

**A father's tale: stories and experiences of
fathers whose children have been diagnosed
with Autism Spectrum Disorder.**

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**A research study submitted in partial fulfillment of
the requirements of the University of East London for
the Professional Doctorate in Educational and Child
Psychology**

MAY 2013

STUDENT DECLARATION

This work has not previously been accepted for any degree and it is not being concurrently submitted for any degree.

This research is being submitted in partial fulfillment of the requirements of the Doctorate in Educational and Child Psychology.

This thesis is the result of my own work and investigation, except where otherwise stated. Other sources are acknowledged by explicit references in the text. A full list is appended.

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Louis John Camilleri

May 2013

ACKNOWLEDGEMENTS

A very special note of gratitude and appreciation goes out to all those fathers who have kindly participated in this research. This study would not have been possible without them. This research is dedicated to them and their families.

I would like to thank Dr. Mary Robinson, my Professional and Academic Tutor at the University of East London, for the guidance, support, and encouragement that she has supplied throughout all the three years of the Professional Doctorate. Her input, expertise, and support were invaluable.

I would also like to thank Dr. Laura Cockburn, my second tutor at the University of East London. Her help, knowledge and expertise were greatly appreciated.

I would also like to acknowledge and greatly thank Dr. Daniela Mercieca and Dr. Duncan Mercieca for their feedback, support and encouragement. Their ideas, critique and feedback were extremely useful and important for the completion of this study.

Thank you also to Mr. Stanley Zammit, for the support that he offered all throughout my studies.

Acknowledgement and thanks also goes to my partner, Maureen, my mother Doris and my father Charles, who have supported me during the many difficult moments of this research and all throughout the course of the Professional Doctorate.

ABSTRACT

Very little has been researched about the experience of fathering a child with a diagnosis of Autism Spectrum Disorder (ASD). An explorative narrative research design was used to gain a better understanding of how fathers (N=10) experience their children who have been diagnosed with ASD, and thus answer the question: “What stories do fathers of children with ASD tell about fatherhood and about their fathering experiences?” Data to inform this study was gathered through in-depth and unstructured interviews. Each of the fathers’ narratives was storied using Clandinin and Connelly’s (2000) notion of human experience that is defined in terms interaction, correct, continuity, and situation. The resulting narratives were written in the ‘third-person-omniscient’. This phase of the study was followed by a ‘commentary phase’ that sought to describe the connectedness between the 10 narratives storied. The study illustrates how the challenges fathers of children diagnosed with ASD encountered affected their fathering experiences and their notions of fatherhood. The study also sheds light on the aspirations, hopes, dreams, concerns and reservations these fathers have with regards to the future of their children.

Key words: *Narrative Inquiry; Narratives; Fathers; Fathers of children with ASD; Autism.*

Word Count: 40,525 words

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CHAPTER 1 – INTRODUCTION

1.1. Introduction

This thesis reports on a study that sought to describe the experiences of fathers of children diagnosed with ASD. The study used a narrative method of inquiry, where narratives were used to gain a better understanding of the fathers' experience. The “narrative” method used in this inquiry did not only influence the findings of the study, but also influenced the whole process of the inquiry.

This chapter will provide an introduction to the study and will also provide an overview of the context where the study was carried out. It will also present a brief definition and overview of autism in the Maltese context. Consequently, my motive, my position and the rationale for pursuing this study will be presented. This will be followed by an overview of the key theoretical perspectives that this study draws upon.

1.2. The context of Malta

This study was carried out in Malta between 2011 and 2013. For this reason, this section will focus on contextual information regarding Malta, which could be useful for the reader to better understand the system in which the fathers, who participated in this study, lived in during the process of this study.

Statistics from the National Statistics Office (NSO, 2012) indicate that today's population in Malta is 416,110 (NSO, 2012). The employed population in Malta is 168,730. According to the NSO (2012), the “challenges to the Islands' economy are the relatively small domestic market and the disadvantages brought about by insularity” (p. iii). These factors, particularly insularity, are noteworthy issues for the context of this study. Statistics from the National Statistics Office (NSO, 2012) also indicate that 43,503 families in Malta receive “Child Allowance” benefits, whilst 801 families receive a “Disabled Child Allowance”. Education in Malta consists of pre-primary, primary, secondary, post-secondary and tertiary stages. Compulsory education in Malta starts at the age of 5 years, and spans up to the age of 16 years.

Education is provided by the state from the pre-primary stage (3-5 years of age) up until the tertiary stage (18+ years of age).

In Malta, children diagnosed with ASD generally attend mainstream education. Ever since the 2005 educational reform, called '*For All Children to Succeed*' (Ministry of Education, Youth & Employment, 2005), there has been a strong focus on Inclusive Education. Educational Services that are available in Malta that see to the needs of children diagnosed with ASD are: INSPIRE Foundation, Equal Partners Foundation, Malta Autism Centre, and Department for Student Services (DSS). The Ministry of Education provides Educational Psychology (EP) services at the School Psychological Service (SPS), and other services related to education at DSS. The Ministry of Health provides the services of Clinical Psychologists, Pediatricians and other health services at the Child Development Assessment Unit (CDAU). Both units mentioned (SPS & CDAU) are involved with identifying ASD and also with providing support and guidance to parents and their children. However, the constantly increasing demands placed on both services make it difficult for the organizations to see to the identification of the condition and also provide adequate support for the children and families (Dalli, 2013).

1.3. Autism

“Autism is a life-long developmental disability that impinges on how an individual interacts with other people” (National Autistic Society, 2013). The term “Autism” is generally associated with a phenotype consisting of “aloofness, with limited or absent communication, and stereotypical movements and interests” (Steyaert & De La Marche, 2008, p. 1092). The DSM-IV (American Psychiatric Association, 2000) classification system describes the ‘symptomology’ of Autism in terms of a triad: impairment in social interaction, impairment in communication, and restricted imagination (manifested by inflexible and repetitive patterns of behaviour and interests). Cashin and Barker (2009, p. 191) postulate that this description, referred to as ‘The Triad of Impairment’, focuses on typical behavioral manifestations observed in Autism. They argue that this ‘traditional’ triad does little to inform therapy, and propose the “The Cognitive Processing Triad of Impairment” (Cashin & Barker, (2009, p. 191). This consists of: visual processing of information; difficulties with

thinking abstractly; and deficits in theory of mind. Both of these ‘triads’ are central to the construct of Autism (Cashin & Barker, 2009).

