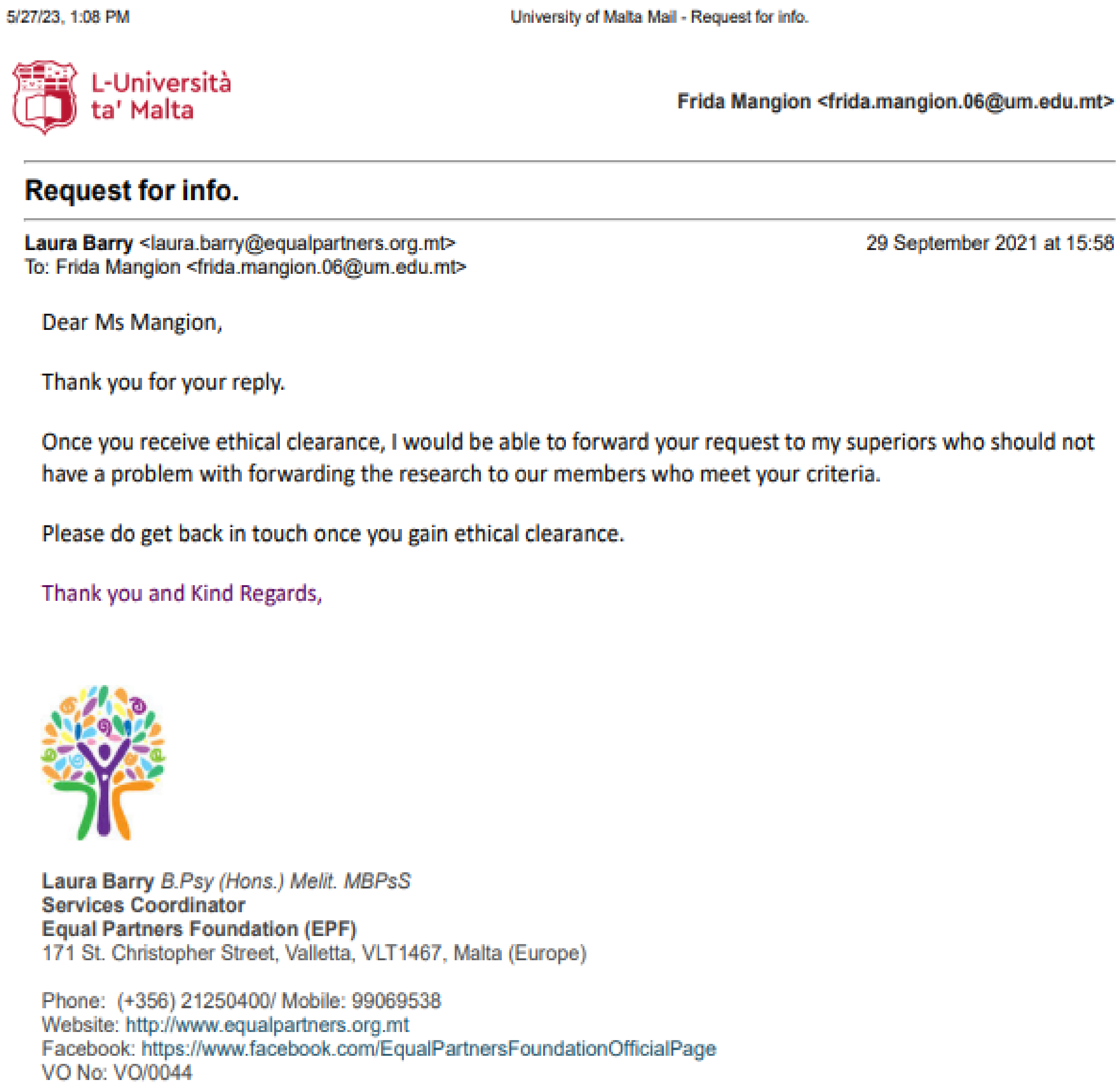
Please do not hesitate to contact me during the participant recruitment phase should I be of any assistance.

Kind regards,

Christine Sant

Senior Executive I (Liaison & Risk Management Department)

AĠENZIJA SAPPORT



5/27/23, 1:08 PM University of Malta Mail - Request for info.

L-Università ta' Malta

Frida Mangion <frida.mangion.06@um.edu.mt>

Request for info.

Laura Barry <laura.barry@equalpartners.org.mt> 29 September 2021 at 15:58
To: Frida Mangion <frida.mangion.06@um.edu.mt>

Dear Ms Mangion,

Thank you for your reply.

Once you receive ethical clearance, I would be able to forward your request to my superiors who should not have a problem with forwarding the research to our members who meet your criteria.

Please do get back in touch once you gain ethical clearance.

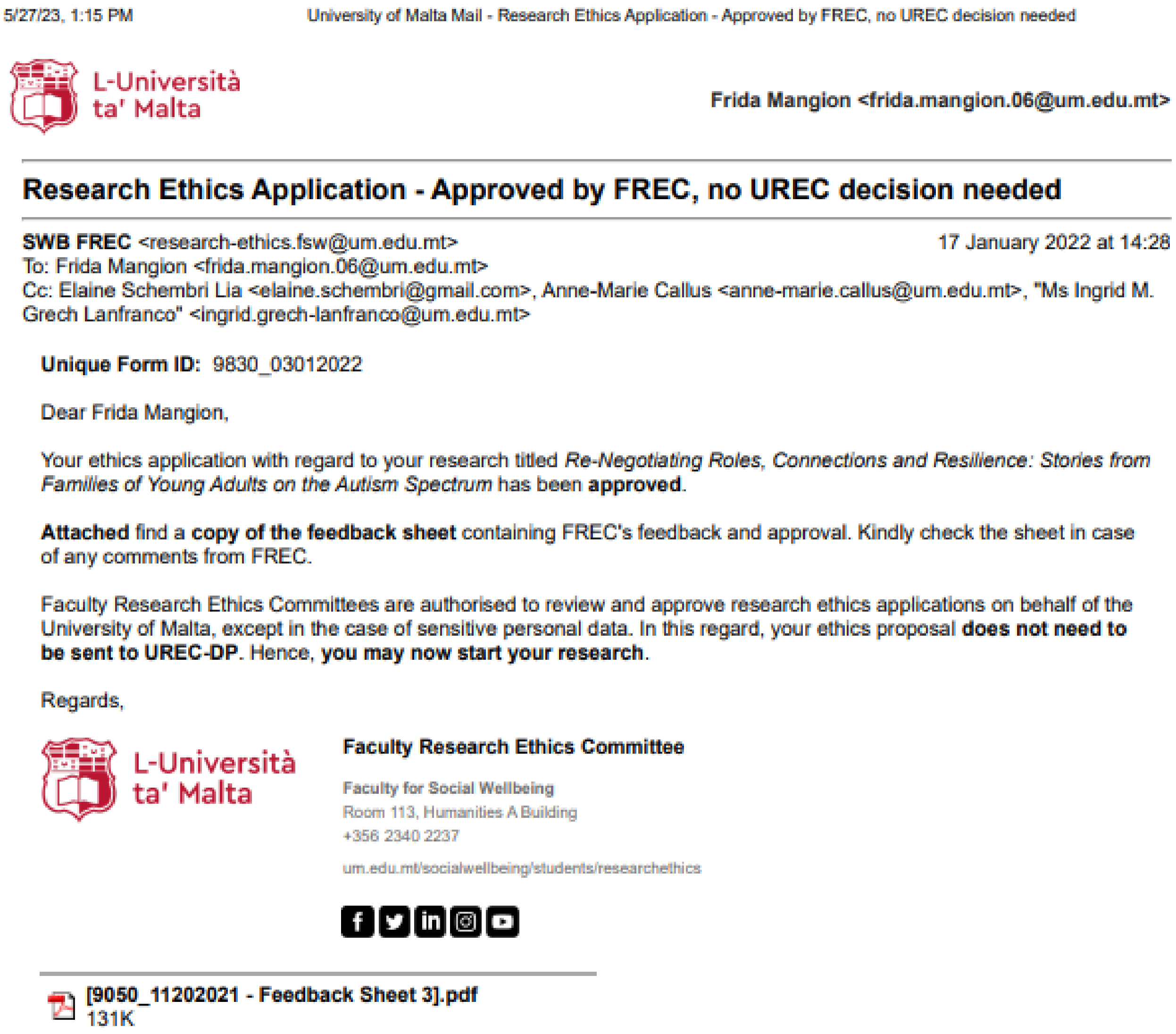
Thank you and Kind Regards,

Laura Barry *B.Psy (Hons.) Melit. MBPsS*
Services Coordinator
Equal Partners Foundation (EPF)
171 St. Christopher Street, Valletta, VLT1467, Malta (Europe)

Phone: (+356) 21250400/ Mobile: 99069538
Website: http://www.equalpartners.org.mt
Facebook: https://www.facebook.com/EqualPartnersFoundationOfficialPage
VO No: VO/0044

Appendix B

FREC Approval



5/27/23, 1:15 PM University of Malta Mail - Research Ethics Application - Approved by FREC, no UREC decision needed

L-Università ta' Malta

Frida Mangion <frida.mangion.06@um.edu.mt>

Research Ethics Application - Approved by FREC, no UREC decision needed

SWB FREC <research-ethics.fsw@um.edu.mt> 17 January 2022 at 14:28
To: Frida Mangion <frida.mangion.06@um.edu.mt>
Cc: Elaine Schembri Lia <elaine.schembri@gmail.com>, Anne-Marie Callus <anne-marie.callus@um.edu.mt>, "Ms Ingrid M. Grech Lanfranco" <ingrid.grech-lanfranco@um.edu.mt>

Unique Form ID: 9830_03012022

Dear Frida Mangion,

Your ethics application with regard to your research titled *Re-Negotiating Roles, Connections and Resilience: Stories from Families of Young Adults on the Autism Spectrum* has been **approved**.

Attached find a **copy of the feedback sheet** containing FREC's feedback and approval. Kindly check the sheet in case of any comments from FREC.

Faculty Research Ethics Committees are authorised to review and approve research ethics applications on behalf of the University of Malta, except in the case of sensitive personal data. In this regard, your ethics proposal **does not need to be sent to UREC-DP**. Hence, **you may now start your research**.

Regards,

L-Università ta' Malta

Faculty Research Ethics Committee

Faculty for Social Wellbeing
Room 113, Humanities A Building
+356 2340 2237

um.edu.mt/socialwellbeing/students/researchethics

[9050_11202021 - Feedback Sheet 3].pdf
131K

Appendix C

Request for Permission to Conduct Research (English and Maltese)

5th October, 2021

Request for permission to conduct research

Dear Agency,

My name is Frida Mangion and I am a student at the University of Malta, presently reading for a Masters in Family Therapy and Systemic Practice. I am presently conducting a research study for my dissertation titled Re-Negotiating Roles, Connections and Resilience: Stories from families of Young Adults on the Autism Spectrum. This study aims to explore how families, where there is a young adult diagnosed on the autism spectrum, have adjusted to the autism and how they are negotiating and working through their roles as a family system over time because of their challenges and opportunities. This project is being conducted under the supervision of Ms Elaine Schembri Lia and my co-supervisor Dr Anne-Marie Callus.

I am hereby asking for your assistance, to act as a gatekeeper. For this research, I aim to interview 2/3 sets of family units. The inclusion criteria are as per the following: families with young adults diagnosed with ASD Level 1 and 2 over 18 to 30 years of age, families with both parents; 1 to 2 siblings and the participants must be receiving social support at the time of the interview. The interviews will be held in Maltese or English and at a convenient time and place for the participants. As a researcher, I am also interested in observing the family's interactions after the interview for about one hour. The information elicited from this observation will enrich data gathering.

Data collected will be gathered through the use of audio-recorded interviews with parents, young adult on the autism spectrum and their sibling/s respectively. During the interview, the participants will be asked to narrate their personal experiences with autism.

Participation will be entirely voluntary and participants will be free to withdraw at any point, without any repercussions. Data collected will be protected with anonymity and the personal data of participants will be pseudonymized to make it as non-identifiable as possible. Anonymity will be maintained as per the Data Protection Act Guidelines and the University of Malta Regulations. Extra caution will be taken, especially given the sensitive data to be gathered, so as not to divulge any information that may disclose the participant's identity. However, there can be a chance that someone may recognize the family through the unique experience/s they share. The data is only accessed by the supervisor, co-supervisor, myself and in exceptional cases my examiners.

Please also note that, participants, have the right under the General Data Protection Regulation (GDPR) and national legislation to access, rectify and where applicable ask for any data to be erased within one month time frame from interview date. All data collected will be kept in a locked cabinet and the research data will be stored safely on a password-protected computer. Once the study is over and following the publication of results, by November 2023, all the research material will be destroyed.

Should you require further information, please do not hesitate to contact me, my supervisor and co-supervisor.

Thank you for your kind consideration of this request.

Sincerely,

Schembrilia.

Frida Mangion
frida.mangion.06@um.edu.mt

Elaine Schembri Lia
esche02@um.edu.mt

____

Signature of Gatekeeper

Date: _______________

5 t’Ottubru, 2021

Talba għall-permess biex issir riċerka

Għażiż/a Aġenzija,

Jiena, Frida Mangion, studenta fl-Università ta’ Malta, u bħalissa qed insegwi Masters fit-Terapija għall-Familja u Prattiċi Sistemiċi. Ir-riċerka għad-dissertazzjoni tiegħi jisimha: Negozjar mil-ġdid ta’ Rwoli, Konnessjonijiet u Reżiljenza: Stejjer minn familji t’ Adulti fuq l-Ispettru ta’ l-Awtiżmu. L-għan ta’ dan l-istudju hu li jesplora kif familji, fejn hemm adulti fuq l-ispettru ta’ l-awtiżmu, adattaw għal-awtiżmu u kif jinnegozjaw u jaħdmu madwar l-irwoli tagħhom bħala familja mażżmien fl-isfidi li jiltaqgħu magħhom. It-tutur tiegħi hi Ms Elaine Schembri Lia u l-kosuperviżur Dr Anne-Marie Callus.

Qed niktiblek biex nitlob l-għajnuna tiegħek sabiex tgħinni naċċessa parteċipanti għal dan listudju. Il-ġbir tal-informazzjoni se jinvolvi l-parteċipazzjoni ta’ 2/3 settijiet ta’ familji. Il-kriterji t’ inkużjoni jinkludu dan li ġej: familji fejn hemm adulti fuq l-ispettru ta’ l-awtiżmu fil-Livell 1 u Livell 2 fuq l-ispettru ta’ bejn 18 u 30 sena, familji b’żewġ ġenituri li jgħixu flimkien, familji fejn hemm 1 sa 2 aħwa u fuq kollox il-parteċipanti jkunu qed jirċievu sapport soċjali fil-perjodu li lintervista sseħħ. L-intervista se ssir bil-Malti jew Ingliż u f’post u ħin konvenjenti għal familja.

Bħala riċerkatrici, nixtieq ukoll nosserva kif il-membri tal-familja jinteraġixxu flimkien għal madwar siegħa, wara li tintemm l-intervisti mal-membri tal-familja kollha. L-informazzjoni miġbura minn din l-osservazzjoni se ssaħħaħ il-kwalita’ tar-riċerka miġbura.

L-intervista li se ssir mal-ġenituri, adulti bl-awtiżmu u l-aħwa tagħhom se tkun irrekordjata blawdjo u maqluba fi kliem, kif irrekordjata (traskrizzjoni).Matul l-intervista, se nkun qed nistieden lil parteċipanti jirrakkontaw l-erperjenza personali tagħhom madwar l-awtiżmu.

Il-parteċipazzjoni f’dan l-istudju hija għal kollox volontarja u l-parteċipanti se jkunu liberi li jieqfu jieħdu sehem meta jixtiequ, mingħajr ebda riperkussjoni. Siltiet mil-informazzjoni miġbura waqt l-intervista jistgħu jiġu riprodotti f’format anonimu jew bl-użu ta’ psewdonimu. Dan jfisser li lidentità tal-parteċipant, mhix se titniżżel fit-traskrizzjonijiet jew fin-noti tal-intervista, imma minflok, se jkun assenjat/a kodiċi. Il-kodiċijiet li jorbtu l-informazzjoni tal-parteċipant ma' lidentità tiegħu/ha se jinżammu b'mod sigur u separat mill-informazzjoni, f'file kodifikat fuq ilkompjuter, protetti b'password, u r-riċerkatriċi, tutur akkademika, l-ko-superviżur, u f'każijiet eċċezzjonali l-eżaminaturi biss se jkollhom aċċess għal din l-informazzjoni. Kwalunkwe materjal stampat se jitqiegħed f'armarju msakkar. Kwalunkwe materjal li jidentifika l-parteċipant/a f'dan listudju se jinżamm b'mod sigur sakemm isir l-istudju u jkun mħassar sa Novembru, 2023.

Ta' min jsemmi li l-parteċipanti għandhom id-dritt, skont ir-Regolament Ġenerali dwar ilProtezzjoni tad-Data (GDPR) u l-leġiżlazzjoni nazzjonali, li jaċċessaw, jikkoreġu u fejn hu applikabbli, jitlob li l-informazzjoni li tikkonċernahom titħassar. L-informazzjoni kollha li tinġabar fl-istudju se titħassar meta jintemm l-istudju u wara li joħorġu r-riżultati.

Għal iżjed informazzjoni, tiddejjaqx tikkuntattja lili jew lit-tutur/i tiegħi. Id-dettalji tagħna ssibhom hawn taħt. Napprezza jekk tikkunsidra din it-talba.

Tislijiet,

Schembri Lia.

Frida Mangion

frida.mangion.06@um.edu.mt

Elaine Schembri Lia

esche02@um.edu.mt

____

Firma tal-Gatekeeper

Data: _____________

Appendix D

Information about the study for Parents of Young Adults on the Autism Spectrum

(English and Maltese)

Re-Negotiating Roles, Connections and Resilience: Stories from families of Young Adults on the Autism Spectrum

Tuesday 5th October, 2021

Information about the study for Parents of Young Adults on the Autism Spectrum

My name is Frida Mangion and I am a student at the University of Malta, reading for a Masters in Family Therapy and Systemic Practice. I am presently researching as part of my dissertation titled Re-Negotiating Roles, Connections and Resilience: Stories from families of Young Adults on the Autism Spectrum; this is being supervised by Ms Elaine Schembri Lia, email address: esche02@um.edu.mt and my co-supervisor Dr Anne-Marie Callus, email address: annemarie.callus@um.edu.mt. My study aims to explore how families, where there is a young adult diagnosed on the autism spectrum, is adjusting to the autism and how they are negotiating and working through their roles as a family system over time given their challenges and opportunities.