The terms Autism and Autism Spectrum Disorder (ASD) are often used interchangeably in literature. The use of the term ASD is sometimes used along with, and even instead of, the term Pervasive Developmental Disorder (PDD). This, in turn, has led to a great deal of “diagnostic ambiguity” (Steyaert and De La Marche, 2008, p. 1092). The term ‘spectrum’ refers to the broad range of abilities and impairments children with ASD display. Thus, Autism Spectrum Disorder is used as a generic term to describe individuals who have PDD, Autism or autistic type features (Steyaert & De La Marche, 2008). In this study, the terms Autism (or autism) and ASD have been used interchangeably.

1.3.1. Autism in the context of Malta

In an article published on World Autism Awareness Day in 2012, in one of Malta’s leading online newspapers, the president of the Malta Autism Parents Association commented:

“20 years ago, this condition was not diagnosed unless a person was having severe difficulties. At times, communication difficulties were a more common diagnosis. But in this day and age, there has been a lot of information and studies on autism... But having your son diagnosed with autism isn't a walk in the park... it's highly stressful to learn that your child has this condition... One of the most difficult and stressful times for a family is when they first learn that their child has autism. It's something very hard to accept, which is met with denial, but once accepted, things start to seem a little bit easier and the child can benefit much more since.” (Barry, 2012, Retrieved from <http://www.maltatoday.com.mt/>).

There are no studies or official statistics that describe the prevalence of ASD in Malta. Yet, it is estimated that the statistics in Malta are similar to worldwide statistics: i.e. 1 in every 100 children, with males more likely to be born with this condition than females (Barry, 2012). In Malta, trained professionals from the fields of pediatrics, psychology or psychiatry generally identify the condition. Educational Psychologists (EPs) are also involved in diagnosis. Their input is particularly important in light of the advice that they can provide with regards to the child’s educational needs.

With regards to the identification of ASD in the Maltese context, there is no single assessment tool that professionals use. Rather, there are a number of tools and checklists that are used together with observation and consultation. Consequently, EPs make recommendations for intervention programmes and provision of support, including “statementing”. Statementing is the process through which a child’s needs are recognized and appropriate support outlined. Furthermore, the ‘statementing’ process in Malta also involves the allocation of a Learning Support Assistant (LSA). Psychologists, Psychiatrists and other professionals, such as Occupational Therapists, Pediatricians, and Speech Language Pathologists, usually work together when trying to determine if a child meets the criteria for ASD. However, there is no official protocol or policy that guides professionals in the diagnostic process.

1.4. My story

Autism was once a condition that used to make me feel uneasy. The ‘uneasiness’ was not caused by the atypical behaviors observed. Rather, it was due to the vagueness and ‘mystique’ that surrounded the condition. Before I ever met an individual with ASD I did not know what the term actually meant. What did it mean to ‘live in a world of your own’? What did it mean to be ‘unaware’ of what was going on around you? I remember listening to lecturers during my undergraduate studies describing children with autism in this manner: as being aloof, and as living in parallel worlds. In 2006 I started working in direct contact with children diagnosed with ASD. This is when I realized that what I was told about children with autism was only partially true. The years spent working with ‘autistic’ children led me to come up with my own notion of autism. For me, autism was a different way of life: it seemed like a reaction to conventional rules of social interaction. For me, children with autism were special children with a unique way of seeing the world.

The experience of working with children with ASD taught me a lot of things about autism. It helped me comprehend the distinctiveness of the condition as well as appreciate the unique and extraordinary children that I worked with. Whilst working with these extraordinary children I had the opportunity to meet their mothers and fathers on a daily basis. The parents that I worked with were all concerned and resourceful people who were committed wholeheartedly to their children’s wellbeing.

What always fascinated me was the eagerness and enthusiasm with which they met their children at the conclusion of the sessions, even if their children were not as enthusiastic to see them.

Even though fathers were not always as ‘present’ as mothers, they were always there to accompany their children during meetings and other events. Some fathers even seemed to have taken up their children’s day-to-day responsibilities. As a male, I always wondered what fathers of children with autism went through. I was always curious to learn about their experiences. When talking to fathers about their children’s progress I asked myself; what are they actually thinking? What is going through their minds? How are they feeling about their children’s condition? How is the condition affecting them? My work as a Trainee Educational Psychologist (TEP) at School Psychology Services made these questions even more pertinent, as I found myself engaging in consultation with both mothers and fathers of children with autism more frequently. These questions were important for the formulation of the design of this study. These questions, my wish to learn about fathers’ experiences, and my wish to further help the families of children with autism, are what led me to pursue this study.

1.5. Study Rationale

Notwithstanding my interest in the subject, a question that I asked at the beginning of the study was: “why research fathers of children with ASD in the first place? The answer could be found in Blankenhorn’s (1995) claim that men, as fathers, could offer something very unique to their children. Notwithstanding this, and the increased interest in researching fatherhood that is evident in the recent decade (Flippin & Crais, 2011), “we seem to know far less about fathers than we know about mothers” (Dowd, 2000, p. 2). Literature seems to indicate that fathers could make positive contributions towards a “child’s language and symbolic play development” (Flippin & Crais, 2011, p. 24). Shannon, Tamis-LeMonda, London & Cabrera (2002) postulate that fathers may also play an important role in the development of ‘atypically’ developing children, and especially with children who encounter difficulties with communication and social interaction. Such claims seem to warrant further research on a father’s involvement in the rearing of children diagnosed with ASD.

Osborne, McHugh, Saunders, & Reed (2008) maintain that involving fathers may be incredibly important, particularly for children with ASD. Father involvement may be important not only from a developmental perspective, but also from a ‘macro-perspective’. Osborne et al. (2008) argue that father involvement may aid in reducing stress levels of both parents and create greater family cohesion, which in turn could have a positive effect on the child with ASD. Researching fathers and their experience could be seen as a potentially beneficial activity, particularly in light of the fact that research seems to indicate that the time fathers are spending with their children appears to be on the rise (Flippin & Crais, 2011). This trend could be due to many factors. One of these could be “the loss of a disproportionate number of jobs by men when compared to women, partly due to the recent economic crisis and partly due to an increase in women earning advanced degrees” (Garfield & Isacco, 2011, p. 32). Another factor could be the increased diversification in family structures and a consequent need for parents to shed archetypical gender roles and transition to more co-parenting cooperative roles (Tremblay & Pierce, 2011).

Thus, as a Trainee Educational Psychologist constantly working together with both mothers and fathers of children diagnosed with ASD, I felt that it was important to develop further understanding of a father’s experience. Learning about how a father experiences his children and their diagnosis, as well as learning about what fathers need and want, could help with identifying strategies that could benefit the father, the child and the whole of the family. Thus, this study, which focuses on the narratives of fathers of children with autism, was deemed useful to the current socio-political context of Malta, where discussions about men and their involvement in family lives continue to occupy political debate. This study was also deemed useful to EPs, to administrators at the School Psychology Services, as well as to other professionals who work with children with autism and their families, as it focuses on understanding the perspectives of key stakeholders in the children’s lives. Furthermore, this study was seen to be important particularly in light of the relative gap that there exists in research that regards ‘fathers of children with ASD’, and could thus be used to aid in the development of ‘father friendly’ services and policies.

The following chapter will focus on identifying literature that focuses on fatherhood, and on the available literature that focuses on fathers of children with ASD.

CHAPTER 2 - REVIEW OF LITERATURE

2.1. Introduction

This chapter will present a literature review undertaken between September 2012 and May 2013, when the final report of this study was submitted. The review focuses on identifying relevant literature concerning the subject matter of fathers of children diagnosed with Autism Spectrum Disorder (ASD). The literature search is systematic (i.e. exhaustive and comprehensive) and critical (i.e. analyzing the literature from various perspectives). This review is fundamentally a scientific activity (Bem, 1995) aimed towards systematically and explicitly producing a methodical reproducible search of contemporary knowledge on the subject matter (Fink, 2005).

2.2. The structure of the literature review

This literature review is structured in a way that is aimed towards understanding better how a child and a diagnosis, together with the difficulties associated with ASD, could affect a father's experience of fatherhood. The review starts by providing a summary of the theoretical perspectives regarding a father's involvement with his child, as well as theoretical perspectives regarding the potential impact a father could have on his child and on the child's various surrounding ecological levels. Consequently, overviews of two systematic searches are presented. The objective of the systematic searches was to help explicate various aspects of the dyadic relationship that could exist between fathers and their children.

The first search (SEARCH-1, Figure 2.1. p. 21), focused on the literature concerning fatherhood. This part of the review was conducted with the intention of identifying literature relating to fathering and fatherhood. The second search focused on research on fathers of children diagnosed with ASD. This systematic search of literature (SEARCH-2, Figure 2.2. p. 25) was conducted with the intention of gaining insight into this particular target population: fathers of children with ASD. This search was also intended to help answer questions such as: "are fathers of children with ASD under-researched?" and "why should fathers of children with ASD be researched in the first place?"

2.3. A father's involvement with his child – key theoretical perspectives

Researcher from the University of Illinois at Urbana-Champaign Joseph Pleck (2007, p. 201) proposes the notion of 'Ecological-Parental Capital' to describe an integrative model through which the importance of father involvement could be explicated. Pleck (2007) based his model on Bronfenbrenner's (1979, 1986) 'Ecological Theory of Proximal Process' and the 'Social Capital Theory' (Coleman, 1988, as cited in Pleck, 2007). Bronfenbrenner's (1979, 1986) notion of numerous 'ecological' levels mutually influencing the child's development (i.e. the father-child dyad; the father-mother dyad; and the father-mother-child triad) sheds light on the possible catalytic position held by fathers. Thus, the increasingly complex interactive patterns between the child and the father are what could further 'propel' the development of the child (Pleck, 2007).

Alternatively, Social Capital Theory (Coleman, 1988, as cited in Pleck, 2007) proposes 2 different types of 'capital' that fathers could provide their children with. These are financial capital and social capital. Financial capital could take the form of food, shelter and education. Social capital, on the other hand could consist of paternal behaviors that promote a child's "psychosocial development, school readiness and educational aspirations" (Pleck, 2007, p. 198). Social capital could also consist of providing the child with an introduction to the fathers' connections to the community (Pleck, 2007). Pleck (2007) termed his framework "integrated ecological-parental capital theory of paternal influence" (p. 201). Such a model sheds light on a father's potential involvement in the multiple domains of a child's life.

According to Brown, Mangelsdorf and Neff (2012), one of the most important theoretical frameworks for understanding a father's involvement with his children is that of Lamb, Pleck, Charnov, and Levine (1985). Lamb et al. (1985) put forward a tripartite conceptual model that describes paternal involvement as consisting of three separate constructs: accessibility, responsibility, and interaction. Brown et al. (2012, p. 422) define accessibility, responsibility, and interaction in the following way: 'accessibility' is seen as the extent that fathers are available, both physically and psychologically, to see to their children's needs; 'responsibility' is the degree of

initiative fathers take to see to the child's welfare and care; 'interaction' is defined as the engagement, both direct and indirect, between a father and his child.