Your Participation

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

Data collected will be gathered from the experiences of 2-3 sets of parents, young adults on the autism spectrum and their siblings First, the different family members will be interviewed and asked to narrate their personal experiences around autism as a family. The interviews will take approximately one hour and will be held in Maltese or English and at a convenient time and place for the participants. Following this, I will observe each family interacting together in their natural setting for around one hour. The information elicited from this observation will enrich the data gathered through the 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 may also refuse to answer any questions which make you feel uncomfortable even if you choose to participate. You are also free to withdraw from the study at any time, without needing to provide any explanation or incur any negative repercussions. Should you choose to withdraw, any data collected from your interview will be deleted, however, this may only be done by not later than one month following the interview.

If you choose to participate, it is important to note that you will not be eliciting any direct benefits. However, your participation is likely to give voice to the narratives of participants, especially to young adults on the autism spectrum, and their family narratives, who are most often left out from the interviewing process. Moreover, your contribution will be supporting professionals and therapeutic services to provide services that are attuned to the challenges faced by families of young adults on the autism spectrum.

Your participation does not entail any known or anticipated risks. However, should the interview trigger any undesirable outcomes, the researcher will support you to liaise with professional/s who may provide the necessary follow up.

Data Management

The data gathered will be treated with strict confidentiality and the personal data of participants will be pseudonymized to make it as non-identifiable as possible. Anonymity will be maintained as per the guidelines of the Data Protection Act and the University of Malta Regulations. Extra caution will be taken, especially given the sensitive data to be gathered, so as not to divulge any information that may disclose the participant's identity. However, there can be a chance that someone may recognize you through the unique experience/s you share. The original data, including the recordings, will be only accessed by the supervisor, co-supervsior and researcher, and in exceptional cases her examiners.

All data collected will be kept in a locked cabinet and the research data will be stored safely on a password-protected computer. Once the study is over and following the publication of results, by November 2023, all the research material will be destroyed.

____________________________ FRIDA MANGION

Participant’s name (in block) Researcher’s name (in block)

____________________________ ____________________________

Participant’ signature Researcher’s signature

____

Date

Negozjar mil-ġdid ta' Rwoli, Konnessjonijiet u Reżiljenza: Stejjer minn familji t' Adulti fuq l-Ispettru ta' l-Awtiżmu

Tlieta 5 t'Ottubru, 2021

Ittra ta' tagħrif għall-Ġenituri t'Adulti fuq l-Ispettru ta' l-Awtiżmu

Jiena Frida Mangion, studenta fl-Università ta' Malta, u bħalissa qed insegwi Masters fit-Terapija għall-Familja u Prattiċi Sistemiċi. Ir-riċerka għad-dissertazzjoni tiegħi jisimha: Negozjar mil-ġdid ta' Rwoli, Konnessjonijiet u Reżiljenza: Stejjer minn familji t' Adulti fuq l-Ispettru ta' l-Awtiżmu; it-tutur tiegħi hi Ms Elaine Schembri Lia, imejl: esche02@um.edu.mt u l-ko-superviżur Dr AnneMarie Callus, imejl: anne-marie.callus@um.edu.mt. L-għan ta' dan l-istudju hu li jesplora kif familji, fejn hemm adulti fuq l-ispettru ta' l-awtiżmu, adattaw għal-awtiżmu u kif jinnegozjaw u jaħdmu madwar l-irwoli tagħhom bħala familja maż-żmien fl-isfidi li jiltaqgħu magħhom.

Il-parteċipazzjoni tiegħek

L-informazzjoni kollha li tingħabar fir-riċerka tintuża biss għall-fini ta' dan l-istudju.

L-informazzjoni se tkun miġbura mil-esperjenzi ta' 2/3 settijiet ta' ġenituri, adulti fuq l-ispettru ta' l-awtiżmu u l-aħwa tagħhom. Il-membri varji fil-familja se jintalbu biex jieħdu sehem f'intervista u se jkunu mistoqsija biex jirrakkontaw l-istorja personali tagħhom bħala familja, madwar lawtiżmu. L-intervista se ddum madwar siegħa u se ssir f'post u ħin addatt għalik/hom, bil- Malti jew Ingliż. Bħala riċerkatriċi jiena nteressata wkoll nosserva għal perjodu ta' siegħa, il-mod li bih il-familja tiegħek tinteraġixxi ma' xulxin. Din l-osservazzjoni se sseħħ wara l-intervista. Linformazzjoni miġbura minn din l-osservazzjoni hija mistenija ssaħħaħ il-kwalita' ta' linformazzjoni miġbura mil-intervista.

Il-parteċipazzjoni tiegħek f'dan l-istudju tkun għal kollox volontarja; fi kliem ieħor, inti liberu/a li taċċetta jew tirrifjuta li tieħu sehem, mingħajr ma tagħti raġuni.

Inti wkoll liberu/a li twaqqaf il-parteċipazzjoni tiegħek fl-istudju meta tixtieq, mingħajr ma jkollok tagħti spjegazzjoni u mingħajr ebda riperkussjoni. Jekk tagħżel li ma tkomplix tipparteċipa, l-informazzjoni li tkun laħqet ittieħdet fl-intervista tiegħek titħassar. Importanti li tgħamel dan sa mhux aktar tard minn xahar wara lintervista. Jekk tagħżel li tipparteċipa, jekk jogħġbok innota li m'hemm l-ebda benefiċċju dirett għalik. Iżda, l-parteċipazzjoni tiegħek mistennija toffri leħen lil istejjer tal-parteċipanti, speċjalment t'adulti fuq l-ispettru ta' l-awtiżmu li ħafna drabi jitħallew barra mil-proċess ta' lintervista u lil familji tagħhom. Ta' min wieħed jsemmi li din ir-riċerka mistennija toffri sapport lil professjonisti li joffru servizzi terapewtiċi sabiex joffru/ joħolqu servizzi li jindirizzaw l-isfidi li familji bi tfal bl-awtiżmu jaffaċċjaw.

Il-parteċipazzjoni tiegħek ma fiha l-ebda riskju magħruf jew mistenni. Madanakollu, f'kas li lintervista tqanqal effetti mhux mistennija, ir-riċerkatriċi se tkun tista' tghinek tgħamel kuntatt ma' professjonista/i li jistghu jsegwu lilek jew lil familja tiegħek.

Immaniġjar tad-Data

Jekk taqbel li tipparteċipa, tintalab tieħu sehem f'intervista li se tkun rekordjata bl-awdjo u maqluba fi kliem, kif irrekordjata (traskrizzjoni). Siltiet mil-informazzjoni miġbura waqt l-intervista jistgħu jiġu riprodotti f'format anonimu jew bl-użu ta' psewdonimu. Bħala parteċipant/a, għandek id-dritt, skont ir-Regolament Ġenerali dwar il-Protezzjoni tad-Data (GDPR) u l-leġiżlazzjoni nazzjonali, li taċċessa, tikkoreġi u fejn hu applikabbli, titlob li l-informazzjoni li tikkonċernak titħassar fi żmien xahar. L-informazzjoni kollha li tinġabar fl-istudju se titħassar meta jintemm l-istudju u wara li joħorġu r-riżultati.

Id-dettalji personali tiegħek mhux se jiġu żvelati f'xi pubblikazzjoni, rapport jew preżentazzjoni li tista' toħroġ minn din ir-riċerka. Madanakollu, jista' jkun hemm il-possibilta' li xi ħadd jagħraf lidentita' tiegħek jew tagħkom minħabba l-esperjenza unika li se tirrakkonta/ tirrakontaw.

Dan jfisser li l-identità tiegħek mhix se titniżżel fit-traskrizzjonijiet jew fin-noti tal-intervista, imma minflok, se tiġi assenjat/a kodiċi. Il-kodiċijiet li jorbtu l-informazzjoni dwarek mal-identità tiegħek

se jinżammu b'mod sigur u separat mill-informazzjoni, f'file kodifikat fuq il-kompjuter tarriċerkatriċi, protetti b'password, u r-riċerkatriċi u tutur akkademika biss se jkollhom aċċess għal din l-informazzjoni. L-informazzjoni oriġinali, nkluż dik rekordjata, se tkun aċċessibbli missuperviżur, ko-superviżur u minni bħala riċerkattriċi, kif ukoll f'każijiet eċċezzjonali mil-eżaminaturi tiegħi.

Kwalunkwe materjal stampat se jitqiegħed f'armarju msakkar. Kif ukoll, kwalunkwe materjal li jidentifikak bħala parteċipant/a f'dan l-istudju se jinżamm b'mod sigur sakemm isir l-istudju. Il-materjal kollu jiġi mħassar sa Novembru, 2023.

Tislijiet,

Schembri Lia.

Frida Mangion | Elaine Schembri Lia

frida.mangion.06@um.edu.mt | esche02@um.edu.mt

____

Isem tal-parteċipant

____

Firma tal-Parteċipant

____

Data

Appendix E

Information about the study for Young Adults on the Autism Spectrum

(English and Maltese)

Re-Negotiating Roles, Connections and Resilience: Stories from families of Young Adults on the Autism Spectrum

Tuesday 5th October, 2021

Information about the study for Young Adults on the Autism Spectrum

My name is Frida Mangion and I am a student at the University of Malta, reading for a Masters in Family Therapy and Systemic Practice. I am presently researching as part of my dissertation titled

Re-Negotiating Roles, Connections and Resilience: Stories from families of Young Adults on the Autism Spectrum; this is being supervised by Ms Elaine Schembri Lia, email address: esche02@um.edu.mt and my co-supervisor Dr Anne-Marie Callus, email address: annemarie.callus@um.edu.mt. My study aims to explore how families, where there is a young adult diagnosed on the autism spectrum, is adjusting to the autism and how they are negotiating and working through their roles as a family system over time given their challenges and opportunities.

Your Participation

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

Data collected will be gathered from the experiences of 2-3 sets of parents, young adults on the autism spectrum and their siblings First, the different family members will be interviewed and asked to narrate their personal experiences around autism as a family. The interviews will take approximately one hour and will be held in Maltese or English and at a convenient time and place for the participants. Prior to this interview I will also seek your permission to speak to your parents and sibling/s about yourself. Following this, I will observe each family interacting together in their natural setting for around one hour. The information elicited from this observation will enrich the data gathered through the 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 may also refuse to answer any questions which make you feel uncomfortable even if you choose to participate. You are also free to withdraw from the study at any time, without needing to provide any explanation or incur any negative repercussions. Should you choose to withdraw, any data collected from your interview will be deleted, however, this may only be done by not later than one month following the interview.

If you choose to participate, it is important to note that you will not be eliciting any direct benefits. However, your participation is likely to give voice to the narratives of participants, especially to young adults on the autism spectrum, and their family narratives, who are most often left out from the interviewing process. Moreover, your contribution will be supporting professionals and therapeutic services to provide services that are attuned to the challenges faced by families of young adults on the autism spectrum.

Your participation does not entail any known or anticipated risks. However, should the interview trigger any undesirable outcomes, the researcher will support you to liaise with professional/s who may provide the necessary follow up.

Data Management

The data gathered will be treated with strict confidentiality and the personal data of participants will be pseudonymized to make it as non-identifiable as possible. Anonymity will be maintained as per the guidelines of the Data Protection Act and the University of Malta Regulations. Extra caution will be taken, especially given the sensitive data to be gathered, so as not to divulge any information that may disclose the participant's identity.

However, there can be a chance that someone may recognize you through the unique experience/s you share. The original data, including the recordings, will be only accessed by the supervisor, co-supervsior and researcher, and in exceptional cases the examiners.

All data collected will be kept in a locked cabinet and the research data will be stored safely on a password-protected computer. Once the study is over and following the publication of results, by November 2023, all the research material will be destroyed

____________________________	FRIDA MANGION
Participant’s name (in block)	Researcher’s name (in block)
____________________________	____________________________
Participant’ signature	Researcher’s signature

____

Date

Negozjar mil-ġdid ta' Rwoli, Konnessjonijiet u Reżiljenza: Stejjer minn familji t' Adulti fuq l-Ispettru ta' l-Awtiżmu

Tlieta 5 t'Ottubru, 2021

Ittra ta' tagħrif għal-Adulti fuq l-Ispettru ta' l-Awtiżmu

Jiena Frida Mangion, studenta fl-Università ta' Malta, u bħalissa qed insegwi Masters fit-Terapija għall-Familja u Prattiċi Sistemiċi. Ir-riċerka għad-dissertazzjoni tiegħi jisimha: Negozjar mil-ġdid ta' Rwoli, Konnessjonijiet u Reżiljenza: Stejjer minn familji t' Adulti fuq l-Ispettru ta' l-Awtiżmu; it-tutur tiegħi hi Ms Elaine Schembri Lia, imejl: esche02@um.edu.mt u l-ko-superviżur Dr AnneMarie Callus, imejl: anne-marie.callus@um.edu.mt. L-għan ta' dan l-istudju hu li jesplora kif familji, fejn hemm adulti fuq l-ispettru ta' l-awtiżmu, adattaw għal-awtiżmu u kif jinnegozjaw u jaħdmu madwar l-irwoli tagħhom bħala familja maż-żmien fl-isfidi li jiltaqgħu magħhom.

Il-parteċipazzoni tiegħek

L-informazzjoni kollha li tinġabar fir-riċerka tintuża biss għall-fini ta' dan l-istudju.

L-informazzjoni se tkun miġbura mil-esperjenzi ta' 2/3 settijiet ta' ġenituri, adulti fuq l-ispettru ta' l-awtiżmu u l-aħwa tagħhom. Il-membri varji fil-familja se jintalbu biex jieħdu sehem f'intervista u se jkunu mistoqsija biex jirrakkontaw l-istorja personali tagħhom bħala familja, madwar lawtiżmu. L-intervista se ddum madwar siegħa u se ssir f'post u ħin addatt għalik/hom, bil- Malti jew Ingliż. Bħala riċerkatriċi jiena nteressata wkoll nosserva għal perjodu ta' siegħa, il-mod li bih il-familja tiegħek tinteraġixxi ma' xulxin. Din l-osservazzjoni se sseħħ wara l-intervista. Linformazzjoni miġbura minn din l-osservazzjoni hija mistenija ssaħħaħ il-kwalita' ta' linformazzjoni miġbura milintervista.

Il-parteċipazzjoni tiegħek f'dan l-istudju tkun għal kollox volontarja; fi kliem ieħor, inti liberu/a li taċċetta jew tirrifjuta li tieħu sehem, mingħajr ma tagħti raġuni. Inti wkoll liberu/a li twaqqaf ilparteċipazzjoni tiegħek fl-istudju meta tixtieq, mingħajr ma jkollok tagħti spjegazzjoni u mingħajr ebda riperkussjoni. Jekk tagħżel li ma tkomplix tipparteċipa, l-informazzjoni li tkun laħqet ittieħdet fl-intervista tiegħek titħassar. Importanti li tgħamel dan sa mhux aktar tard minn xahar wara l-intervista.

Jekk tagħżel li tipparteċipa, jekk jogħġbok innota li m'hemm l-ebda benefiċċju dirett għalik. Iżda, l-parteċipazzjoni tiegħek mistennija toffri leħen lil istejjer tal-parteċipanti, speċjalment t'adulti fuq l-ispettru ta' l-awtiżmu li ħafna drabi jitħallew barra mil-proċess ta' l-intervista u lil familji tagħhom. Ta' min wieħed jsemmi li din ir-riċerka mistennija toffri sapport lil professjonisti li joffru servizzi terapewtiċi sabiex joffru/ joħolqu servizzi li jindirizzaw l-isfidi li familji bi tfal blawtiżmu jaffaċċjaw.

Il-parteċipazzjoni tiegħek ma fiha l-ebda riskju magħruf jew mistenni. Madanakollu, f'kas li lintervista tqanqal effetti mhux mistennija, ir-riċerkatriċi se tkun tista' tghinek tgħamel kuntatt ma'professjonista/i li jistghu jsegwu lilek jew lil familja tiegħek.

Immaniġġjar tad-Data

Jekk taqbel li tipparteċipa, tintalab tieħu sehem f'intervista li se tkun rekordjata bl-awdjo u maqluba fi kliem, kif irrekordjata (traskrizzjoni). Siltiet mil-informazzjoni miġbura waqt l-intervista jistgħu jiġu riprodotti f'format anonimu jew bl-użu ta' psewdonimu. Bħala parteċipant/a, għandek id-dritt, skont ir-Regolament Ġenerali dwar il-Protezzjoni tad-Data (GDPR) u l-leġiżlazzjoni nazzjonali, li taċċessa, tikkoreġi u fejn hu applikabbli, titlob li l-informazzjoni li tikkonċernak titħassar fi żmien xahar. L-informazzjoni kollha li tinġabar fl-istudju se titħassar meta jintemm l-istudju u wara li joħorġu r-riżultati.

Id-dettalji personali tiegħek mhux se jiġu żvelati f'xi pubblikazzjoni, rapport jew preżentazzjoni li tista' toħroġ minn din ir-riċerka. Madanakollu, jista' jkun hemm il-possibilta' li xi ħadd jagħraf lidentita' tiegħek jew tagħkom minħabba l-esperjenza unika li se tirrakkonta/ tirrakontaw.

Dan jfisser li l-identità tiegħek mhix se titniżżel fit-traskrizzjonijiet jew fin-noti tal-intervista, imma minflok, se tiġi assenjat/a kodiċi. Il-kodiċijiet li jorbtu linformazzjoni dwarek mal-identità tiegħek se jinżammu b'mod sigur u separat millinformazzjoni, f'file kodifikat fuq il-kompjuter tarriċerkatriċi, protetti b'password, u r-riċerkatriċi u tutur akkademika biss se jkollhom aċċess għal din l-informazzjoni. Linformazzjoni oriġinali, nkluż dik rekordjata, se tkun aċċessibbli mis-superviżur, kosuperviżur u minni bħala riċerkattriċi, kif ukoll f'każijiet eċċezzjonali mil-eżaminaturi tiegħi.

Kwalunkwe materjal stampat se jitqiegħed f'armarju msakkar. Kif ukoll, kwalunkwe materjal li jidentifikak bħala parteċipant/a f'dan l-istudju se jinżamm b'mod sigur sakemm isir l-istudju. Ilmaterjal kollu jiġi mħassar sa Novembru, 2023.

Tislijiet,

Schembrilia.

Frida Mangion	Elaine Schembri Lia
frida.mangion.06@um.edu.mt	esche02@um.edu.mt

____

Isem tal-parteċipant

____

Firma tal-Parteċipant

____

Data

Appendix F

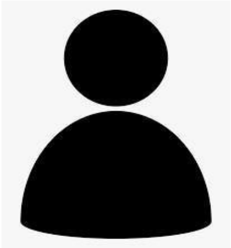
Easy to Read Information letter to take part in a study (English and Maltese)

Re-Negotiating Roles, Connections and Resilience: Stories from families of Young Adults on the Autism Spectrum

DATE: October, 2021

Information letter to take part in a study

	I am Frida and I am a student at the University of Malta reading a Masters in Family Therapy and Systemic Practice. I am writing to invite you to take part in a study that I am doing. In this letter, you will find all the information about the study and about how you can take part.
	This study is about the stories of families where there is a young adult on the autism spectrum and how family members adapted through the various challenges and opportunities presented to them over time.
	To do this study, I would like to interview 2/3 young adults with autism, their sibling/s and parents. During the interview, Frida will ask participants questions. Apart from that, Frida will be observing the participating families for an hour after carrying out all the interviews.