With regards to the nature and structure of paternal involvement, Pleck (1997, 2004, 2010) argues that the tripartite model described above overlooks certain aspects of paternal involvement that could be important for positive developmental outcomes. Pleck (2004, 2010) operationalized further the tripartite model and argues that the focus of the 'engagement' construct should be shifted from 'time spent' to 'participation in positive activities'. Furthermore, Pleck (2004, 2010) postulates that paternal warmth and qualitative responsiveness are other important aspects of paternal involvement.

2.4. A father's identity – key theoretical perspectives

A question that is very pertinent to this study is that of 'what does it mean to be a father?' One generally assumes that a man becomes a father when he has his first child. On one hand, from a biological perspective, such a notion is hard to debate. On the other hand, the psychosocial implications of the term are less clear and leave a lot of room for debate. Eggebeen & Knoester (2001) remark on how "in the flurry of research on fathers, what is forgotten is that fatherhood may have consequences for men" (p. 381). Eggebeen & Knoester (2001) postulate that if fatherhood is seen solely as a biological and statistical phenomenon this could lead towards overlooking the transformative aspects brought about by the experience of fatherhood, as well as the ensuing implications and responsibilities.

Litton Fox & Bruce (2001) propose 'Identity Theory' as a means to explain a man's transition into fatherhood. 'Identity Theory' (Litton Fox & Bruce, 2001; Stets & Burke, 2000) puts forward the notion that the self is made up of a number of identities that are structured by role relationships. Some relationships, e.g. father-child relationships, are more important to one's innermost sense of self than others and are thus "organized hierarchically" (Litton Fox & Bruce, 2001, p. 396). An individual's hierarchy is reflected in the degree of commitment to an identity. This, in turn, is demonstrated by the behaviors associated with that identity with which an individual is seen to engage (Litton Fox & Bruce, 2001).

When applied to fatherhood, the theory suggests that a key element in the father identity is the extent to which a father identifies with the status and role associated with being a father and consequently engages in behaviors which are a function of his ‘father-identity’ (Litton Fox & Bruce, 2001). The relational nature of an individual’s identity implies that a father’s behaviors are also influenced by external social factors. These external social factors, whilst being important in influencing the behaviors a father decides to engage in, also contribute towards shaping a father’s notion of ‘self’ (Stryker, 1987).

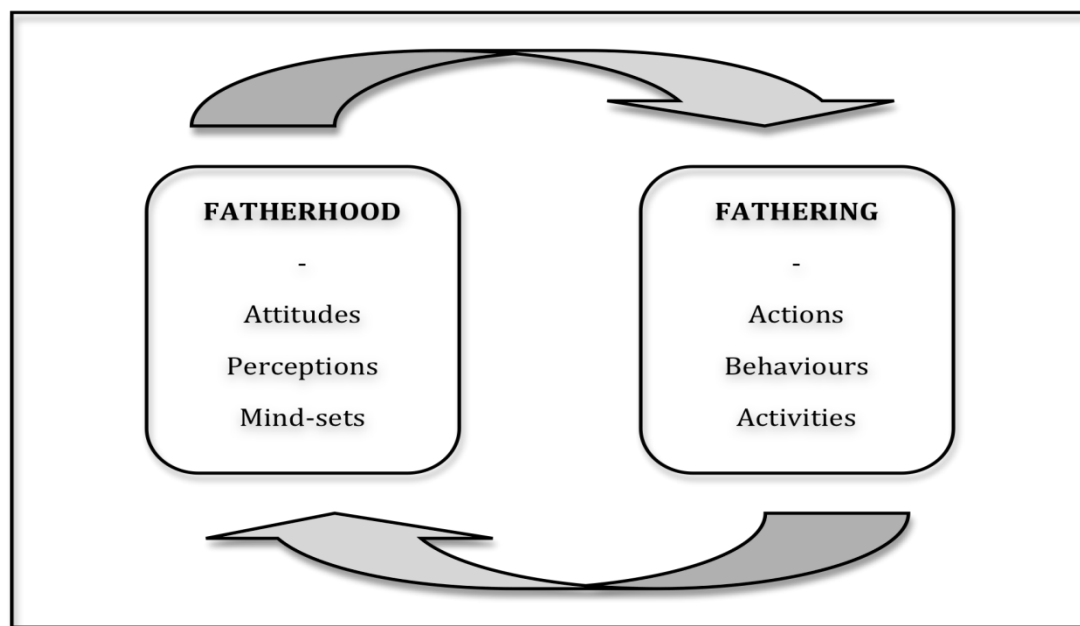


Figure 1.1 - Interconnectedness between the concept of fatherhood and fathering. Adapted from Stryker (1987) and Stets & Burke (2000).

Thus, the core of a father’s identity is the categorization of the self in the ‘father group’, and consequent incorporation into the ‘self’ of the meanings and expectations associated with such a role (Stets & Burke, 2000). Furthermore, ‘father identity’ seems to be influenced by the interconnectedness between ‘fatherhood’ and ‘fathering’ (Figure 1.1). In this case, the term ‘fathering’ focuses on behavior driven aspects of the father identity and is concerned with how men think they should be ‘behaving’ as fathers. On the other hand, the notion of ‘fatherhood’ refers to attitudinal perspectives and is concerned with the status of being a father.

2.5. Fathers' notions of fatherhood and fathering

A literature search based on English-medium and peer-reviewed literature, with a date range of 2002-2012, sought to inquire about the various dimensions of 'fatherhood' and the behaviors associated with 'fathering' (SEARCH – 1, Figure 2.1). The literature search was conducted on PsycARTICLES and PsycINFO databases using the key word 'Fatherhood'.

This search initially identified 218 articles. The objective of this literature search was to gain further insight into research concerning the attitudes and the perceptions of fathers which contributed towards their meaning of fatherhood and consequently towards their fathering attitudes and behaviors. After applying exclusion criteria (Records that were not full-text, peer reviewed academic journals, and studies that did not focus on the fathers' meaning of fatherhood and on their fathering attitudes and behaviors), 6 studies (see Appendix 1) were deemed relevant to the objective of this search (see figure 2.1. p. 21). The following is an overview of these articles, and aims to shed light on various aspects of the process of identity formation for fathers, on a father's perception of the meaning of fatherhood and on the consequences of fatherhood in terms of fathering behaviors.