	Each interview will be done individually and it will take about an hour.
	I would like to record the interview because it will be very difficult for me to remember all that you tell me. Only my supervisor, Ms. Elaine Schembri Lia, co-supervisor Dr Anne-Marie Callus and myself, and in exceptional cases my examiners, will be able to listen to the recordings. After I finish my study, I will destroy the recordings by November, 2023.
	After we do the interview, I will make a summary and you are free to add or remove anything. If you want, you can also check what you said with someone you trust to make sure that its okay. This may be done until data is analysed, within a month from the interview.
	When I write about the study, I will use parts of what you said but will not use your real name. However, there can be a chance that someone reads my study and may recognize you through the stories you present. If you choose to participate in my study, it means that this will be ok for you.

✋	I know that I do not have to take part in this project if I do not want to. If I take part and I want to stop, it will not be a problem. I can stop at any time up to one month after the interview. I do not have to give reasons for stopping. I can also not answer any questions which I do not feel comfortable answering.
⚖	I will act according to what Maltese law says on how the information that I have about you should be stored. This means that I will keep the information in a secure place. I will also destroy all the information from the interviews, including recordings, after I finish my study by November, 2023.

	If you take part, you will have a chance to talk about what is important to you as the sibling of a young adult with autism. You will also be helping others learn more about what is important for persons on the autism spectrum and their families and how they move on and structure their lives as a family.
	I do not envisage any problems arising for you if you take part in my research and talk about your experiences. Having said that if something happens that upsets me during the interview, I can inform Frida who will liaise with the social worker supporting our family.
	This letter of information is for you to keep.
	If you want to take part or if you have any questions, you can contact me on frida.mangion.06@um.edu.mt. You can also speak to my supervisor Ms Elaine Schembri Lia on esche02@um.edu.mt and co-supervisor on anne-marie.callus@um.edu.mt.

Best wishes

Frida Mangion

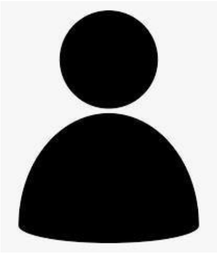
Negozjar mil-ġdid ta’ Rwoli, Konnessjonijiet u Reżiljenza: Stejjer minn familji ta’Adulti fuq l-Ispettru ta’ l-Awtiżmu

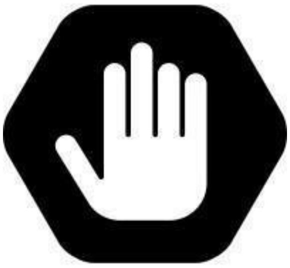
DATA: Ottubru, 2021

Ittra ta’ informazzjoni biex tieħu sehem fi studju

	Jien Frida Mangion u jien studenta fl- Università ta’ Malta u qed nsegwi Masters fit-Terapija għall-Familja u Prattiċi Sistemiċi. Qed nikteb biex nistiednek tieħu sehem fi studju li qed nagħmel. F’din l-ittra ssib l-informazzjoni dwar dan l-istudju u dwar kif tista’ tieħu sehem.
	Dan l-istudju hu dwar l-istejjer ta’ familji fejn hemm adulti fuq lispettru ta’ l-awtiżmu u kif dawn adattaw bħala familja, quddiem l-isfidi u l-opportunitajiet li ġew ippreżentati lilhom matul iż-żmien.
	Biex nagħmel dan l-istudju, jien nixtieq nagħmel intervisti ma’ 2/3 adulti bl-awtiżmu, l-aħwa u l-ġenituri tagħhom. Matul l-intervista, jien se nkun qed nistieden lil parteċipanti jwiegbu xi mistoqsijiet. Apparti minn hekk jiena se tkun qed nosserva kif il-familja tinteraġixxi flimkien għal siegħa wara l-intervista.

	L-intervista se ssir b’mod individwali u se ddum madwar siegħa.

	Jien nixtieq li nirrekordja l-intervista fuq awdjo għax ikun diffiċli għalija li niftakar kull ma tgħidli. Jien, s-superviżur tiegħi, Ms Elaine Schembri Lia u l-ko-superviżur Dr AnneMarie Callus, u f’każijiet eċċezzjonali l-eżaminaturi tiegħi, biss se nkunu nistgħu nisimgħu dak li jiġi rikordjat. Wara li nispiċċa l-istudju, f’Novembru 2023, dak li nkun irrikordjajt neqirdu.
	Wara li nagħmlu l-intervista, se ngħamel sommarju u inti tkun tista’ tara jekk tixtieqx tbiddel, iżżid jew tneħħi xi ħaġa. Jekk trid, tkun tista’ wkoll tiċċekkja dak li għidt ma’ xi ħadd li tafda biex tara li hu tajjeb. Dan jista’ jsir sakemm l-informazzjoni tiġi analizzata, fi żmien xahar mill-intervista.
	Meta nikteb dwar l-istudju, se nuża’ partijiet minn dak li għidt inti, imma mhux se nuża’ ismek ta’ veru. Jista’ jkun li jkun hemm xi ħadd li jaqra l-istudju tiegħi u jista’ jagħrfek mill-istejjer li tiddeskrivi. Jekk tagħżel li tipparteċipa f’dan l-istudju, dan jfisser li m’għandekx problema b’dan.

	Ma hemmx għalfejn tieħu sehem f’dan l-istudju jekk ma tridx. Jekk tapplika biex tieħu sehem u wara jerġa’ jibdielek, ma jkunx jimporta. Tista’ tieqaf meta trid fi żmien xahar minn wara l-intervista. Ma jkunx hemm għalfejn tgħid għaliex trid tieqaf. Tista’ anke ma twegibx għal mistoqsijiet li mintix komdu bihom, ma jimpurtax.
	Jien se nimxi skont ma tgħid il-liġi Maltija dwar kif għandi nżomm l-informazzjoni li għandi dwarek. Dan ifisser li nżomm l-informazzjoni f’post sigur. Ifisser ukoll li neqred l-informazzjoni mill-intervisti, inkluż dak li nkun irrikordjajt meta nispiċċa l-istudju sa Novembru, 2023.
	Jekk tieħu sehem, inti jkollok iċ-ċans titkellem fuq dak li hu importanti għalik bhala ħu jew oħt persuna bl-awtiżmu / tifel jew tifla bl-awtiżmu. Tkun qiegħed/qegħda wkoll tgħin lil ħaddieħor jitgħallem aktar dwar dak li hu importanti għall-persuni fuq l-ispettru ta’ l-awtiżmu u l-familji tagħhom u kif dawn jistgħu jimxu ‘l quddiem u jibnu ħajjithom bħala familja.
	Jien ma naħsibx li se jkun hemm problemi għalik jekk int tieħu sehem. Imma jekk tiġri xi ħaġa li ddejqek, jekk ikollok bżonn tista’ tinforma lil Frida biex tgħamel kuntatt mal-ħaddiema soċjali li qed taħdem mal-familja tiegħi.

📄	Din l-ittra ta’ informazzjoni hi għalik biex iżżommha.
?	Jekk tixtieq tieħu sehem, jew jekk għandek xi mistoqsijiet, tista’ tikkuntatjani fuq frida.mangion.06@um.edu.mt. Tista’ wkoll tkellem lis-supervisor tiegħi Ms Elaine Schembri Lia fuq esche02@um.edu.mt.

Tislijiet

Frida Mangion

Appendix G

Parents’ Consent Form (English and Maltese)

Participant’s Consent Form

Re-Negotiating Roles, Connections and Resilience: Stories from families of Young Adults on the Autism Spectrum

I, the undersigned, give my consent to take part in the study conducted by Frida Mangion. This consent form specifies the terms of my participation in this research study.

1. I have been given written and/or verbal information about the purpose of the study; I have had the opportunity to ask questions and any questions that I had were answered fully and to my satisfaction.

2. I also understand that I am free to accept to participate or to refuse or stop participation at any time without giving any reason and without any penalty. Should I choose to participate, I may choose to decline to answer any questions asked. If I choose to withdraw from the study, any data collected from me will be erased if my withdrawal occurs up to one month following the interview.

3. I understand that the researcher is also interested in observing my family interacting together after the interview for about an hour. The information elicited from this observation will enrich the data gathering process.

4. I understand that I have been invited to participate in an interview in which the researcher will ask me a set of open-ended questions to explore how my family has adjusted following my child’s diagnosis with autism and how we are negotiating and working through our roles as a system over time. I am aware that the interview will take approximately one hour and will be audio-recorded. I understand that the interview is to be conducted in a place and at a time that is convenient for me.

5. I understand that my participation does not entail any known or anticipated risks. However, should the interview trigger any undesirable outcomes, the researcher will liaise with the social worker who has been supporting us.

6. I understand that I will not be benefitting from any direct benefits. However, my participation is likely to give voice to the narrative of our family story, especially my child on the autism spectrum. Moreover, my contribution will be supporting professionals and therapeutic services to provide/ design services that are attuned to the challenges faced by families of children on the autism spectrum like ourselves.

7. I understand that, under the General Data Protection Regulation (GDPR) and national legislation, I have the right to access, rectify, and where applicable, ask for the data concerning me to be erased within a period of one month.

8. I understand that all data collected, including the recordings will be destroyed on completion of the study, by November 2023, and following publication of the results of the study.

9. I have been provided with a copy of the information letter and understand that I will also be given a copy of this consent form.

10. I am aware that, this interview will be audio-recorded and converted to text as it has been recorded (transcribed).

11. I am aware that, extracts from my interview may be reproduced in these outputs using a pseudonym [a made-up name or code – e.g., respondent A].

12. I am aware that my data will be pseudonymised; i.e., my identity will not be noted on transcripts or notes from my interview, but instead, a code will be assigned. The codes that link my data to my identity will be stored securely and separately from the data, in an encrypted file on the researcher's password-protected computer, and only the researcher, the supervisor,co-supervisor, and in exceptional cases her examiners, will have access to this information and will listen to the audio-recordings. Any hardcopy materials will be placed in a locked cupboard. Any material that identifies me as a participant in this study will be stored securely for the duration of the study.

13. I am aware that my identity and personal information will not be revealed in any publications, reports or presentations arising from this research. However, there can be a chance that someone may recognize me through the unique experience/s I/we share and given the small nature of our population, despite the researcher’s efforts to maintain anonymity.

I have read and understood the above statements and agree to participate in this study.

Name of participant: ____________________________

Signature: ____________________________________

Date: ______________________________

Schembrilia.

Frida Mangion

Elaine Schembri Lia

frida.mangion.06@um.edu.mt

esche02@um.edu.mt

Formola tal-Kunsens għall-Ġenituri

Negozjar mil-ġdid ta’ Rwoli, Konnessjonijiet u Reżiljenza: Stejjer minn familji ta’ Adulti fuq l-Ispettru ta’ l-Awtiżmu

Jiena, hawn taħt iffirmat/a, nagħti l-kunsens tiegħi li nieħu sehem fl-istudju ta’ Frida Mangion. Din il-formola tal-kunsens tispjega t-termini tas-sehem tiegħi f’din ir-riċerka.

1. Ingħatajt l-informazzjoni bil-miktub u/jew bil-fomm dwar l-iskop tar-riċerka; kelli lopportunità nagħmel il-mistoqsijiet, u kull mistoqsija ngħatajt tweġiba għaliha b’mod sħiħ u sodisfaċenti.

2. Nifhem ukoll li jiena liberu/a li naċċetta li nieħu sehem, jew li nirrifjuta, jew li nwaqqaf ilparteċipazzjoni tiegħi meta nixtieq mingħajr ma nagħti spjegazzjoni jew mingħajr ma niġi penalizzat/a. Jekk nagħżel li nipparteċipa, jaf niddeċiedi li ma nweġibx kull mistoqsija li ssirli. F’każ li nagħżel li ma nkomplix nieħu sehem fl-istudju importanti li ngħamel dan fi żmien xahar, l-informazzjoni miġbura mingħandi se titħassar.

3. Nifhem li r-riċerkatriċi hija nteressata tosserva għal perjodu ta’ siegħa, il-mod li bih ilfamilja tiegħi tinteraġixxi ma’ xulxin. Din l-osservazzjoni se sseħħ wara l-intervisti malmembri kollha tal-familja. L-informazzjoni miġbura minn din l-osservazzjoni hija mistenija ssaħħaħ il-kwalita’ ta’ l-informazzjoni miġbura mil-intervista.

4. Nifhem li ġejt mistieden/mistiedna nipparteċipa f’intervista u l-persuna li qed tagħmel irriċerka se tkun qed ssaqsini set ta’ mistoqsijiet li jtuni l-opportunita’ niftaħ fuq lesperjenza tiegħi/ tagħna. B’dan il-mod ir-riċerkattriċi se tesplora kif il-familja tiegħi, fejn hemm tifel/ tifla fuq l-ispettru ta’ l-awtiżmu, addattajna għal awtiżmu u kif nnegozzjajna l-irwoli bħala

familja maż-żmien. Jiena konxju/a li l-intervista se ddum bejn wieħed u ieħor siegħa u se tkun awdjo rrekordjata. Nifhem li l-intervista se ssir f’post u f’ħin li huma komdi għalija.

5. Nifhem li l-parteċipazzjoni tiegħi ma fiha l-ebda riskju magħruf. Għaldaqstant, f’kas li lintervista tqanqal effetti mhux mistennija, ir-riċerkatriċi se tghinni nagħmel kuntatt mal-ħaddiema soċjali li qed ssegwi l-familja.

6. Nifhem li bil-parteċipazzjoni tiegħi f’dan l-istudju, m’hemm l-ebda benefiċċju dirett għalija. Iżda l-parteċipazzjoni tiegħi mistennija tagħti vuċi lin-narrativa tal-familja tagħna, speċjalment lit-tifel/ tifla tiegħi li hi/huwa fuq l-ispettru ta’ l-awtiżmu. Nifhem ukoll li din ir-riċerka jaf toffri sapport lil professjonisti li joffru servizzi terapewtiċi sabiex joffru/ joħolqu servizzi li jindirizzaw l-isfidi li familji bi tfal bl-awtiżmu jaffaċċjaw.

7. Nifhem li, skont ir-Regolament Ġenerali dwar il-Protezzjoni tad-Data (GDPR) u lleġiżlazzjoni nazzjonali, għandi dritt naċċessa, nikkoreġi u, fejn hu applikabbli, nitlob li linformazzjoni li tikkonċernani titħassar fi żmien xahar.

8. Nifhem li l-informazzjoni kollha miġbura se titħassar meta jintemm l-istudju, Novembru 2023, u joħorġu rriżultati.

9. Ingħatajt kopja tal-ittra ta’ tagħrif biex inżommha u nifhem li se ningħata wkoll kopja ta’ din il-formola tal-kunsens.

10. Konxju/a li, din l-intervista se jkun/tkun rekordjata bl-awdjo u maqluba fi kliem, kif irrekordjat/a (traskrizzjoni).

11. Konxju/a li, siltiet mill-intervista tiegħi jistgħu jiġu riprodotti f'format anonimu jew bl-użu ta' psewdonimu [isem ivvintat jew kodiċi - eż. parteċipant A].

12. Jiena konxju/a li l-informazzjoni tiegħi se tkun psewdonimizzata, jiġifieri l-identità tiegħi mhix se titniżżel fit-traskrizzjonijiet jew fin-noti tal-intervista, imma minflok, se niġi assenjat/a kodiċi. Il-kodiċijiet li jorbtu l-informazzjoni dwari mal-identità tiegħi se jinżammu b'mod sigur u separat mill-informazzjoni, f'file kodifikat fuq il-kompjuter tar-riċerkatur/riċerkatriċi, protetti b'password, u r-riċerkatriċi u tutur akkademika biss se jkollhom aċċess għal din l-informazzjoni u f'każijiet eċċezzjonali l-eżaminaturi tagħha. Kwalunkwe materjal stampat se jitqiegħed f'armarju msakkar. Kwalunkwe materjal li jidentifikani bħala parteċipant/a f'dan l-istudju se jinżamm b'mod sigur sakemm isir listudju.

13. Konxju/a li l-identità tiegħi u d-dettalji personali tiegħi mhux se jiġu żvelati f'xi pubblikazzjoni, rapport jew preżentazzjoni li tista' toħroġ minn din ir-riċerka. Madanakollu, jista' jkun hemm il-possibilta' li xi ħadd jagħraf l-identita' tiegħi jew tagħna minħabba l-esperjenza unika li se nirrakkonta/ nirrakontaw. Speċjalment minħabba li ngħamel parti minn popolazzjoni żgħira, minkejja li r-riċerkatriċi se tgħamel dak kollu possibbli sabiex tiżgura l-anonimita'.

Qrajt u fhimt l-istqarrijiet t'hawn fuq, u naqbel li nipparteċipa f'dan l-istudju.

Isem il-parteċipant/a: ______________________

Firma: _________________________________

Data:__________________________________

Frida Mangion

frida.mangion.06@um.edu.mt

Schembrilia.

Elaine Schembri Lia

esche02@um.edu.mt

Appendix H

Third Party Consent Form for Young Adults on the Autism Spectrum

(English and Maltese)

Participant's Third Party Consent Form

Re-Negotiating Roles, Connections and Resilience: Stories from families of Young Adults on the Autism Spectrum

I, the undersigned, give my consent to take part in the study conducted by Frida Mangion. This consent form specifies the terms of my participation in this research study.

1. I have been given written and/or verbal information about the purpose of the study; I have had the opportunity to ask questions and any questions that I had were answered fully and to my satisfaction.

2. I also understand that I am free to accept to participate or to refuse or stop participation at any time without giving any reason and without any penalty. Should I choose to participate, I may choose to decline to answer any questions asked. If I choose to withdraw from the study, any data collected from me will be erased if my withdrawal occurs up to one month following the interview.

3. I understand that the researcher is also interested in observing my family interacting together after the interview for about an hour. The information elicited from this observation will enrich the data gathering process.

4. I understand that I have been invited to participate in an interview in which the researcher will ask me a set of open-ended questions to speak about my experience as a young adult on the autism spectrum. I am aware that the interview will take approximately one hour and will be audio-recorded. I understand that the interview is to be conducted in a place and at a time that is convenient for me.

5. It has also been explained to me that during the interviews with my family, they will be asked to describe my relationship with different members of the family.

6. I understand that my participation does not entail any known or anticipated risks. However, should the interview trigger any undesirable outcomes, the researcher will liaise with the social worker who has been supporting us.

7. I understand that I will not be benefitting from any direct benefits. However, my participation is likely to give voice to the narrative of our family story, especially my child on the autism spectrum. Moreover, my contribution will be supporting professionals and therapeutic services to provide/ design services that are attuned to the challenges faced by families of children on the autism spectrum like ourselves.

8. I understand that, under the General Data Protection Regulation (GDPR) and national legislation, I have the right to access, rectify, and where applicable, ask for the data concerning me to be erased within a period of one month.

9. I understand that all data collected, including the recordings will be destroyed on completion of the study, by November 2023, and following publication of the results of the study.

10. I have been provided with a copy of the information letter and understand that I will also be given a copy of this consent form.

11. I am aware that, this interview will be audio-recorded and converted to text as it has been recorded (transcribed).

12. I am aware that, extracts from my interview may be reproduced in these outputs using a pseudonym [a made-up name or code – e.g., respondent A].

13. I am aware that my data will be pseudonymised; i.e., my identity will not be noted on transcripts or notes from my interview, but instead, a code will be assigned. The codes that link my data to my identity will be stored securely and separately from the data, in an encrypted file on the researcher’s password-protected computer, and only the researcher, the supervisor,co-supervisor, and in exceptional cases her examiners,will have access to this information and will listen to the audio-recordings. Any hard-copy materials will be placed in

a locked cupboard. Any material that identifies me as a participant in this study will be stored securely for the duration of the study.

14. I am aware that my identity and personal information will not be revealed in any publications, reports or presentations arising from this research. However, there can be a chance that someone may recognize me through the unique experience/s I/we share and given the small nature of our population, despite the researcher's efforts to maintain anonymity.

I have read and understood the above statements and agree to participate in this study.

Name of participant: ____________________________

Signature: ____________________________________

Date:

Schembrilia.

Frida Mangion

Elaine Schembri Lia

frida.mangion.06@um.edu.mt

esche02@um.edu.mt

Formola tal-Kunsens għall-Adulti fuq l-Ispettru ta' l-Awtiżmu (Third Party)

Negozjar mil-ġdid ta' Rwoli, Konnessjonijiet u Reżiljenza: Stejjer minn familji ta' Adulti fuq l-Ispettru ta' l-Awtiżmu

Jiena, hawn taħt iffirmat/a, nagħti l-kunsens tiegħi li nieħu sehem fl-istudju ta' Frida Mangion. Din il-formola tal-kunsens tispjega t-termini tas-sehem tiegħi f'din ir-riċerka.

1. Ingħatajt l-informazzjoni bil-miktub u/jew bil-fomm dwar l-iskop tar-riċerka; kelli lopportunità nagħmel il-mistoqsijiet, u kull mistoqsija ngħatajt tweġiba għaliha b'mod sħiħ u sodisfaċenti.

2. Nifhem ukoll li jiena liberu/a li naċċetta li nieħu sehem, jew li nirrifjuta, jew li nwaqqaf ilparteċipazzjoni tiegħi meta nixtieq mingħajr ma nagħti spjegazzjoni jew mingħajr ma niġi penalizzat/a. Jekk nagħżel li nipparteċipa, jaf niddeċiedi li ma nweġibx kull mistoqsija li ssirli. F'każ li nagħżel li ma nkomplix nieħu sehem fl-istudju importanti li ngħamel dan fi żmien xahar, l-informazzjoni miġbura mingħandi se titħassar.

3. Nifhem li r-riċerkatriċi hija nteressata tosserva għal perjodu ta' siegħa, il-mod li bih ilfamilja tiegħi tinteraġixxi ma' xulxin. Din l-osservazzjoni se sseħħ wara l-intervisti malmembri kollha tal-familja. L-informazzjoni miġbura minn din l-osservazzjoni hija mistenija ssaħħaħ il-kwalita' ta' l-informazzjoni miġbura mil-intervista.

4. Nifhem li ġejt mistieden/mistiedna nipparteċipa f'intervista u l-persuna li qed tagħmel irriċerka se tkun qed ssaqsini set ta' mistoqsijiet li jtuni l-opportunita' niftaħ fuq lesperjenza tiegħi/ tagħna. B'dan il-mod ir-riċerkattriċi se tesplora kif il-familja tiegħi, fejn hemm tifel/

tifla fuq l-ispettru ta’ l-awtiżmu, addattajna għal awtiżmu u kif nnegozzjajna lirwoli bħala familja maż-żmien. Jiena konxju/a li l-intervista se ddum bejn wieħed u ieħor siegħa u se tkun awdjo rrekordjata. Nifhem li l-intervista se ssir f’post u f’ħin li huma komdi għalija.

5. Nikkonferma li rċevejt spjegazzjoni li matul l-intervista mal-membri tal-familja tiegħi, huma se jkunu mistoqsija jiddeskrivu r-relazzjonijiet tiegħi magħhom.

6. Nifhem li l-parteċipazzjoni tiegħi ma fiha l-ebda riskju magħruf. Għaldaqstant, f’kas li lintervista tqanqal effetti mhux mistennija, ir-riċerkatriċi se tghinni nagħmel kuntatt mal-ħaddiema soċjali li qed ssegwi l-familja.

7. Nifhem li bil-parteċipazzjoni tiegħi f’dan l-istudju, m’hemm l-ebda benefiċċju dirett għalija. Iżda l-parteċipazzjoni tiegħi mistennija tagħti vuċi lin-narrativa tal-familja tagħna, speċjalment lit-tifel/ tifla tiegħi li hi/huwa fuq l-ispettru ta’ l-awtiżmu. Nifhem ukoll li din ir-riċerka jaf toffri sapport lil professjonisti li joffru servizzi terapewtiċi sabiex joffru/ joħolqu servizzi li jindirizzaw l-isfidi li familji bi tfal bl-awtiżmu jaffaċċjaw.

8. Nifhem li, skont ir-Regolament Ġenerali dwar il-Protezzjoni tad-Data (GDPR) u lleġiżlazzjoni nazzjonali, għandi dritt naċċessa, nikkoreġi u, fejn hu applikabbli, nitlob li linformazzjoni li tikkonċernani titħassar fi żmien xahar.

9. Nifhem li l-informazzjoni kollha miġbura se titħassar meta jintemm l-istudju, Novembru 2023, u joħorġu rriżultati.

10. Ingħatajt kopja tal-ittra ta’ tagħrif biex inżommha u nifhem li se ningħata wkoll kopja ta’ din il-formola tal-kunsens.

11. Konxju/a li, din l-intervista se jkun/tkun rekordjata bl-awdjo u maqluba fi kliem, kif irrekordjat/a (traskrizzjoni).

12. Konxju/a li, siltiet mill-intervista tiegħi jistgħu jiġu riprodotti f’format anonimu jew bl-użu ta’ psewdonimu [isem ivvintat jew kodiċi - eż. parteċipant A].

13. Jiena konxju/a li l-informazzjoni tiegħi se tkun psewdonimizzata, jiġifieri l-identità tiegħi mhix se titniżżel fit-traskrizzjonijiet jew fin-noti tal-intervista, imma minflok, se niġi assenjat/a kodiċi. Il-kodiċijiet li jorbtu l-informazzjoni dwari mal-identità tiegħi se jinżammu b’mod sigur u separat mill-informazzjoni, f’file kodifikat fuq il-kompjuter tarriċerkatur/riċerkatriċi, protetti b’password, u r-riċerkatriċi u tutur akkademika, u f’każijiet eċċezzjonali l-eżaminaturi tagħha biss se jkollhom aċċess għal din l-informazzjoni. Kwalunkwe materjal stampat se jitqiegħed f’armarju msakkar. Kwalunkwe materjal li jidentifikani bħala parteċipant/a f’dan l-istudju se jinżamm b’mod sigur sakemm isir listudju.

14. Konxju/a li l-identità tiegħi u d-dettalji personali tiegħi mhux se jiġu żvelati f’xi pubblikazzjoni, rapport jew preżentazzjoni li tista’ toħroġ minn din ir-riċerka. Madanakollu, jista’ jkun hemm il-possibilta’ li xi ħadd jagħraf l-identita’ tiegħi jew tagħna minħabba l-esperjenza unika li se nirrakkonta/ nirrakontaw. Speċjalment minħabba li ngħamel parti minn popolazzjoni żgħira, minkejja li r-riċerkatriċi se tgħamel dak kollu possibbli sabiex tiżgura l-anonimita’.

Qrajt u fhimt l-istqarrijiet t’hawn fuq, u naqbel li nipparteċipa f’dan l-istudju.

Isem il-parteċipant/a: ______________________

Firma: __________________________________

Data: ___________________________________

Schembrilia.

_________________________________ _________________________________

Frida Mangion Elaine Schembri Lia

frida.mangion.06@um.edu.mt esche02@um.edu.mt

Appendix I

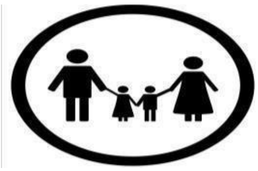
Assent Form for Minor Siblings (English and Maltese)

Re-Negotiating Roles, Connections and Resilience: Stories from families of Young Adults on the Autism Spectrum

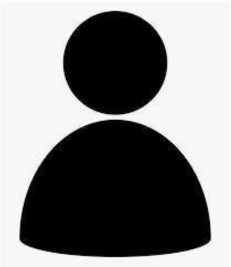
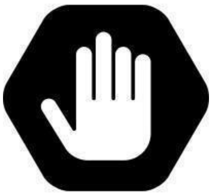
Frida Mangion - Masters in Family Therapy and Systemic Practice trainee

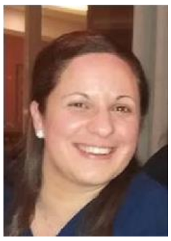
Assent Form

'Assent' means that you agree with everything that is written below. If you agree with everything that is written, sign in the last part.

	I have been given information about the study and had the chance to ask questions and get a reply.
	After the interview, Frida will ask me to observe my family interacting with each other for about one hour.
	I know that I will be interviewed, which means that Frida will ask me a set of questions about my experience in my family.

	I know that the interview will be approximately one hour long.

	I know that Frida will record the interview on audio. I also know that only Frida, her supervisor and co-supervisor, and in exceptional cases her examiners, will be able to listen to the recordings. After the study is finished, Frida will destroy the recordings by November, 2023.
	I know that after we do the interview, Frida will summarise what I have said so that I can see if I want to change, add or remove anything. If I want, I can also check what I said with someone I trust to make sure that it's okay. This may be done until data is analysed, within a month from the interview.
	I know that when Frida writes about the study, she will use parts of what I said but will not use my real name. However, there can be a chance that someone reads the study, they may recognize me through the experiences I share. I am still ok to participate in this case.
	I know that I do not have to take part in this project if I do not want to. If I take part and I want to stop, it will not be a problem. I can stop at any time up to one month after the interview. I do not have to give reasons for stopping. I can also not answer any questions which I do not feel comfortable answering.

	I know that Frida will act according to what Maltese law says about how to store information about me. This means that the information will be in a secure place. Frida will also destroy all the information from the interviews, including recordings, after the study is finished [November, 2023].
	I know that by taking part in the interview, I will have a chance to talk about what is important to me as the sibling of a young adult with autism. I will also be helping others learn more about what is important for persons on the autism spectrum and their families.
	I know that Frida will be doing her best to keep me safe and comfortable during this interview. If something still happens that upsets me during the interview, I can inform Frida who will liaise with the social worker supporting our family.
	I have received the information letter about the study and I will also have a copy of this assent form.
	I would like to apply to take part in the project that Frida Mangion is doing.

I have understood everything that is written here and if I had any questions, they have been answered. I would like to take part in this study.

Name and surname: ______________________________

Signature: ______________________________________

Date: ____

Frida Mangion	Elaine Schembri Lia
	Schembrilia.
Researcher's Name and Signature	Supervisor's Name and Signature
Email Address: frida.mangion.06@um.edu.mt	Email Address: esche02@um.edu.mt

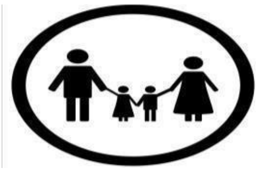
Negozjar mil-ġdid ta' Rwoli, Konnessjonijiet u Reżiljenza: Stejjer minn familji t' Adulti fuq l-Ispettru ta' l-Awtiżmu

Frida Mangion - Masters fit-Terapija għall-Familja u Prattiċi Sistemiċi

Formola t' 'Assent' għall-aħwa minuri

'Assent' ifisser li inti taqbel ma' dak li hawn miktub hawn taħt.

Jekk taqbel ma' dak kollu li hawn miktub iffirma fl-aħħar parti.

	Jiena għandi l-informazzjoni dwar l-istudju u kelli ċans insaqsi mistoqsijet dwar l-istudju u kelli risposta.
	Wara l-intervista, Frida se ssaqsini biex tosserva lil familja tiegħi jinteraġixxu flimkien għal siegħa.
	Jien naf li se jkolli intervista, li bażikament tfisser li Frida se tkun qed ssaqqsini sett ta' mistoqsijiet dwar l-esperjenza tiegħi fil-familja.
	Jien naf li l- intervista se ddum madwar siegħa.

● REC	Jien naf li Frida Mangion se tirrekordja l-intervista fuq awdjo. Jien naf ukoll li Frida, s-superviżur u l-ko-superviżur, u f’każijiet eċċezzjonali l-eżaminaturi tagħha, biss se jkunu jistgħu jisimgħu dak li ġie rrikordjat. Wara li jispiċċa l-istudju, Frida se teqred dak li ġie rrikordjajt f’Novembru, 2023~~.~~
📝	Jien naf li wara li nagħmlu l-intervista, se tgħamel sommarju ta’ dak li nkun għidt biex nara jekk nixtiqx inbiddel, inżid jew inneħħi xi ħaġa. Jekk inkun irrid, nista’ wkoll niċċekkja dak li għidt ma’ xi ħadd li nafda biex nara li hu tajjeb. Dan jista’ jsir sakem l-informazzjoni tiġi analizzata, sa xahar wara l-intervista.
👤	Jien naf li meta Frida se tikteb dwar l-istudju, se tuża’ partijiet minn dak li għidt jien, imma mhux se tuża’ ismi ta’ veru. Xorta, jista’ jkun li jkun hemm xi ħadd li jaqra l-istudju u jista’ jagħrafni mill-istejjer li nghid. Minkejja dan xorta nixtieq nipparteċipa.
✋	Jien naf li ma hemmx għalfejn nieħu sehem f’dan l-istudju jekk ma rridx. Jekk napplika biex nieħu sehem u wara jerġa jibdieli, ma jkunx jimporta sakemm ngħamel dan fi żmien xahar mil-intervista. Nista’ nieqaf meta rrid. Ma jkunx hemm għalfejn ngħid għaliex irrid nieqaf.

	Jien naf li Frida se timxi skont ma tgħid il-liġi Maltija dwar kif għandha tinżamm l-informazzjoni dwari. Dan ifisser li l-informazzjoni tkun f'post sigur. Ifisser ukoll li Frida se teqred l-informazzjoni mil-intervisti, inkluż dak li tkun irrekordjat meta l-istudju jispiċċa sa [Novembru, 2023].
	Jien naf li bis-sehem tiegħi, ikolli ċ-ċans nitkellem fuq dak li hu importanti għalija bħala oħt jew ħu adult bl-awtiżmu. Inkun qiegħed/qegħda wkoll ngħin lil ħaddieħor jitgħallem aktar dwar dak li hu importanti għall-persuni fuq l-ispettru ta' l-awtiżmu u l-familji tagħhom.
	Jien naf li mhux suppost ikun hemm problemi għalija jekk nieħu sehem. Imma jekk tiġri xi ħaġa li ddejaqni nista' ninforma lil Frida biex tgħini naċċessa l-għajuna tal-ħaddiema soċjali li qed ssegwi l-familja tagħna.
	Jien irċevejt ittra ta' informazzjoni dwar dan l-istudju u se jkolli wkoll kopja ta' din il-formola tal-kunsens.
	Jiena qed napplika għax nixtieq li nieħu sehem f'dan il-proġett li se jsir minn Frida Mangion.

Jiena fhimt dak kollu li hawn miktub, u jekk kelli xi mistoqsijiet dawn ġew imwieġba. Jien nixtieq nieħu sehem f'dan l-istudju.

Isem u kunjom: ________________________________

Firma: ____

Data: ____

Frida Mangion

Elaine Schembri Lia

Schembrilia.

Isem tar-riċerkatriċi u Firma

Isem tas-superviżur u Firma

Email Address: frida.mangion.06@um.edu.mt

Email Address: esche02@um.edu.mt

Appendix J

Interview Guides for Parents, Young Adults with ASD and Siblings (English and Maltese)

Parent Interview Guide

Demographic data:

a. Name: ____

b. Age: ____

c. Occupation: ____________________________________

d. Marital status: __________________________________

e. Years in present relationship: _______________________

f. Number of children: ______________________________

g. Order of the young adult with autism in the sibling relationship: _______

h. Sources of support:

____

____

Audio-recording will start now:

Your experience of having a child on the autism spectrum:

1. Tell me about yourself.
2. Tell me about your family.
3. Tell me about your journey with autism particularly during adolescent years.
4. How has the occurrence of parenting a child on the autism spectrum impacted:

- you,
- your relationship with your partner,
- your relationship with the child with autism, - your relationship with the other children.

- your relationship with the family of origin such as parents and siblings?

5. What were your main challenges over time?

6. Which opportunities were presented to you as a result of this experience?

7. What are/ were your main sources of support? Can you mention some services received over time: as a family, as a couple and your child with ASD?

8. What memories/stories come to mind as you think of your experiences as a family with a child on the autism spectrum? How are these significant to you? Would you like to share any photos, drawings or letters that describe your journey as a family over time?

9. What aspirations do you have for:

- your future,
- you and your partner,
- that of your family,
- that of your child with autism and, - your other children?

10. Do you have any suggestions, based on your own experience/s of how services may support families going through a similar journey? And which service/s (if any) was most beneficial for your family?

11. Do you have anything to say about the society we live in? How do you think the latter was a source of support or hinderance for your family and the experiences you went through? How this may improve?

Ending:

1. Is there anything else you wish to share about your experience of being a parent to a child on the autism spectrum?

2. How did it feel to be part of this interview?

****

Your contribution is greatly appreciated. Thank You!

Young Adult on the Autism Spectrum Interview Guide

Demographic data:

a. Name: ____

b. Age: ____

c. Scholastic Year: _____________________________________

Audio-recording will start now:

Your experience as a young adult on the autism spectrum

1. Tell me about yourself
2. Describe your family.
3. How would you describe your relationship with your mother?
4. How would you describe your relationship with your father?
5. How would you describe your relationship with your sibling/s?
6. What do you enjoy doing most with your parents and siblings?
7. What do you enjoy doing the least with your parents and siblings?
8. What do you like most about your brother/s or sister/s?
9. Is there something about them you don’t like that you wish to tell me about?
10. How do you feel when you think about your family (Prompt: use of emotions cards)?
11. What do you wish to say about your extended family such as grandparents, uncles/aunties, cousins etc ...? How is your relationship with them and what do you like most about them?
12. Tell me about your schoolmates and friends (including those outside school).
13. What does the word autism mean to you?
14. What are your wishes/ desries for your future, the future of you parents and siblings?