One of the studies, carried out by Goodsell, Barrus, Meldrum and Vargo, (2010) suggests that 'fatherhood' should be conceptualized in various contexts. In their study Goodsell et al. (2010) analyzed expectant fathers' narratives (N=42, USA). They maintain that notions of fatherhood are susceptible to the effects of space (geographical location and culture) and time (epochs and eras). Furthermore, they postulate that a father's notion of fatherhood is dependent upon the father's context, and is thus very subjective. Researchers suggest work, family, education, religion, and leisure, as some of the contexts that contribute to define a man's notion of fatherhood. They also suggest that such elements or contexts could be in concordance with each other or in dissonance. Thus, Goodsell et al. (2010) use the concept of 'harmony' to explain the dynamic multiplicity of the various contexts of fatherhood and suggest that 'harmony' is the result of how all the various life domains relate to each other.

Duckworth and Buzzanell (2009) explored fathers' (N=18, USA) interviews and compared them with previous data that was collected in earlier studies. In their study,

they used a qualitative, explorative, research design with semi-structured interviews as their primary data collection tool. Thus, they strived to gain a better understanding on how fathers balanced work responsibilities and family responsibilities. Duckworth and Buzzanell's (2009) study indicates men's description of work-family balance as a negotiation between work and life. The study also indicates that the fathers interviewed tended to prioritize family over work. It also emerged that many of the fathers believed that work was necessary for them to care for their family. With regards to their notions of 'working fathers' and 'fatherhood', the findings of this study indicated that for the men interviewed, fatherhood represented "webs of responsibilities towards others" and "community engagements" (Duckworth & Buzzanell, 2009. p. 558). Furthermore, "problem solving constituted one of their main activities" (Duckworth and Buzzanell, 2009. p. 558).

A small-scale longitudinal study provides another perspective on fatherhood. This qualitative longitudinal study (Miller, 2010) focused on men's (N=17, UK) experiences of first-time fatherhood. It sheds light on the hopes and intentions men have with regards to fathering. The study interviews fathers before and after the birth of their first child, and thus investigates how men's 'fathering intentions' are actually practiced (Miller, 2010). Findings of this study suggest that "paid work, hours spent in the work place, ideals of hegemonic masculinities and associated discourses continue to frame, in significant ways these men's experiences of becoming fathers" (Miller, 2010. p. 376).

However, Miller's (2010) study also provides evidence of increased 'nurturing' involvement of first time fathers with their children when compared with previous fathers' generations (Miller, 2010). Furthermore, central to the study's findings is the participant's great sense of achievement when becoming fathers. Miller (2010) postulates that the shift away from fathering identities that revolve around hegemonic masculinities, whilst being very gradual, is constant, and is shifting towards fathering practices that are more caring.