Ending:

1. Do you wish to say anything more before we end the interview or perhaps draw another picture?

2. How did you feel to be part of this interview? (Prompt: emotions cards)

****

Your contribution is greatly appreciated. Thank You!

Siblings of Young Adults on the Autism Spectrum Interview Guide

Demographic data:

a) Name:

b) Age:

c) Scholastic Year: Audio-recording will start now:

Your experience as a sibling of a young adult on the autism spectrum:

1) Tell me about yourself
2) Describe your family.
3) How would you describe your relationship with your mother?
4) How would you describe your relationship with your father?
5) How would you describe your relationship with your sibling/s?
6) What do you enjoy doing most with your parents and siblings?
7) What do you enjoy doing the least with your parents and siblings?
8) What do you like most about your brother or sister with autism?
9) Is there something about them you don't like that you wish to tell me about?
10) How do you feel when you think about your family (Prompt: use of emotions cards)? Have you noticed any changes occurring over time? What helped you adapt? What hindered this adaptation?
11) How do you feel that autism affected your family? What do you like or dislike about autism? Does the word autism mean anything to you?

12) Do your friends know about your brother/sister's autism?

13) Do you get to meet your brother's/ sister's friends?

14) How do you feel about the services your brother/sister receives?

15) What about your extended family such as grandparents, uncles/aunties, cousins etc ...?

How is your relationship to them? What do you like about them? What don't you like?

16) If you had to meet a child whose brother/sister has just been diagnosed with autism, what would you tell him/her? Why?

17) What do you aspire for your future, that of your parents, that of your brother/sister with autism?

Ending:

1. Do you have any wishes for your parents and brother?
2. Do you wish to add anything else?
3. How did you feel to be part of this interview? (Prompt: emotions cards)

****

Your contribution is greatly appreciated. Thank You!

Negozjar mil-ġdid ta’ Rwoli, Konnessjonijiet u Reżiljenza: Stejjer minn familji t’ Adulti fuq l-Ispettru ta’ l-Awtiżmu - GWIDA GĦALL-INTERVISTA MAL-ĠENITUR

Informazzjoni Demografika:

a. Isem: ____

b. Eta’: ____

c. Impjieg: ______________________________________

d. Stat Ċivili: ____________________________________

e. Snin fir-relazzjoni preżenti: _______________________

f. Numru ta’ tfal fil-familja: ______________________________

g. Ordni ta’ t-tifel/a bl-awtiżmu fost l-aħwa fil-familja: ____________________

h. Sorsi ta’ sapport:

____

____

Irrekordjar bl-awdjo jibda issa:

Nixtieq nisma’ dwar l-esperjenza tiegħek bħala ġenituri ta’ tifel/ tifla fuq l-ispettru ta’ lawtiżmu:

1. Għidli dwarek.
2. Għidli dwar il-familja tagħkom.
3. Għidli dwar il-vjaġġ tiegħek/ tagħkom madwar l-awtiżmu.
4. Ghidli kif l-esperjenza bħala ġenitur ta’ tifel/a bl-awtiżmu impattat:

- lilek,
- ir-relazzjoni tiegħek mal-partner,
- ir-relazzjoni tiegħek mat-tifel/a bl-awtiżmu,
- ir-relazzjoni tiegħek mat-tfal l-oħra fil-familja,

- ir-relazzjoni tiegħek mal-familja t’oriġini, eżempju ġenituri u aħwa?

5. X’kienu l-ikbar sfidi matul iż-żmien?

6. Tista’ ssemmi xi opportunitajiet li ġew ippreżentati lilek riżultat ta’ din l-esperjenza?

7. X’kienu jew x’inhuma s-sorsi kruċjali li offrew sapport? Tista’ ssemmi xi servizzi li rċevejtu matul iż-żmien, bħala familja, bħala kopja jew li ġej offruti lit-tifel/a blawtiżmu?

8. X’memorji/ stejjer jiġu f’moħħok meta taħseb fl-esperjenza tiegħek bħala familja ta’ tifel/ tifla bl-awtiżmu? Kif dawn huma sinnifikanti għalik? Tixtieq taqsam xi tpenġijiet, ritratti jew ittri/ kitbiet li jiddeskrivu l-vjaġġ tagħkom bħala familja matul iż-żmien?

9. X’inhuma l-aspirazzjonijiet tiegħek għal:

- futur tiegħek,
- tiegħek u tas-sieħeb/a,
- tal-familja,
- tat-tifel/a bl-awtiżmu u
- tfal l-oħra fil-familja?

10. Għandek xi suġġerimenti, ibbażati fuq l-esperjenza/i tiegħek, sabiex is-servizzi pprovduti joffru sapport lil familji li qed jgħaddu minn vjaġġ simili għal tagħkom? Tista’ ssemmi xi servizz li tħoss li kien ta’ benefiċċju kbir għal-familja tiegħek?

11. Xi tghid dwar is-socjeta li nghixu fiha? Kif thoss li din kienet ta’ ghajnuna/xkiel ghal familja tieghek u l-esperjenzi li ghaddejtu minnha? Kif tista’ timpruvja?

Tmiem:

1. Tixtieq jew xtaqt żżid xi ħaġa oħra dwar l-esperjenza tiegħek bħala ġenitur ta’ tifel/a bl-awtiżmu?

2. Kif ħassejtek matul din l-intervista?

****

Il-kontribuzzjoni tiegħek hija ferm apprezzata! Grazzi

GWIDA GĦALL-INTERVISTA MA’ L-ADULT BL-AWTIŻMU

Informazzjoni Demografika:

a. Isem: ____

b. Eta’: ____

c. Sena Skolastika: ________________________________

Irrekordjar bl-awdjo jibda issa:

Nixtieq nisma’ dwar l-esperjenza tiegħek bħala tifel/ tifla fuq l-ispettru ta’ l-awtiżmu

1) Għidli dwarek.

2) Iddeskrivi l-familja tiegħek.

3) Kif tiddeskrivi r-relazzjoni tiegħek m’ommok?

4) Kif tiddeskrivi r-relazzjoni tiegħek ma’ missierek?

5) Kif tiddeskrivi r-relazzjoni tiegħek ma’ ħuk/oħtok/ħutek?

6) Xi tħobb tagħmel l-iktar mal-ġenituri u ħuk/oħtok/ ħutek?

7) Xi tħobb tagħmel l-inqas mal-ġenituri u ħuk/oħtok/ ħutek?

8) Xi tħobb l-iktar dwar ħuk/oħtok/ ħutek?

9) Hemm xi ħaġa dwar ħuk/oħtok/ ħutek li ma tħobbx daqshekk u tixtieq tgħidli dwarha?

10) Xi tħoss meta taħseb fil-familja tiegħek? (Ħeġġeġ l-użu ta’ karti tal-emozzjonijiet)

11) Xi tgħidli fuq il-familja estiża tiegħek bħal nanniet, zijiet, kuġini etc ...? Kif inhi rrelazzjoni tiegħek magħhom? X’ jogħġbok dwarhom?

12) Għidli dwar l-istudenti ta’ l-iskola u sħabek (inkludi dawk barra l-iskola).

13) Xi tfisser għalik il-kelma awtiżmu?

14) X’inhuma x-xewqat għall-futur tiegħek, tal-ġenituri u ta’ ħuk/oħtok/ ħutek?

Tmiem:

1.Tixtieq jew xtaqt żżid xi ħaġa oħra dwar l-esperjenza tiegħek bħala tifel/a bl-awtiżmu jew forsi tippreferi tpenġi xi ħaġa oħra?

2. Kif ħassejtek matul din l-intervista? (Ħeġġeġ l-użu ta' karti tal-emozzjonijiet)

****

Il-kontribuzzjoni tiegħek hija ferm apprezzata! Grazzi

GWIDA GĦALL-INTERVISTA M' AĦWA TA' ADULTI BL-AWTIŻMU

Informazzjoni Demografika:

a) Isem: _______________________________________

b) Eta': ____

c) Sena Skolastika: _______________________________

Irrekordjar bl-awdjo jibda issa:

Nixtieq nisma' dwar l-esperjenza tiegħek bħala oħt/ ħu tifel/tifla fuq l-ispettru ta' l-awtiżmu:

1. Għidli dwarek.
2. Ddeskrivi l-familja tiegħek.
3. Kif tiddeskrivi r-relazzjoni tiegħek m'ommok?
4. Kif tiddeskrivi r-relazzjoni tiegħek ma' missierek?
5. Kif tiddeskrivi r-relazzjoni tiegħek ma' ħuk/oħtok/ħutek?
6. Xi tħobb tgħamel l-iktar mal-ġenituri u ħuk jew oħtok bl-awtiżmu?
7. Xi tħobb tgħamel l-inqas mal-ġenituri u ħuk jew oħtok bl-awtiżmu?
8. Xi tħobb l-iktar dwar ħuk jew oħtok bl-awtiżmu?
9. Xi tħobb l-inqas dwar ħuk jew oħtok bl-awtiżmu?
10. Xi tħoss meta taħseb fil-familja tiegħek? (Ħeġġeġ l-użu ta' karti tal-emozzjonijiet speċjalment f'kas t' aħwa żgħar) Innutajt xi tibdiliet jseħħu maż-żmien? X'għenek tadatta? U x'ma għenekx biex tadatta?

11. Kif tħoss li l-awtiżmu affetwa l-esperjenza tal-familja tiegħek? Xi jdejqek u x'jgħoġbok dwar l-awtiżmu?

12. Sħabek jafu dwar ħuk jew oħtok bl-awtiżmu? Taf tfal oħra li għandhom aħwa blawtiżmu jew diffikultajiet oħra? Kif inhi l-esperjenza tiegħek simili jew differenti minn tagħhom?

13. Tiltaqa' mal-ħbieb ta' ħuk jew oħtok bl-awtiżmu?

14. Kif tħossok dwar is-servizzi li ħuk jew oħtok tirċievi?

15. Xi tgħidli fuq il-familja estiża tiegħek bħal nanniet, zijiet, kuġini etc ...? Kif inhi rrelazzjoni tiegħek magħhom? X' jgħoġbok u xi jdejqek dwarhom? Kif taħseb li ħuk jew oħtok bl-awtiżmu impattaw dawn ir-relazzjonijiet?

16. Kieku kellek tiltaqa' ma' tifel/ tifla li għandhom aħwa li għadhom kemm irċevew dijanjosi ta' l-awtiżmu, x'tgħidilhom u għaliex?

17. X'taspira għall-futur tiegħek, tal-ġenituri u ta' ħuk jew oħtok bl-awtiżmu?

Tmiem:

1.Tixtieq jew xtaqt żżid xi ħaġa oħra dwar l-esperjenza tiegħek bħala ħu jew oħt tifel/a blawtiżmu jew forsi tippreferi tpenġi xi ħaġa oħra (f'kas t' aħwa żgħar)?

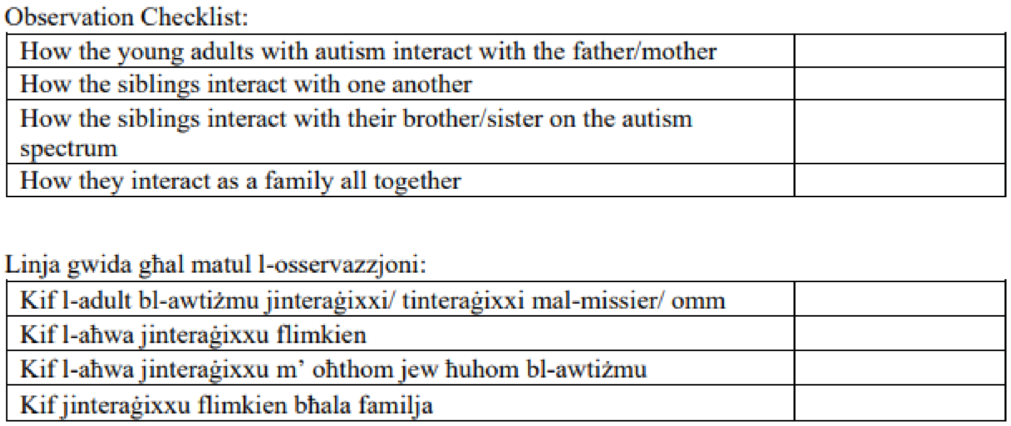
2. Kif ħassejtek matul din l-intervista? (Ħeġġeġ l-użu ta' karti tal-emozzjonijiet speċjalment fejn hemm aħwa iżgħar)

****

Il-kontribuzzjoni tiegħek hija ferm apprezzata! Grazzi

Appendix L

Observation Checklist (English and Maltese)



Observation Checklist:

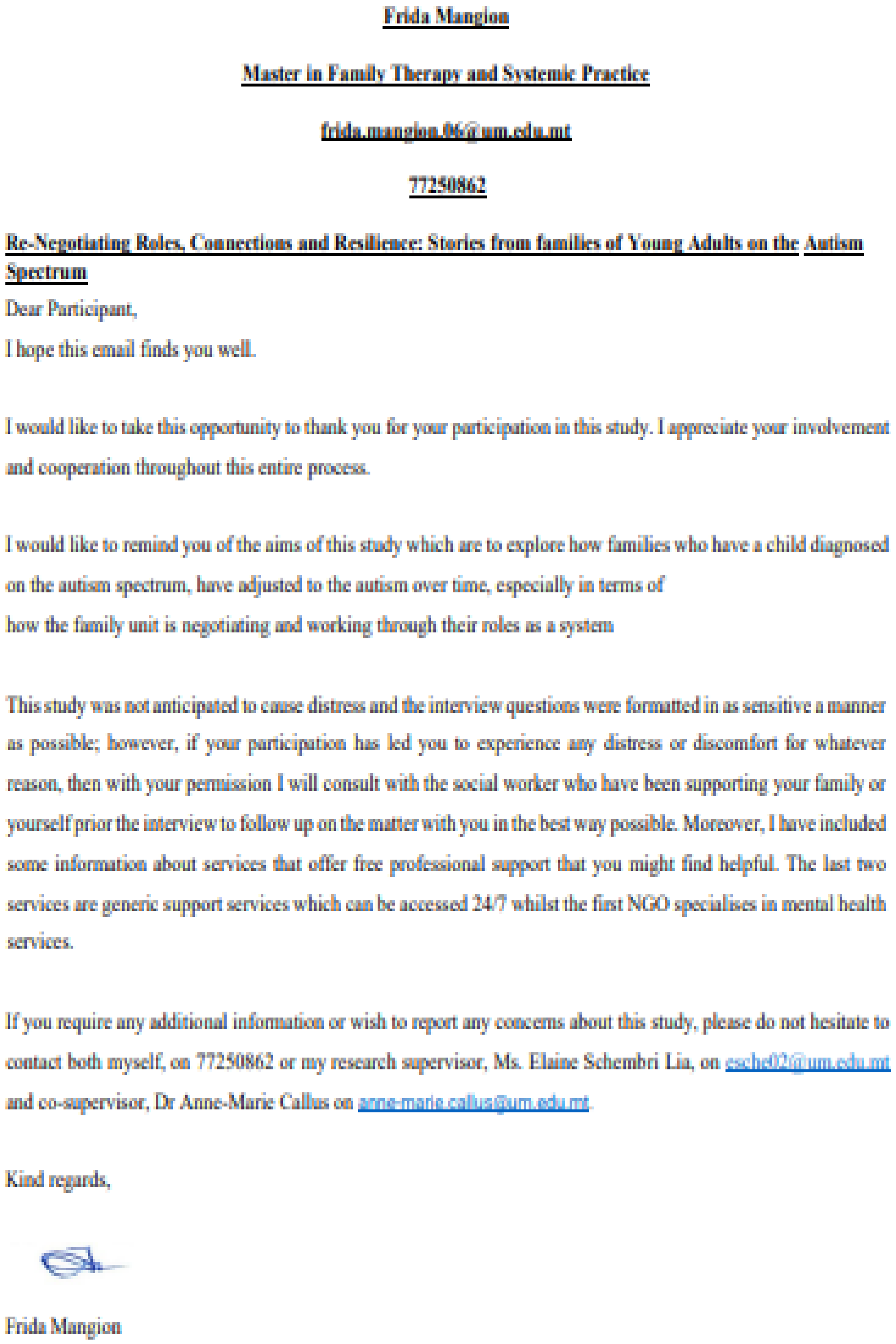
How the young adults with autism interact with the father/mother	
How the siblings interact with one another	
How the siblings interact with their brother/sister on the autism spectrum	
How they interact as a family all together	

Linja gwida għal matul l-osservazzjoni:

Kif l-adult bl-awtiżmu jinteraġixxi/ tinteraġixxi mal-missier/ omm	
Kif l-aħwa jinteraġixxu flimkien	
Kif l-aħwa jinteraġixxu m' oħthom jew ħuhom bl-awtiżmu	
Kif jinteraġixxu flimkien bħala familja	

Appendix M

Information about Support Services (English and Maltese)



Frida Mangion

Master in Family Therapy and Systemic Practice

frida.mangion.06@um.edu.mt

77250862

Re-Negotiating Roles, Connections and Resilience: Stories from families of Young Adults on the Autism Spectrum

Dear Participant,

I hope this email finds you well.

I would like to take this opportunity to thank you for your participation in this study. I appreciate your involvement and cooperation throughout this entire process.

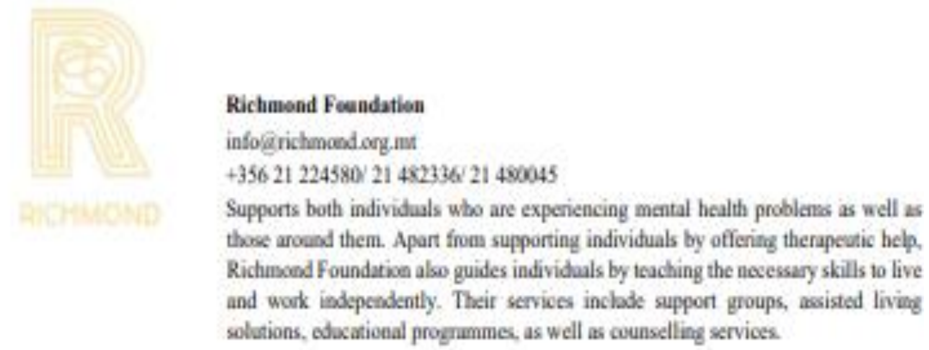
I would like to remind you of the aims of this study which are to explore how families who have a child diagnosed on the autism spectrum, have adjusted to the autism over time, especially in terms of
how the family unit is negotiating and working through their roles as a system

This study was not anticipated to cause distress and the interview questions were formatted in as sensitive a manner as possible; however, if your participation has led you to experience any distress or discomfort for whatever reason, then with your permission I will consult with the social worker who have been supporting your family or yourself prior the interview to follow up on the matter with you in the best way possible. Moreover, I have included some information about services that offer free professional support that you might find helpful. The last two services are generic support services which can be accessed 24/7 whilst the first NGO specialises in mental health services.

If you require any additional information or wish to report any concerns about this study, please do not hesitate to contact both myself, on 77250862 or my research supervisor, Ms. Elaine Schembri Lia, on esche02@um.edu.mt and co-supervisor, Dr Anne-Marie Callus on anne-marie.callus@um.edu.mt.

Kind regards,

Frida Mangion

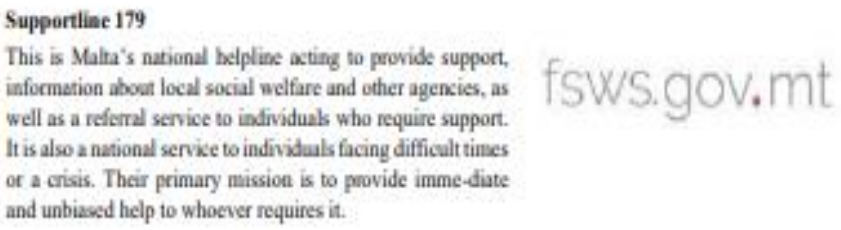


Richmond Foundation

info@richmond.org.mt

+356 21 224580/ 21 482336/ 21 480045

Supports both individuals who are experiencing mental health problems as well as those around them. Apart from supporting individuals by offering therapeutic help, Richmond Foundation also guides individuals by teaching the necessary skills to live and work independently. Their services include support groups, assisted living solutions, educational programmes, as well as counselling services.



Supportline 179

This is Malta's national helpline acting to provide support, information about local social welfare and other agencies, as well as a referral service to individuals who require support. It is also a national service to individuals facing difficult times or a crisis. Their primary mission is to provide imme-diate and unbiased help to whoever requires it.

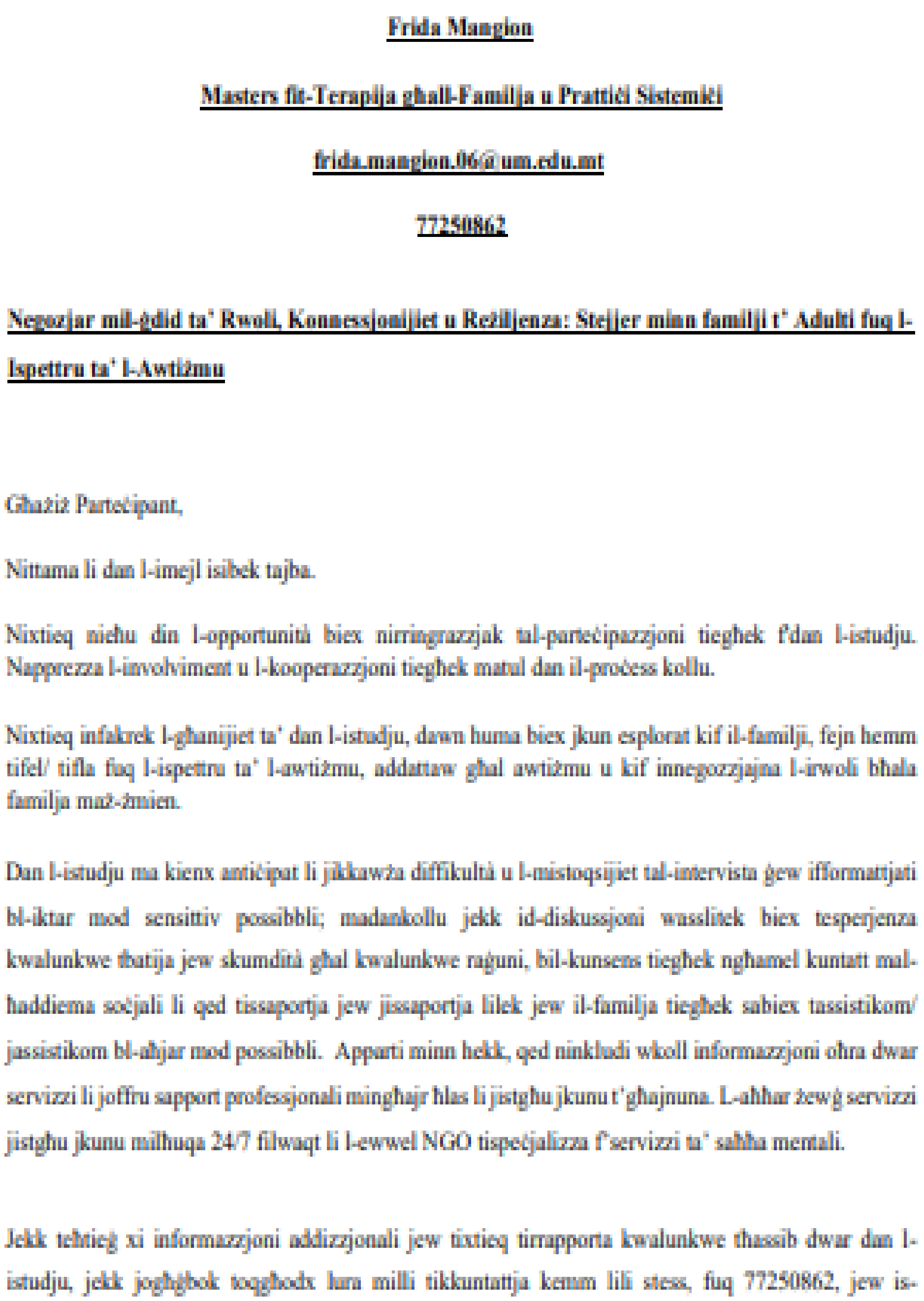
fsws.gov.mt

Kellimni .com

http://kellimni.com/

21244123/21335097

kellimni.com is an online support service in which trained staff and volunteers are available for support 24/7 via email, chat and smart messaging. This service is managed by SOS Malta.



Frida Mangion

Masters fit-Terapija għall-Familja u Prattiċi Sistemiċi

frida.mangion.06@um.edu.mt

77250862

Negozjar mill-ġdid ta' Rwoli, Konnessjonijiet u Reżiljenza: Stejjer minn familji t' Adulti fuq l-Ispettru ta' l-Awtiżmu

Għażiż Parteċipant,

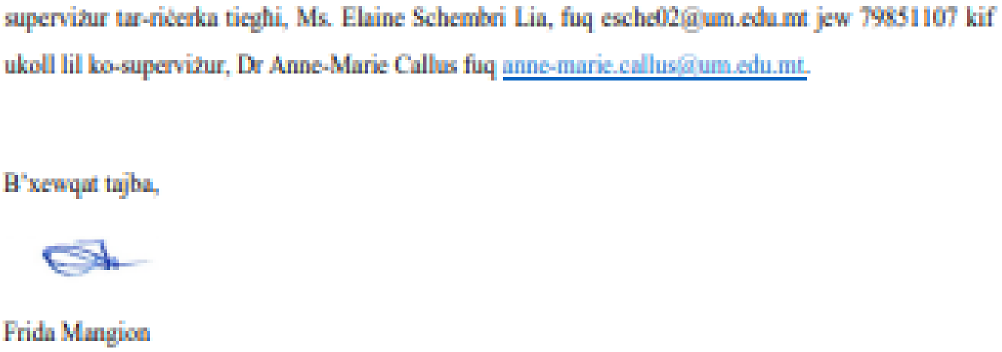
Nittama li dan l-imejl isibek tajba.

Nixtieq nieħu din l-opportunità biex nirringrazzjak tal-parteċipazzjoni tiegħek f'dan l-istudju. Napprezza l-involviment u l-kooperazzjoni tiegħek matul dan il-proċess kollu.

Nixtieq infakrek l-għanijiet ta' dan l-istudju, dawn huma biex jkun esplorat kif il-familji, fejn hemm tifel/ tifla fuq l-ispettru ta' l-awtiżmu, addattaw għal awtiżmu u kif innegozzjajna l-irwoli bħala familja maż-żmien.

Dan l-istudju ma kienx antiċipat li jikkawża diffikultà u l-mistoqsijiet tal-intervista ġew ifformattjati bl-iktar mod sensittiv possibbli; madankollu jekk id-diskussjoni wasslitek biex tesperjenza kwalunkwe tbatija jew skumdità għal kwalunkwe raġuni, bil-kunsens tiegħek ngħamel kuntatt mal-ħaddiema soċjali li qed tissaportja jew jissaportja lilek jew il-familja tiegħek sabiex tassistikom/ jassistikom bl-aħjar mod possibbli. Apparti minn hekk, qed ninkludi wkoll informazzjoni oħra dwar servizzi li joffru sapport professjonali mingħajr ħlas li jistgħu jkunu t'għajnuna. L-aħħar żewġ servizzi jistgħu jkunu milħuqa 24/7 filwaqt li l-ewwel NGO tispeċjalizza f'servizzi ta' saħħa mentali.

Jekk teħtieġ xi informazzjoni addizzjonali jew tixtieq tirrapporta kwalunkwe tħassib dwar dan l-istudju, jekk jogħġbok toqgħodx lura milli tikkuntattja lili stess, fuq 77250862, jew is-



supervižur tar-riċerka tieghi, Ms. Elaine Schembri Lia, fuq esche02@um.edu.mt jew 79851107 kif ukoll lil ko-supervižur, Dr Anne-Marie Callus fuq anne-marie.callus@um.edu.mt.

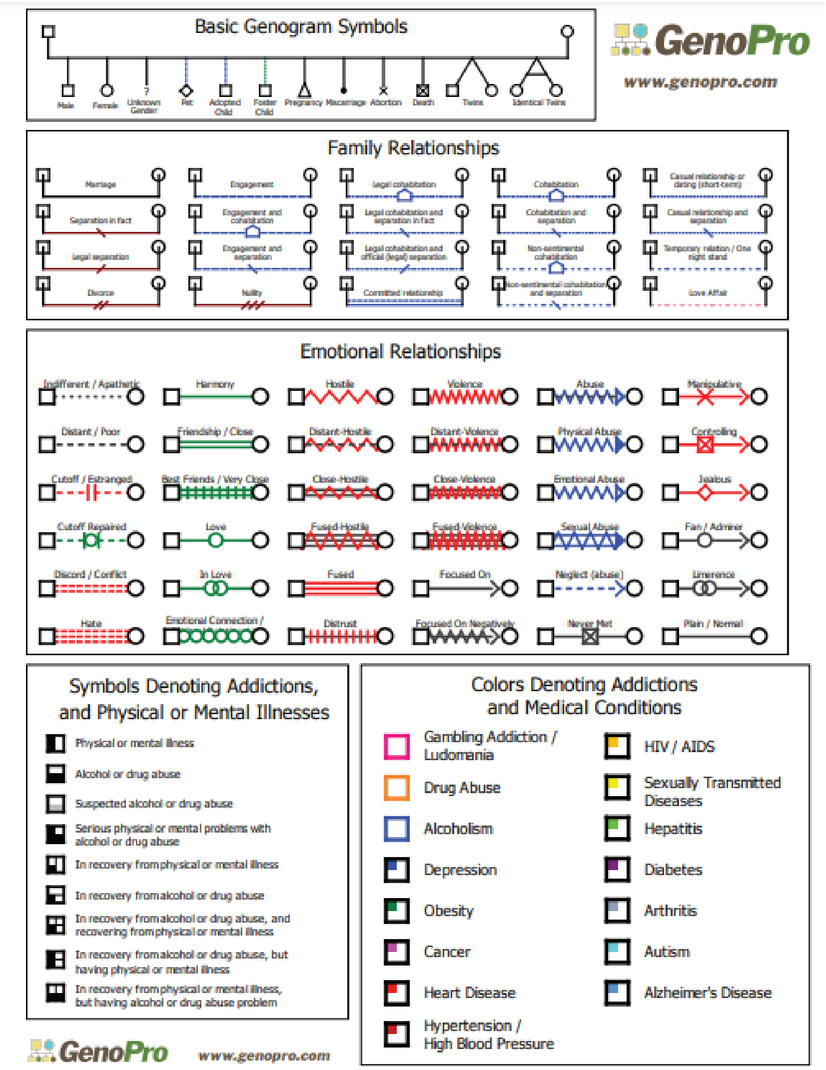
B'xewqat tajba,

Frida Mangion

Appendix N

Genogram Software Symbols

Link to **GenoPro** which is a software application for drawing family trees and genograms: https://genopro.com/



Appendix O

Excerpt from James' Interview

Frida: Tell me about you

James: I am autistic and I am clever, I am handsome and I am funny and Kate (pseudonomous name of the support worker) is my friend.

Frida: Describe your family

James: We are 4; mum, dad, name of his brother and me and 2 dogs.

Frida: Would you like to tell me their names?

James: Ellie and Billie.

Frida: What would you like to say about the relationship with your mother?

James: Sometimes good and sometimes bad.

(The Relational Dynamics)

Frida: Would you like to add something else about this?

James: She fights with family.

(The Relational Dynamics)

Frida: How do you feel about that?

James: We don't like it. (We mean himself the support worker explained), We get upset.

Frida: How would you describe your relationship with your father?

James: We don't have a good bond.

(The Relational Dynamics)

Frida: How do you feel about this?

James: We feel angry and we want a better bond.

(Reaching Out for Connections)

Frida: How would you describe your relationship with your brother?

James: He is my heart; we went to see him with mum and dad as well.

(The Sibling's Experience)

Frida: What do you enjoy doing most with your parents and your brother?

James: We like to do outdoor, we like to swim, and walk and visit family.

Frida: What do you enjoy doing the least with your parents and your brother?

James: We don’t like fighting and staying home.

(The Relational Dynamics)

Frida: What do you like most about your brother?

James: He is fond of me. He jokes with me.

(The Sibling’s Experience)

Frida: How do you feel when you think about your family?

James: We feel happy.

(The Relational Dynamics)

Frida: Is there something you don’t like about your family which you wish to tell me about?

James: We don’t talk enough, and she (mum) has to find time.

(**The Impingement on the Family Dynamics)**

Frida: What do you wish to say about your extended family such as grandparents, uncles, aunties etc ...? How is your relationship with them? What do you like most about them?

James: We go to visit nanna a lot. Nanna is always kissing me. She always makes me feel welcome.

(Reaching Out for Connections)

Frida: Do you have uncles and auties or cousins?

James: We have aunty and uncle they are my mum’s brother and his wife.

Frida: Tell me about your friends?

James: We want friends and autistic like me.

(Reaching Out for Connections)

Frida: What do you understand with the word autism?

James: We are clever but people treat us as stupid and don’t try to understand us and we frustrated.

Frida: What do you desire for your parents, your brother and you?

James: We wish to make them proud.

Frida: And for them what do you wish?

James: We want them to be happy.

(What does the future hold?)

……………………………………………………………………………………………

Appendix P

Results Chapter (Maltese Quotes)

Navigating the Problem

Meta kellu sentejn, James' parents realised **li kien hem problema,** eventually, **anke' s-smigħ beda jkun problema, u morna għand il-pedjatra,** recalled Martin. **Hu qalilna jista' jkun awtiżmu.** This was **l-ewwel darba li smajna biha**. **Kien xokk enormi**, Martin recalled. **Għal ewwel, fittixna s-sapport primarjament minn psychologists** and **CDAU.** Eventually, they engaged James in a program run by **Inspire,** and paid for it, **waqaf minħabba l-Covid, u wara dak, beda jattendi s-Sapport**, he explained. Martin told me that initially they were referred to a psychiatrist from school, yielding minimal positive results, so they sought the advice of another psychiatrist. **Tah mediċini differenti u bil-mod, l-episodji** [tantrums] **bdew jonqsu.**

Martin explained that **dak iż-żmien, ma' kienux konvinti bil-kwalita' ta' risposti li rċevew** locally**. Sa anke marru l-Ingilterra; tawh logħob biex jilgħab bihom, saqsewh xi mistoqsijiet u osservaw ir-reazzjoni tiegħu; "but we think he has autism,"** the British said bluntly. **Kont naqra ddiżappuntat,** said Martin, as he did not expect such a quick conclusion on such an important matter. Sadly**, 'I am not sure if we made the right decision … but at one point, you sort of give up. Meta skoprejna li kien hemm problema, ħadniha bis-serjeta...bħal meta titlef lil xi ħadd, għal bidu teħodha b'mod serju, but slowly, time enables us to get used to it, and we did the same.** Martin expressed that they **ma stajniex ngħixu family life normaligħax is-sitwazzjoni ma kienitx normali, anke on a psychological level, għax għandek tifel b'diżabilita'.**

Mark recalled his mother's reaction **għal ewwel, ommi kienet qisha; it's not a curse that** [the autism] **brought us, but it's like, why? It's like a punishment ... it took a while**

to get her to accept that ... she used to bottle things up and not enjoy life...kienet tara tfal oħra... u kważi tisforza lil ħija jgħamel affarijiet ta' kuljum. Interestingly, when asked to describe himself, James, with a smile, said **I am autistic, and I am clever, I am handsome, and I am funny.**

Mark hinted that Marthese blames **this injection** [MMR]. Given the painful realisation, Marthese attempted to compensate for 'the problem' by assimilating that it could have been worse, **jista' jkollok tifel normali, u f'daqqa waħda jiġrilu xi ħaġa, jew droga, nipprova nikkalma lili nnifsi. Jgħinni li narah healthy.** This facilitated her journey to acceptance. **By nature**, James **kien pjuttost mqareb**; **niftakar li kien dejjem jgħamilha mad-delinkwenti ...ħarab mil-iskola ħafna drabi,** Mark sustained. Martin compares life to a **bunch of playing cards,** and he said **uħud għandhom a worse bunch minn tagħna.** This reasoning keeps him sane.