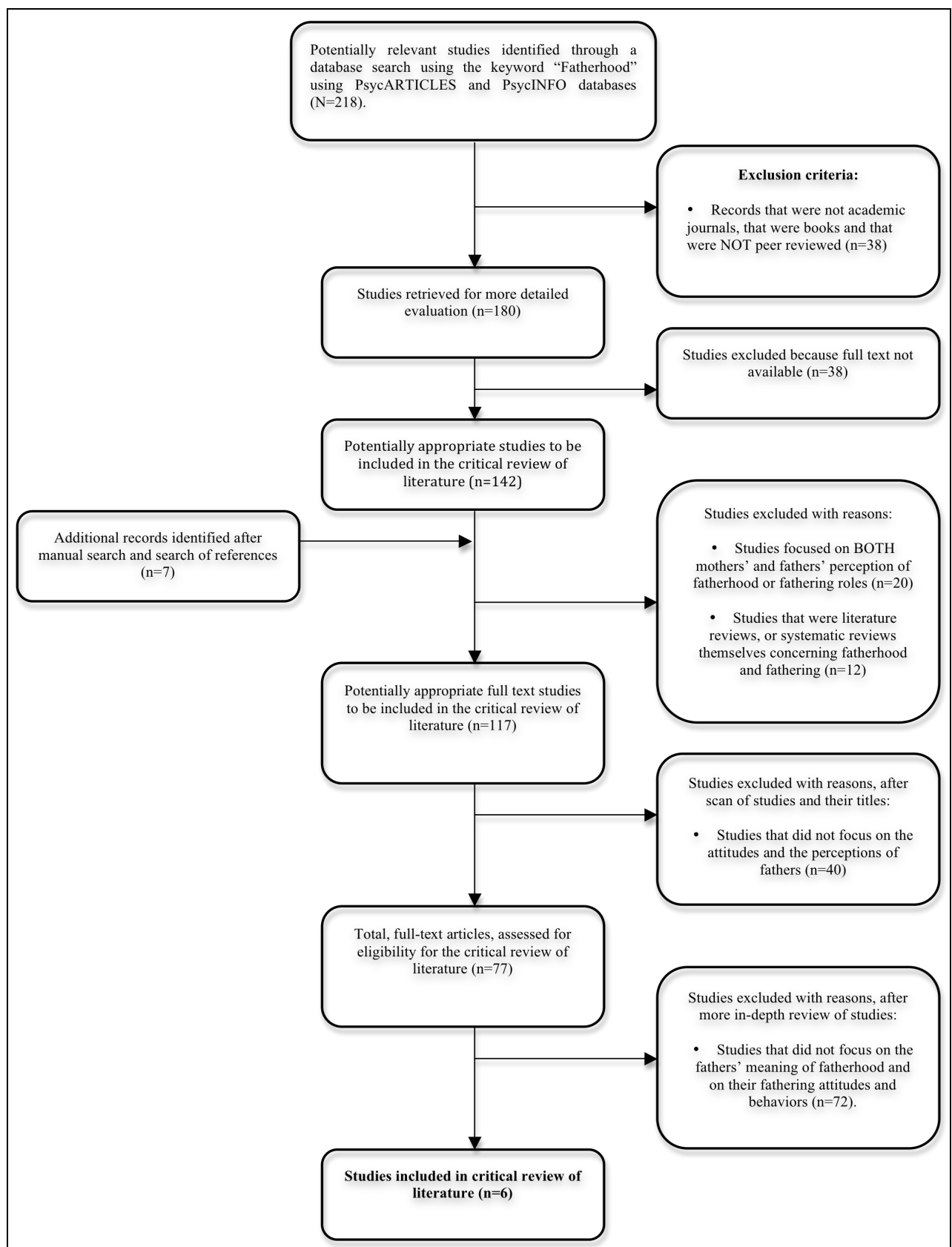


Figure 2.1 - Overview of SEARCH-1

Shirani and Henwood (2011), researchers from Cardiff University School of Social Sciences, also used a qualitative longitudinal design for their study. Their explorative study was aimed towards better understanding the relationships that fathers have with their family. They drew on two case studies of men – middle class, average age 30 years old – who became fathers for the first time in 2000. The study's findings indicate that the concept of 'caring and involved fatherhood' was seen as a characteristic of a 'good father'. Nevertheless, the study also indicates that various life circumstances conditioned the way the fathers involved themselves with their children. The study seems to indicate that the fathers had a desire for idleness, in terms of their fathering duties and responsibilities. However, the study also indicates that this desire, to no longer be needed, was seen by men as a 'tabooed' subject. Thus, the participants seemed to have reframed what they deemed to be threatening for their 'psyche' through the use of humor and laughter (Shirani & Henwood, 2011).

Finn and Henwood (2009), researchers from the University of East London and from Cardiff University respectively, sought to explore the "identificatory positionings" (p. 547) relating to first-time fatherhood present in men's discourses. The study involved interviewing participants, using semi-structured interviews, on three occasions: when their partner was 5-8 months pregnant; when the baby was 2-4 months old; and when their child was 5-9 months old. They utilized a qualitative design to thematically analyze the interviews held with the participants who were men (N=30, UK) aged between 18 and 40 who were first time fathers. The interviews were conducted between 1999 and 2000. Consequently, 3 focus groups with some of the fathers (N=13) were conducted.

The study highlighted the intricate interplay that exists, in father's talk, between the modern father role, who is more present and nurturing, and the traditional father, who has "a specific, differentiated, and virtuous role" (Finn and Henwood, 2009, p. 559). The authors, however, suggested that the men interviewed tended to talk about espousing a 'hybridized' fathering identity that included both nurturing and 'guidance' aspects. They also commented that men, "whilst commonly constructing their role as not for mothers, nonetheless the imagined figure of virtue and the motherly-father identification were intertwined" (Finn & Henwood, 2009, p. 559). In this case, Finn and Henwood (2009) defined the 'motherly-father' identity as gender

nonconformist, which entails performing responsibilities that could be seen as typical motherly chores, whilst also being comfortable with expressing thoughts and feelings.

Eerola and Huttunen (2011), researchers at the Department of Education, University of Jyväskylä in Finland, sought to explore the contemporary narratives and storylines of fatherhood as told by young Finnish fathers (N = 16, Finland). Participant men were first-time fathers aged 23-29 years (22-27 years at the time of the birth of their child). Eerola and Huttunen (2011) used narrative inquiry, in which narratives were understood as constructors of knowledge, to come up with three different narratives: the modern; the transitional; and the postmodern narratives of fathering.

The modern narrative was characterized by differentiated parental roles where the father is primarily the family's breadwinner and participates in the children's upbringing by taking up the role of the mother's assistant. The transitional narrative of fathering is characterized by the father's search for his role and is thus consisting of a father's endeavor to engage with a family-centered life-style. The postmodern narrative is characterized by the father's full participation in family planning, and engagement in nurturing and care-giving activities (Eerola and Huttunen, 2011).

In summary, the literature referenced in this section seems to indicate that fatherhood is a multifaceted phenomenon. Eerola and Huttunen's (2011) account of modern, transition and postmodern narratives serve as a sound platform from which to understand better the concept of fatherhood and its related behaviors. A father's narrative account could be conditioned by the situation of the observer (father) vis-à-vis his family, his neighborhood, his education and his religion (Goodsell et al., 2010), amongst many other variables and contexts.

Duckworth and Buzzanell (2009) look into the context of 'work' and its relevance to such narratives. Work could be seen as the factor which enables a father to take care of his family and consequently enable him to be placed in the midst of the various problem solving scenarios he finds himself in (Duckworth & Buzzanell, 2009). Such behaviour is indicative of hegemonic notions of masculinities and associated discourses (Miller, 2010). Miller (2010) suggests that fathers could find themselves at the center of a tug-of-war between such hegemonic notions, also related to the providers' role, and notions of 'involved and nurturing' fatherhood, which are

also seen as important aspects of a good father. In this regards, Finn & Henwood (2009) talk about the notion of ‘hybridized’ responsibilities that depicts fathers as nurturing and guiding providers.

In conclusion, Goodsell et al., (2010) propose that fatherhood identity could be a product of the harmonious configuration of fathering behaviors across various contexts. However, Duckworth and Buzzanell (2009) argue that the focus of a father’s world is his family, which, according to them, provides a father with a meaning and a reason for living. What is noteworthy in this review is the lack of literature that takes into consideration the impact of having a child with developmental difficulties on a father’s notion of ‘Fatherhood’.

Thus, the next section will focus on the possible impact of having a child with ASD on fathers.

2.6. Does ASD influence fathering?

A systematic literature search (SEARCH 2, Figure 2.2) based on English-medium and peer-reviewed literature, with a date range of 1992-2012, was conducted on PsycARTICLES, PsycINFO, Academic Research Complete, Education Research Complete and ERIC databases using the phrases: ‘Fathering children with ASD’, ‘Fathers of children with ASD’.