Manifestation of Autism Symptoms

Marthese and Martin's parents **ssaportjawna** [them] **meta setgħu, niftakar meta kellu tantrum kont tinduna ... li kienu xxukjati.** Mark shares that his grandmother **waqgħet f'depression għax ma setghetx taċċetaha ... ta' ħija** [diagnosis] **kienet her breaking point.** Unfortunately, to date, **hi tibqa' tittama u titlob li jsir miraklu.**

Ten years ago, ma kienx hawn ħafna servizzi. We happened to experience autism at the very beginning, continued Martin. **Ma kienux jafu how to handle him at school, avolja they surely meant well,** Martin added. Mark recalled that his brother **kien l-unika wieħed bl-awtiżmu** at their school, **u kont nitħassru.**

Martin recounted that at one point; **l-facilitator bdiet tirraporta li James beda jħabbat rasu ma' desks u jħarbat il-klassi,** which was uncharacteristic if him. The facilitator hinted that James was aggressive towards her; we **were surprised għax qatt m'għamel xi ħaġa ta' dak it-tip**, said Martin. **F'daqqa waħda, l-behaviour tiegħu inbidel**

ida-dar ukoll; sar aggressiv ħafna … kemm il-mara u jien spiċċajna bil-gdim, tbenġil, u demm. Martin assumed his son experienced **a breakdown għax aktar ma beda jgħaddi ż-żmien, hu** [James] **beda jifhem iktar li kien differenti mil-oħrajn… dan kien il-mod ta' kif hu beda jipproċessa l-ambjent ta' madwaru.** Likewise, Marthese narrated that James **kien jħossu differenti; hekien jara tfal oħra, u kien jħossu mdejjaq għax kien jinduna li kellu problema** believing **dan kien trigger għad-depression.**

Martin recalled vividly receiving an urgent call from school. With a sad tone because James had written li **ried jmut ... konna wasalna f'sitwazzjoni fejn ma stajtx mmur għax xogħol darba għal xahrejn sħaħ. Kien sar aggressiv minn x'ħin jqum sa x'ħin jiġi biex jorqod. Kien jigdem lilu nnifsu u jsabbat rasu ma' l-art u mal-ħajt, imma l-aktar lejna.** Martin showed me how he **kien jiġbdu fuq saqqu u kien jibqa' jżommu sakemm James kien jgħejja.** Martin knew that if James had to have a window of opportunity, **kien jigdem** [him]**, joqros** [him]**, u jekk ma toqgħodx attent kien jweġġak.**

His mood would change **f'salt.** Recounting the exhaustion, Martin explained that it used to take him **sagħtejn jistragilja ma' James** during a tantrum. **Kont nispiċċa eżawrit and** in disbelief at James' physical strength. Marthese painfully recounted that this aggressive behaviour restarted during his teenage years; James **kien jkollu loud tantrums; kien jgħatiha daqqiet vjolenti.** After each of these tantrums, she **used to break down.** At that point, she showed me the area where she had **twenty stitches, u kien qatali widnejja.** Tremendously convinced, she added, **dan mhux tantrum; imma aggressivita'; tantrum għalija mild. Rajt xeni kbar, tat-twerwir, tkissir, TV jitkisser u ħafna drabi kont nkun waħdi.**

Mark frequented his brother's same school; he recalled that people **kienu jippretendu li hu ħa jikkalmah.** He was once him to sit next to his brother during one of his tantrums, and he attacked him. **Kien qaċċatli l-ġilda, kien qisu intilef minn sensieh.** Mark said it was not easy to make sense of his brother's **jitlef it-tempra.** I could feel that she was not proud of this decision; however, Marthese admitted that **kienet xtrat manetti biex torbtu u ivvintat ċinturin biex tobtu mal-manetti lura mas-sufan ħalli ma jqumx għaliha** [her]**.** However, he would still retaliate. Martin admitted having difficulty comprehending such **aggressivita', ma stajtx nifhem; kont rrabjat ...** Martin feels that one of their **l-ikar żball tagħna kien li konna nitkellmu fuq il-problemi ta' James quddiemu; because kien jifhem.**

Impact of Traumatic Experiences on the Couple

When asked to speak about their relationship, Marthese confessed that her husband focuses entirely on work, meaning that she is **the one who has to keep up with everything.** Claiming that her husband was **very supportive fil-bidu... kien jiddispjaċih… konna differenti. We used to complement each other**, said Martin. Martin recalled that he used to be involved **daqs martu.**

Il-mara kienet ċċempilli x-xogħol, and u kont nisma' t-twerżiq u l-għajjat fil-background …kont mmur id-dar qisni miġnun. Kont nsib massakru d-dar…xagħar il-mara ma' l-art, **darba anke l-ear lobe. Żminijiet terribli,** he added. **Dan l-aħħar, qisu l-mara taffaċċja l-problemi.**

Naħseb kien waqa' f'depression bejn x-xogħol u dak li ġara lil James, said Marthese. **I sometimes collapsed alone mingħajr is-sapport ta' ħadd**. Martin describes this shift as an **aftermath** of their son's autism; **we never recovered.** This experience **ġabet a bit of bitternesslejn il-ħajja u lejja,** said Martin. Mark also witnessed his parents' romantic relationship changing**; he said ommi u missieri m'għadhomx close.** According to Mark, **il-ġenituri tiegħi accepted it at different stages of their lives … u b'mod differenti.** He feels that his mother **sometimes projected her anger onto the relationship. Whereas missieri,**

raġel kalm ħafna biex jaħrab mil-problema, looks like his escapismkien ix-xogħol, sustained Mark.

Martin feels that **l-familja tagħna kienet ruined.** The family situation seemed like **hell at one point because we were coming** [home] **to hell.** The psychiatrist was the only professional who validated Martin's feelings and used to tell me**għaddejt milli għaddejt, u għadek hawn; dan achievement kbir.** Martin confessed to the psychiatrist that he was **kontinwament jiġi blamed**, the psychiatrist normalised this and was the first professional to **jirreferi** [the couple] **għal terapista**. When asked if they were ever referred to family services, Marthese explained that no family services were ever offered as **is-servizzi jiffukaw primarjament fuq it-tifel, mostly education.**

Renegotiating Roles

In digesting the news, the family members had to reposition their roles to deal with autism. Mark explained that despite the need to abandon certain family rituals, his parents managed to re-negotiate their roles to attend to their family needs. Mark confessed that **wieħed biss kien jiġi għal-prize day għax l-ieħor jrid joqgħod ma' James.**

Marthese affirmed that no, **the life she planned came different. I had to try to turn around and adapt, James turned my life upside down**. With a cracked voice, Marthese added, **kont nħobbu x-xogħol tiegħi... kelli nibqa'd-dar, nissagrifika il-karriera, kollox.**

The Sibling's Experience

Marthese recalled Mark's anger towards James when he would hit her. **Ġieli ħallejt lil Mark waħdu,** confessed Marthese**, u ma kontx lanqas ngħajjat għal għajnuna ħalli ma jarax dawk ix-xeni.** Martin recalled that they did their best not to resort to Mark as he was still very young, but **kultant, kellna bżonn l-għajnuna ta' Mark u kien jirrabja ħafna għal James; kien jirreaġixxi unreasonably, imma kont nifhmu għax James kien qed**

jkissirna. Martin went through a similar process as he recalled episodes when **kien jgħajjat ma' James**, as **ma kienx jifhem għala kien qed jkun mean lejhom. It is complex; kultant, tkun trid tisħet kollox u ssaqsi, għala aħna? X'għamilna ħażin?**

Marthese is fond of the r-**relazzjoni sabiħa** she shares with Mark nowadays. As Mark was growing up, she realised that her primary focus had been on James, and at one point, she reminded herself that she needed **tieħu ħsiebu** [Mark] too. Mark expressed that his mum **hija overprotective ħafna ... meta kien żgħir, kont nħoss li she projected the aspirations she had, both mine and my brother's, on me, kienu qisu kelli a double responsibility li kienet tgħejjini.** Growing up, Mark's form of escapism was through **safar u spending a lot of time outdoors;** like his father, he used to regret going back home.

The Impingement on the Family Dynamics

James shared that **sometimes** [the relationship with his mother] **is good but sometimes bad …** he **doesn't like that his mother fights with his family. It makes him feel upset.** However, when asked to describe his relationship with his father, James admits they **do not have a bond; this makes him feel angry as he wants a better one**. Mark shared that although his father doesn't show it, **he loves** them both **immensely.** Mark said their father **naqas milli jgħamel l-affarijiet li s-soltu tagħmel ma' missierek. Kont nħoss li abbandunani, imma llum nifhmu.**

Mark admitted that, at first, **kien jgħid jmissu jistħi, qed jħarbatli ħajti b'dawn il-kummiedji kollha.** Mark explains how he was expected to care for his brother with autism**; min eta' żgħira kont nisma', 'ara li tieħu ħsieb lil ħuk u oqgħod miegħu'. Kont nħossni li m'għandix ngħid il-problemi tiegħi lil ġenituri. 'Għandna biżżejjed problemi b'ħuk; żżidx tiegħek ukoll...'** his parents used to say. To date, Mark has difficulty disclosing certain issues with his parents.

Despite this, Mark shares that his **tawni a very good childhood. Meta tikber, tara l-affarijiet f'dawl differenti... I am not sorry, għax kieku ma kienx hekk, kont nkun persuna differenti.** Mark also insists that he owes a lot to his grandparents, **kienu very supportive;** they did not only compensate but also **overcompensated,** especially when **ħija kien għaddej mil-agħar tiegħu.**

Reaching Out for Connections

James yearns for connection outside the family. He does not have friends and **would love to have autistic friends like** [him]**.** Mark mentioned that his brother is highly sociable, **enjoys company** … **and everyone loves him**.

Nowadays, Marthese enjoys spending time with James and describes him **bħal forever baby.** She said **joqgħod jistennini quddiem it-televixin filgħaxija. Nitgħanqu; dawk affarijiet sbieħ,** said Marthese fondly. **Janes tani l-enerġija… kieku ma kienx għalih, m'inhiex fejn jien illum,** insists Marthese. James expressed that he likes it when his family engages in outdoor activities rather than staying indoors: **we like to swim, walk, and visit family.**

Martin said **li nara lil James kuntent** reassures him. When asked to share how he feels when he thinks of his family, James said that he **feels happy,** although he feels that **they do not talk enough.** James explained that his **mum is always busy and doesn't want to talk to him.** Martin admits that the communication barrier hinders their relationship and, to some extent, poses dilemmas as to why James communicates with strangers, including me as the researcher, but not with family members. Equally, Mark would give anything to communicate with his brother. **Kien ilu jixxennaq għal din il-komunikazzjoni** [he] **minn meta kien tifel żgħir**. I was curious to know what the communication device meant for James; hearing the device **give him a voice** was fascinating.

Mark appreciates James' ability to communicate non-verbally; **dejjem ħassejt li mil-ħasra tiegħu u mil-manjieri, aħna nafu u nħossu dak li l-ieħor qed jħoss,** emphasised Mark. James enthusiastically said **my brother is my heart, he is fond of me, and he jokes with me.** Mark explained that they**dejjem ħa nkunu hemm għal xulxin;** he tearfully added, **we are each other's best friends till death do us part.** Mark claims to be very protective towards his brother; **nħossni reponsabbli** for him; **he is my little brother,** he emphasized. **We have an unbreakable bond… jiġri x'jiġri bejnietna,** concludes Mark. Also, James added receives a lot of affection from **his grandmother, she always kisses** [him] **and makes** [him] **feel welcome.**

Societal Norms

Initially, Marthese had attempted to conform to societal norms and used to tell James **to be quiet, he would stomp his feet...** and she used to **feel uncomfortable. I hoped he would be normal.** Marthese attests that she **accepted it now... everyone has something... maybe they look at him with disgust or handsomely, but it won't affect me.** Interestingly, when asked what he understood with the word autism, without hesitation, James said, **we are clever, but people treat us as stupid and don't try to understand.**

Marthese reflected on society's judgments against what does not fit within the "normal" parameters. She firmly believes that **for biex is-soċjeta' timpruvja, wieħed jrid jesperjenza l-awtiżmu b'mod personali jew jkollu fil-familja... biex tkun iktar aware tagħha...** otherwise, **ħadd m'hu interessat. Hija diffiċli għax hija hidden disability; n-nies ma jistgħux jifhmu l-awtiżmu. Għax int tara tifel jew tifla, u f'daqqa waħda jgħamel jew tgħamel xi ħaġa, and rightly so, it shocks you,** she explained. Martin narrated that once James **kellu tantrum barra, u n-nies rawh, imma ħadd ma pprova jgħinni. Umbagħad kkalma, u konna bil-qiegħda fuq il-fence, u ġie pulizija, u spiċċajt l-għassa; ħasbu li kont qed nsawtu.**

You have to continue with your life; you cannot lose yourself

Dak iż-żminijiet, jekk kellek bżonn LSA, Marthese explained, **ridt tħallas. Kont spiċċajt naħdem fl-istess skola,** and with the money earned; I paid for the LSA, narrated Marthese. **Umbagħad għidt rrid ngħamel xi ħaġa aħjar,** Marthese started studying, opened her small enterprise, and despite describing the experience as **very painful**, characterised by **ħafna konfużjoni, għax tibda tgħid dan it-tifel mhux se jiġi normali, u fl-istess ħin, trid tistudja...; kienet diffiċli ....** however, **irnexxieli,** said Marthese. Martin exclaimed **rreħistejna u bqajna fuq saqajna; it was our duty**. Similarly, Marthese speaks about what supported her to go on, **il-mod ta' kif il-bniedem jsib way to survive; you survive u tipprova ssib l-afafrijiet is-sbieħ li hemm. Tris tkompli b'ħajtek; ma tistax titlef lilek nnifsek. L-parti pożittiva hi li tibda tara il-ferħ veru tal-ħajja.**

What Does the Future Hold?

The future seems to elicit fear and hope simultaneously in James' family. Marthese and Martin are concerned about James once they pass away; **din hi l-biża' tagħna,** exclaimed Marthese. Consequently, they would like him **jkun aktar indipendenti** to put their mind at rest**.** Mark wants to ensure that his brother has **jkollu kollox u l-iktarħajja komda possibbli. Ħa jkollna futur sabiħ flimkien,** he insisted. Mark also expressed gratitude for his parents' **hardwork u sagrifiċċji** and he feels it is time for them **li jkunu biżżejjed**. **Għamlu ħafna, u taw ħafna.**

James concluded the interview by saying; **we felt happy** [to participate in the interview] **because you are trying to help autistic like me … we appreciate it.**

Micallef's Family Story

Meaning Making

Wara li taqqabdnieh, exclaimed Charlie; the change happened **meta tajnih l-MMR,** confided Rose. **Anke ppruvajna nġibu second opinions, u tibda tgħid m'għandi lil ħadd fil-familja; kif jista' jkun?** continued Charlie. **Meta tibda tinżel, qisu bħal meta jkollok problema u tara kif se ssib soluzzjoni.** As a result, **tajna lil Nicholas l-MMR sit xhur wara.**

The testimony of a mother who shared her story in church encouraged Rose**; il-bambin jgħatina t-tfal b'ċertu diffikultajiet għax nistgħu nieħdu ħsiebhom, mhux lil dawk li ma jistgħux. Dawn il-kliem baqgħu ttimbrati f'moħħi,** she said while touching her forehead. **Kien hemm mumenti fejn kelli aptit nsabbat rasi mal-ħajt**, admitted Rose. Rose expressed her gratitude towards God, compared to the realities she comes across when she attends hospital appointments with her son; **Jiena rajt tfal bl-ALS u... ngħidlu, imma tiegħi m'għandu xejn fejn din it-tifla. Oħrajn, li għandhom l-awtiħmu u full autism ... tagħna m'għandux fully,** shared Rose.

The Couple's Relationship

Rose's face lightened when asked about her relationship status, **iva, aħna miżżewġin,** and with a sweet laugh, she added, **ilna flimkien għal ħafna snin.** The affinity towards each other struck me; as Rose described her personality, she turned and looked at her husband; **ir-raġel tiegħi jgħidli li għandi qalbi tad-deheb, imma jien rasi iebsa.** They teased each other after this comment, and they both laughed when Charlie sighed, **ilha hekk minn dejjem.** When asked to describe their family, Simon immediately mentioned that soon his parents would **celebrate their anniversary.**

Rose explained that she **naħdem full-time reduced … nipprova nlaħħaq mal-familja u d-dar**. Previously, she **kelli nnaaqqa għal-to part-time minħabba l-ġiri t'appuntamenti tat-tifel** appointments, **dan fisser inqas income**. **L-commitments kollha kellhom jiffukaw fuq il-bżonnijiet tat-tfal**. Indeed, Charlie's dream was also impacted as he **kelli nabbanduna l-idea li jkolli Ph.D.**

The Relational Dynamics

When asked to describe their family, Rose said, **il-familja tagħna magħquda**, and Charlie instantly validated her comment. The children also shared this reflection. Simon and Nicholas had a positive view of their family; my **family is fine**; **I love my mum** [did a heart shape with his fingers], **and my father too,** said Nicholas; he even enjoys the family rituals like, for example, **eating dinner along with them or go outside to eat something.** At the same time, Simon mentioned that he **enjoys taking the car to the car wash with his father, and playing football with his father.** Simon reflected on a deeper level; he said confidently that his **family feels joyful because...** they've **been a core to me ever since I was a little kid.**

When they were young, Simon and Nicholas used to **jiġġieldu; Simon huwa aktar physical,** explained Charlie; he **kien jiġġieled,** said Rose, **u l-ieħor kien jweġġa',** continued Charlie. **Simon ma' kienx jirrealizza li seta' jweġġaw minħabba li kien ikbar minnu; kemm –il darba bagħat lil Nicholas l-iskola b'girfa,** explained Rose. The **l-estrem 'l ieħor issa smiled** at Rose as **jmorru tajjeb ħafna flimkien,** continued Charlie. Nicholas attests that **he often plays with his brother**, describing this as what he likes most about their relationship. Nicholas feels that **games connect** them; however, when asked to describe their relationship, he rated it as **50/50; sometimes, he is nice and others mean.** Simon describes his relationship with his brother as **going down; they fight a lot.**

Rose insists that her children **dejjem jgħidulha l-verita' u ma jaħbu xejn; għax ma tkunx tista' tgħinnom jekk jiġri xi ħaġa.** Despite being **eighteen u jista' jieħu deċiżjonijiet,** she feels Simon trusts her... and seeks her opinion. **Simon huwa follower, mhux leader; kultant nibżgħu li xi ħadd jista' jtih eżempju ħażin,** and he takes it on board, said Charlie backed up by Rose. **Dejjem ppruvajna nipproteġuh mid-dinja ta' barra,** explained Rose.

Simon is concerned that **the course will not make** [him] **a footballer… his parents are telling him that** [he] **has to train with a club and start improving himself immediately.** Simon recalled that his **mother used to tell** [him] **that if** [he] **failed his subjects,** [he] **won't even get a job, simple as that.** Similarly, Nicholas spoke about feeling pressured to achieve good results and said **Dad is pushing me a lot, so he tells me to pay attention to this, that, …it's kind of like so tough** he admitted.

The ASD Journey

Charlie chose the word **survivors**, **u thank God bqajna mgħaqudin,** he stated. **Għaddejna milli għaddejna.** The couple highlighted a **financial struggle; it was a money issue** that fuelled **argumenti bejniethom;** Rose continued saying that **loans, kontijiet, u petrol … kollha riedu jitħalsu**. And Charlie pointed out that **anke professjonisti… Ma tistax tuża tal-gvern, hemm waiting lists twal, u int għandek bżonn l-assistenza issa, inkella jkun be too late** if you had to wait, argued Charlie. As a result, they even had to sacrifice family outings; the **l-ispejjeż kienu kbar; konna qisna ġo bubble,** remarked Rose; **konna naffordjaw treat darba f'xahar.**

When asked to reflect on their journey around the autism diagnosis, Rose said sharply, **it-tifel tagħna kien jitkellem, aħna u tilajn it-taraġ, kien jgħodd in-numri bl-Ingliż, Malti, u anke Ġermaniż.** I spontaneously remarked he used to communicate, and with that comment, Rose felt validated and said, **ehe, meta kellu two,** she looked at her husband to seek reassurance about the age; he**waqaf jitkellem**, **mhux kompletament,** said Charlie and she agreed. **Ma kienx l-istess; f'daqqa waħda, nbidel,** Rose's facial expressions became heavier.

Fil-bidu, kienet diffiċli, said Rose. **Simon kien jintefa' ma' l-art; kellu ħafna tantrums. Konna nużaw ħafna flashcards miegħu; kont naf li jkun jrid l-ilma meta kien żgħir; kien jgħidli, e e mama. Kont ngħidli xi trid? Kont nġgħelu jitkellem.** Simon exhibited difficulties related to **speech** and **communication; u jesprimi lilu nnifsu** clarified Charlie. **Jekk trid, tista' tifhmu, imma l-word sequence … he mixes masculine with female pronouns,** elaborated Charlie. Through the interview with Simon, I could relate to this as it took quite a toll on me to understand him.

Wara l-Covid, Simon baqa' jinsisti li ried jilgħab l-football, u fittixt sakemm sibtlu club; thank God kklikja ma' sħabu. Charlie said **kienu open-minded u laqgħuh fil-grupp**; this **meant a lot. Over the years, they struggle, and we struggle for them to have friends** declared Charlie. The players are mainly foreigners, enabling him to **integrate better.** Simon happily shared; I **have friends, and my relationship with them is top level… my friends love me so much that sometimes, when I go to training, they support me; they always ask me to go out with them, and I feel happy.** The parents narrated that this group gave Simon more opportunities than just football; **hu joħroġ magħjom anke Paceville,** added Charlie. **Simon jaf juża l-bus,** said Rose fondly, thanks to his friend's mum that Simon as she introduced him to the bus system; she **hi setgħet tifhem għax it-tifel tagħha għandu l-autism,** explained Charlie. **Kienu jmorru tajjeb flimkien,** added Rose.

Rose painfully recalled that **Simon kien jiġi bullied ħafna**; for his sixth birthday, they organised a party, and the boys did not turn up except his best friend. **Kienu jnizzlulu l-qalziet,** she confessed later on. Charlie feels that **tfal lil tfal oħra huma iktar crueller... t-**

tfal huma innoċenti, imma jekk jarawh differenti jwarbuh. The bullying reality is enormous, Rose emphasised. Charlie adds that **tfal bl-autism huma targets għal bullying; u easy prey għax they lack communication...** Simon was also **cyber bullied l-iskola tal-gvern,** and to Charlie's disappointment, the school's and even the police's reaction to this was a **letdown.** Thankfully today, Simon has **kunfidenza fih innfsu, which is a good thing, n-nies jippruvaw jinkuh; ma jtihomx attenzjoni; għandu l-kuraġġ ... u f'ċertu affarijiet, he is stubborn, which is a good thing. Għandu l-opinjoni tiegħu u jesprimiha,** Charlie sighed with relief.

Kienet diffiċli nara t-tfal ta' ħut ir-raġel u lilu, per eżempju, Rose expressed, **tara d-differenza b'għajnejk. Tipprova tgħallmu biex bil-mod jasal sa ċertu punt, u naħseb li rnexxielna ... mhux li hu 100% indipendenti, imma lħaqna 70 – 75 %** said Rose confidently. **Simon qatt ma qata' qalbu matulha; għandu dik ir-reżiljenza fih; jkompli għaddej; huwa intelliġenti u kunfidenti fih nnifsu,** said Charlie.

Charlie **jixtieq jsiblu summer job lil Simon;** it's **ħasra bagħat ħafna CVs, imma kellu interview wieħed …** Rose **tgħidlu jibgħat CV** whenever she comes across an advert; **Jiena nixtiequ jidħol fid-dinja tax-xogħol avolja hu jibża'** added Rose disappointed. Simon i**s helpful ħafna u emotional,** described Charlie, **idealment xi mkien fejn jista' jkun socially helpful.** Simon stated that **when his mother got sick,** [he] **took care of her.**

Simon shared that his **relationship with his father is going tough,** recalling a memory of last summer when **his father screamed at** [him] **and yelled at** [him] **all the time to find a job. I tried everything I could, but I couldn't work it out. I am trying to be a man and find the right job … I want my father to be patient,** 'Simon explained. Nicholas wishes that **his brother would get a job so he starts earning his own money.**

Simon mhu differenti mil-oħrajn; qatt m'għidnielu li għandu autism, said Rose boldly, but on the other hand, Charlie explained that when he speaks to the boys, **ma nidħolx**

f'dettal dwar x'inhu l-autism; ma rridx li jkollhom low self-esteem... jew they blames themselves. Rose is adamant that **tfal bl-autism huma normali, bi ftit diffikultajiet.** Not surprisingly, when I asked Simon what he understands with the word 'autism', he got confused; **I have to ask; I do not know what autism is. I never heard that word,** he innocently explained. Likewise, when Nicholas was asked if he had ever mentioned his brother to his friends, he said yes. **I told them I have a brother but didn't tell them he has autism,** confusing the term with **optimism because I didn't know until now.**

Rose said **Simon huwa mature; jrid jfaddal il-flus; 'I have my stipend; the clothes are in my hands',** Simon told her. Simon wishes to leave the house and **move on;** his friends are asking him to move close to the club; **I thought I would buy an apartment ten minutes away from the stadium; because they** [football teammates/friends] **mean so much to me that I enjoy this community/club.**

Rose feels proud that the values they instilled in their children are reaping the fruits. Rose patiently explains to Simon the value of money to enable him to make an informed decision; she confessed that **mhux dejjem faċli. Kienet diffiċli; kien hemm żmien fejn kienet diffiċli tikkomunika miegħu, tipprova tispjegalu, imma ma jifhmekx; minn naħa 'l oħra ma stajtx nifhem lilu,** Rose exclaimed, a time when she felt **it-tfal kienu qishom punishment fuqha, kienet diffiċli!** she repeated.

Sources of Support or the Lack Thereof

Touched by the enormous constraints the couple had to endure, I wondered whether any support for the couple or family was ever suggested, but Rose said **no.** When asked how autism impacted their relationship, the couple looked at each other and laughed; Charlie said it did, but **positivelygħax dejjem ssaportjaw lil xulxin,** insisted Rose, **speċjalment communication fuq il-parti tal-logistics**. Charlie described their family as **bubbly, ma**

niġġieldux, niddiskutu ħafna għax kulħadd għandu l-opinjoni tiegħu... u unique character continued Charlie. **Dejjem fhimna lil xulxin,** insisted Rose, **u made it a poitn li t-tfal jkun reqin sa d-disgħa so we enjoy quality time together**. However, when she was too exhausted after a demanding day with the boys, Charlie understood her.

When asked if they encountered any sources of support, they explained that, unfortunately, what the services lacked was added as extra pressure on the parent, **għamel hekk, u għamel l-oħra, ħadd ma tagħna manual ta' xi trid tgħamel jekk jkollok l-autism,** asserted Charlie, with his wife nodding in approval. Further, mentioning that there are no **pathways, l-ebda mappa, hemm ix-xokk, u m'għandekx safety net … int diagnosed bl-autism, and now what? X'ħa jiġri? X'ħa nagħmlu?** argued Charlie passionately.

Charlie spoke highly about a tutor their son was in contact with as she saw a window of opportunity. **She saw right; Simon dejjem xtaq jilgħab football, u aħna ħzammejnih lura, għax il-communication level huwa weak,** but she encouraged us to take him to **football friends, dan mhux competitive,** narrated Charlie. **Ħa ħafna gost hemm,** sustained Rose. Simon said enthusiastically, **I chose football because sports football is my passion, it's my life, and I want to keep going until the end...** Simon also did a **diploma in Sports, got a pass in all subjects, and got the certificate.**

At one point, the parents tried to recall all the professionals they'd been to. They feel that one particular **educational psychologist** helped them immensely; **ma ħalleniex waħedna, u apprezzajt immensament,** adds Charlie. His input was crucial as he supported them in understanding that Simon did not fit in the government school. Charlie narrated that **l-educational psychologists were the light at the end of the tunnel; kienu n-nies li sort of gave us answers for the future.** As other sources of support, Rose firmly stated that they **always coped; sibna equilibrium bejnietna, imma meta kienet taħdem biss, u t-tfal**

kienu iżgħar, li n-nanniet kienu jżommuhom sakem tibda l-iskola. When asked to speak about the extended family**,** Simon rated their **relationship as medium… normal.**

The couple recalled the most challenging moments; **kien tifel intelliġenti… they didn't know how to deal with him,** explained Rose. What hurts her most is that Simon grew up when there was no sufficient knowledge of autism, **kientaboo, u kien isolated.** She had to compensate for the lack of learning at school and **tgħamilha ta' teacher** at home. **Dak iż-żmien, kellhom jpoġġu bilqiegħda u jitgħallmu kif jiktbu biex jkunu ppreparati għal-Year 1. Mhux bħal llum, fejn jitgħallmu billi jilgħabu, jien niftakar fil-Kinder 2, Simon kiteb Simon Micallef fuq il-ħajt. Kien diġa' fuq l-autism spectrum dak iż-żmien, u kiteb ismu sħiħ u ċar. Kind of it was a big deal,** narrated Rose passionately.

Charlie mentioned that the **LSAs kienu għadhom fil-bidu,** and Rose recalled that they went on strike during that time. **Kien għamel xahrejn u nofs mingħajr LSA …Jien studjajt miegħu għal half-yearly exams, u ma kiteb xejn fuq il-karta, u ġab zero … academia dejjem kienet diffiċli,** admitted Rose. Rose explained that they even tried sending him to private lessons, but it was hard to find someone one to one during that time. **Xi ħaġa oħra li Charlie u jien għamilna hi li qatt ma konna rrabjati miegħu,** although **academiaqatt ma kienet tajba,** continued Rose. However, **il-concern jibqa',** admitted Charlie, **għax illum, bla riżultati, ma tgħamel xejn**, added Rose.

The new church school offered a positive experience; **a blessing in disguise**; Rose said he was **overprotected** there, but apart from Simon, as parents, they felt supported too, which meant a lot for them. Rose and Charlie were convinced that from then on, **Simon beda jimpruvja.** Charlie says he met ħafna nies **with a golden heart** along this journey**. You see the true colours of many people ... 'Isma', teħodiex hekk, ara, tgħamilx hekk'... jgidulek, 'Isma', smajt d'din? Check this out'. Nirreferi għalihom bħala guardian angels,** Charlie remarked.

Societal Barriers and the Healing of its Exception

Charlie stated feels l**-ġenituri tagħhom jgħoddu mal-kategorija ta’ l-injuranti; ma jippruvawx mqar jaraw l-kelma xi tfisser. ‘Hemm ara, it-tifel m’għandu xejn’**, his parents tell them**… lack of acceptance,** he added**.** Charlie strongly believes that if **jekk ma tesperjenzax l-autism, m’għandekx interess tiċċekja dwaru... Jammetti li l-injoranza ta’ kulħadd hija l-istess injoranza li kellu hu,** he never heard the word autism until they had their children diagnosed. **Darba weħħajt, konna l-knisja, u t-tifel ma qgħadx bi kwietu. Ziti ġiet wara l-quddies u qaltli jekk ma tistax, ġġibux... n-nies huma too quick to judge.... It is a cruel life.**

Rose had a different experience; she recounted that when they attended **quddies, Simonma qgħadx bi kwietu;** thankfully, the archpriest knew about their reality. Once **Simonbeda jiġri fil-knisja, u l-qasis hu u jgħamel il-quddiesa minn fuq il-pulptu qllha ħallih jiġri għax lili mhux jdejjaqni.** Charlie narrated that before they **żżewġu, kienu attivi fil-knisja; li hi, fil-komunita’, waħda mir-regrets. You marginalize yourself once you are no longer active in the community.**

Future Aspirations and Recommendations

Rose strongly wishes that they **jfaddlu flus biex jkunu jistgħu jsiefru waħedhom biex jerggħu jiskopru r-relazzjon tagħhom bħala kopja**. Similarly, Charlie wishes that they **jerġa’ jibda jgħix u jsiefru; u nerggħu nesperjenzaw freedom,** said Charlie enthusiastically. **Forsi xi darba, nerggħu nkunu attivi fil-komunita’,** Charlie said, hopeful. It-tfal qed jikbru, irridu ngħatuhom l-ispazju biex jsibu their way too, **both in terms of jobs and anke personal lives, li jkunu indipendenti, u jafu xi jridu, u eventwalment li jsibu job li they like, u jaraw minn hemm ‘l quddiem għalihom infushom.**

Rose wishes **li Simon li jkun fully independent imma happy, l-ikbar inkwiet tiegħi hu meta niġu nieqsa, jew jiġrilna xi ħaġa.** Rose shared that thanks to Simon, she **tgħallimt li mhux worth it noqgħod ninkwieta ħafna fil-ħajja.** She feels that **meta jkollok tfal bħal tagħha, jiġu l-ewwel, u inti tiġi l-aħħar.**

Rose advocates for **aktar awareness dwar l-autism.** At the end of the interview, she strongly proposes; **servizz jew minn NGO jew sussidjat mil-gvern fejn tfal bl-autism jistgħu joqgħodu filgħaxija sakemm, eżempju, il-ġenituri tagħhom jmorru għal kafe' jew biex jgħidu kelma, jew biex jmorru jieħdu pizza** couple can enjoy a few hours of quality time together, knowing that the children are cared for by trained personnel. She firmly believes that the **CDAU huwa l-fulcrum** to bring awareness or promote services, as every family has to start from there. Charlie adds that **aktar servizzi bħal CDAU huma neċċessarji**, **għax with the current service, trid tistenna sitt sa disa' xhur sakemm jibda il-programm, u t-tifel jilħaq jikber sena oħra.** He believes that **dawk li jiddependu kompletament mis-servizzi tal-gvern ħa jaqgħu lura**. As a result, Charlie feels that families of children with autism require financial family planning support as there are a lot of out-of-pocket expenses, especially for **kopji żgħar b'loan**. He also mentioned the need for a **pathway** that guides families throughout the journey of ASD.

Appendix Q

Email Sent to the Participants to Review the Transcript

Dear _______________,

Trust this email finds you well.

I am currently working on the results chapter. As part of the methods of verification, I greatly appreciate it if you would be kind enough to go through the interview transcript and provide me with feedback, especially if you are not in agreement with the content. If you agree, I will forward the transcript for your perusal.

Once again, thank you for your participation; your contribution was vital to this research. Once you receive the transcript, please feel free to forward me any feedback, comments, and suggestions.

I look forward to hearing from you.

Many thanks and kindest regards,

Frida Mangion

Appendix R

Poem

The Aftermath of ASD

By Marthese, Martin, Mark, James, Rose, Charlie, Nicholas, and Simon

It could have been a worse bunch of cards

Ooo but there is a problem

‘we think he has autism,’ the blunt British insist

questions emerge,

but could it be the MMR?

….

the SHOCK,

desperately in search of meaning

parents ventured into the outside world

scarce resources they met

yet society stared

without any manual in hand,

they had to deal with what they had in front of them

difficult tantrums

the yelling … the shouting … the blows … the crying

TRAUMA

and the list persists

HE hit my mom

HE attacked my wife

due to depression, the mother believed

a punishment indeed

easy prey for bullying, he utterly insists

overwhelmed in disbelief

not different, not stupid, but cleverer than you think

we search for friendships with whom we can link

we are survivors, he claimed

Thank God that united we remained

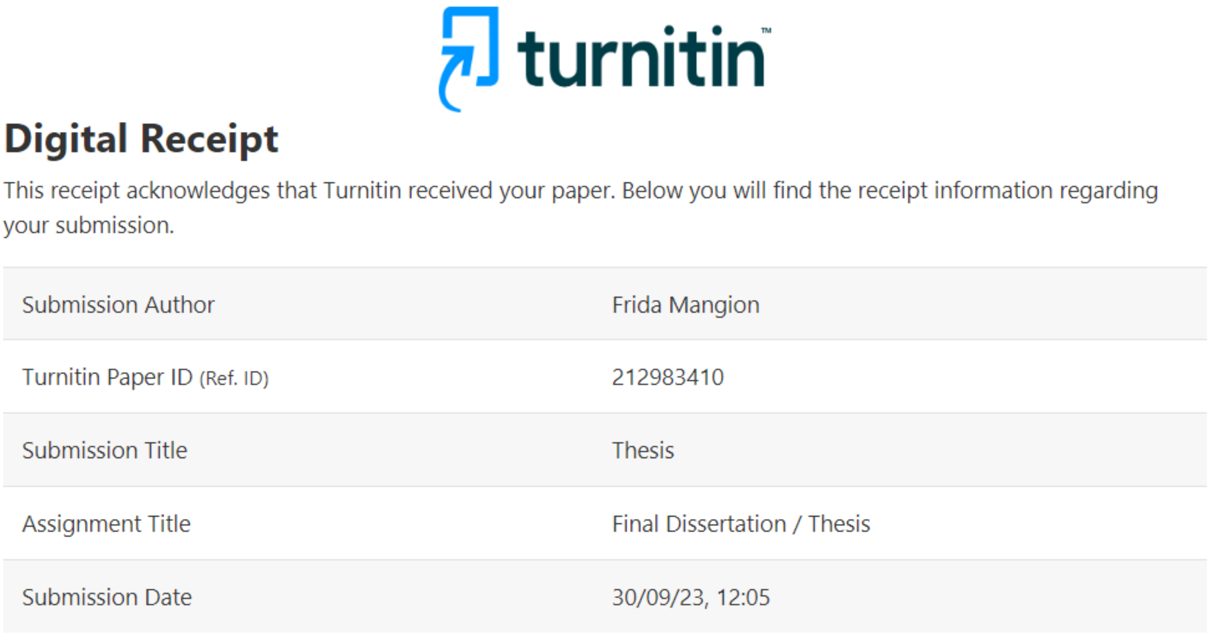
This made me who I am today

They resiliently integrated ASD into their routine

UNDERSTANDING is what we seek!

Appendix S

Turnitin Digital Receipt



Digital Receipt

This receipt acknowledges that Turnitin received your paper. Below you will find the receipt information regarding your submission.

Submission Author	Frida Mangion
Turnitin Paper ID (Ref. ID)	212983410
Submission Title	Thesis
Assignment Title	Final Dissertation / Thesis
Submission Date	30/09/23, 12:05