The literature search was conducted with the intention of gaining further insight into the experience of fathering a child with ASD. It was also aimed at obtaining insight into the research that has been conducted regarding the subject of “fathering and fatherhood of individuals who are fathers of a child diagnosed with ASD” in the past 20 years.

After applying exclusion criteria (Records that were not full-text, peer reviewed academic journals; studies that were not concerning the experiences of fathers of children with autism; and studies that were not relevant to the research question), 25 studies were deemed relevant to the objective of this search (see Figure 2.2. p. 25).

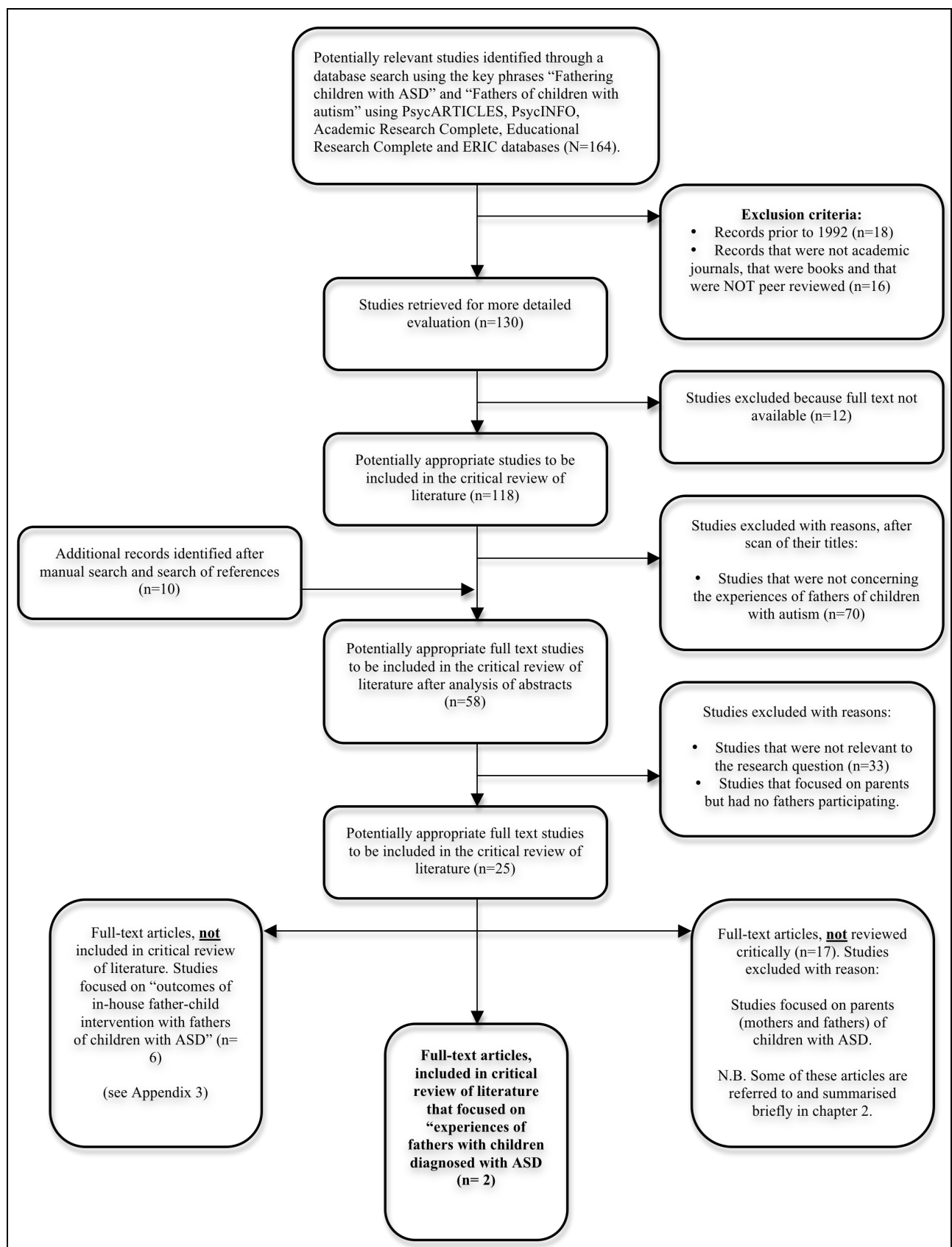


Figure 2.2 - Overview of SEARCH-2

Out of these 25 articles, a total of 2 articles (see Appendix 2) focused specifically on fathers of children with ASD. These articles will be critically reviewed in the coming sections. 6 of the 25 articles focused on in-house training for fathers of children with ASD (see Appendix 3). 17 of the 25 articles did not meet the inclusion criteria of “studies that focused on the effects of a child’s diagnosis of Autistic Spectrum Disorder on fathers”. These studies focused on parents, i.e. mothers and fathers, of children diagnosed with ASD, and on stress, mental health, positive experiences and coping of parents of children with ASD. However, in view of the fact that these studies also included fathers in their sample, and because they provided more contextual understanding on the experience of fathering a child with ASD, the key findings of these studies will be briefly summarized in the following section.

2.6.1. Parents of children with ASD

The studies summarized in this section seek to explore the experiences of parents of children with ASD. The studies illustrate how the diagnosis of ASD could be a cause of stress, ‘intrude’ on family life, and also impinge on the parents’ mental health. The literature identified seems to indicate that parents of children with ASD feel that their lives have been affected in various ways by ASD.

A study conducted by Hutton & Caron (2005) sheds light on the impact of the news of a child’s diagnosis on parents. Parents of children with ASD seem to meet their child’s diagnosis with an array of feelings (Hutton & Caron, 2005). Some seem to meet the diagnosis with a reaction of grief and loss, whilst others meet it with shock and surprise. Occasionally, some parents’ reaction to their child’s diagnosis is also that of self-blame (Hutton & Caron, 2005). Yet, the news of the diagnosis is only a small aspect of parents’ experiences. With reference to this, Cullen & Barlow (2002) maintain that autism “dominates the lives of parents and impinges on the whole of their family life” (Cullen & Barlow, 2002, p. 35).

In their study, Cullen & Barlow (2002) report on how parents of children with ASD feel that their family functioning was disturbed by the difficulties related to their children’s condition. They also report on some of the difficulties that the parents could encounter, namely: “lack of communication and social interaction, the constant demands, the absence of understanding of others’ needs and emotions, tantrums and

the lack of independence” (Cullen & Barlow, 2002, p. 39). Consequently, due to such 24-hour demands, most of the parents felt “isolated, frustrated and bewildered” (Cullen & Barlow, 2002, p. 35). Cullen & Barlow (2002) suggest that parents of children with autism seem to “be living in ‘another world’ removed from wider society” (p. 43).

Lecavalier, Leone and Wiltz (2006) postulate that behaviour problems and lack of prosocial behaviors of autistic children are strongly associated with parental stress. Furthermore, increased financial burdens and restrictions in their social lives seem to significantly increase their levels of stress (Lecavalier, Leone & Wiltz, 2006). According to Baker-Ericzen, Brookman-Frazee and Stahmer (2005), possible sources of stress could also be one or a combination of the following: “the child's uneven intellectual profiles; pervasive disruptive behaviors; and long-term care responsibilities” (p. 194).

Tehee, Honan and Hevey (2009) studied the similarities and differences in fathers’ and mothers’ experience of stress. They argue that when compared with fathers, mothers of children with ASD tend to feel more involved in their children’s everyday lives, but also report higher levels of stress. Tehee et al. (2009) maintain that mothers could experience a greater care-giving burden when compared to fathers. In this regard Hastings, Kovshoff, Ward, Espinosa, Brown & Remington (2005) suggest that as a result of the high levels of stress, mothers of children with autism could experience more symptoms of depression, when compared to fathers. Furthermore, Hastings et al. (2005) postulate that “stress and positive perceptions of fathers are directly related to maternal depression” (p. 635).

According to Olsson and Hwang (2001), mothers of children with autism are at an increased risk of suffering from psychological distress and depression when compared to fathers. Olsson and Hwang (2001) argue that this could be because mothers take on more of the practical responsibilities and everyday tasks, which could in turn also involve relinquishing their employment. Similarly to Olsson and Hwang’s (2001) findings, Hastings (2003) maintains that mothers of children with autism report significantly more symptoms of anxiety than fathers (Hastings, 2003). Hastings’s (2003) study indicates that the fathers’ stress could not be conclusively attributed to mothers’ mental health or to the children’s behaviour problems. Hastings (2003)

consequently argues that “factors other than those measured must account for the fathers’ feelings of stress” (p. 235).

The findings mentioned above focus on negative aspects of a parent’s experience that include stress, anxiety and depression. However, there is also the ‘other side of the coin’, and parenting a child with ASD also has positive aspects. Kayfitz, Gragg and Orr (2010) postulate that there is plenty of literature on parents of children with autism, and other related conditions, which focus on the negative aspects of their parents’ experiences. They argue that academics fail to consider that there might also be “positive aspects to raising a child with autism” (Kayfitz et al., 2010, p. 337). Thus, Kayfitz et al. (2010) studied 23 couples from Ontario that were parents of children diagnosed with ASD. Results of this study indicate that when mothers and fathers report lower levels of stress they also report more positive experiences, indicating that a correlation exists between the ‘level of stress’ and ‘positive experience’. Some of the positive experiences reported in Kayfitz et al.’s (2010) study include: “learning through experience of special problems; the diagnosis being a source of strength and family closeness; personal growth and maturity; source of pride and cooperation; and expanded social networks” (p. 240). The findings also report that the “fathers’ positive experiences were negatively related to their partners’ reports of parenting stress” (Kayfitz et al., 2010, p. 237).

In light of Kayfitz et al.’s (2010) study, one could argue that parents’ positive perceptions and experiences could be dependent on how they cope with the stressors that they are faced with. Dabrowska and Pisula (2010) explored the coping styles used by parents of children with autism. The study sheds light on the relationship between coping styles and parental stress. In fact, emotion-oriented coping, which was defined by Dabrowska and Pisula (2010) as a response to stress characterized by “self-oriented emotional reactions, focusing activity on the reduction of emotional tension caused by the stressor” (p. 271), was a major predictor for parental stress in the samples of parents of children with autism and Down Syndrome. On the other hand task-oriented coping, which consists of making efforts aimed at solving the problem through cognitive restructuring or attempts to alter the situation and solve the problem (Dabrowska and Pisula, 2010), was a predictor of parental stress in the sample of parents of typically developing children.

Hastings, Kovshoff, Brown, Ward, Espinosa and Remington's (2005b) study identified four coping strategies that parents of children with autism used. The strategies identified are: "active avoidance coping; problem focused coping; positive coping; and religious/denial coping strategies" (Hastings et al., 2005b, p. 377). Active avoidance consists of actively striving to avoid dealing with the stressor. Problem-focused coping consists of trying to problem-solve, trying to find help, and searching for support. Positive coping consists of thinking positively, of using positive reframing of potentially stressful stimuli, and using positive self-talk. Religious coping consists of dealing with stress through means that include prayer, congregational support, pastoral care, and finding religious explanations for stressors. The study seems to indicate that positive coping strategies are the most effective type of strategies, whilst avoidance and religious coping are the least effective (Hastings et al., 2005b).

Gray's (2006) research sought to investigate the coping mechanisms of parents of children with autism. He also sought to investigate if the coping strategies changed over a time period of 16 years. The first study in 1990 identified a number of coping strategies that the parents used. These were: the use of treatment services; family support; religion; social withdrawal; and individualism. Gray (2006) indicates that, for the parents that participated in the 2006 study, the difficulties encountered and also the way they coped with such difficulties changed. Gray (2006) also reports that parents in the 2006 study cited fewer coping strategies than they had originally in 1990.

According to Gray (2006), the results of the study were reflective of the decrease in emotional distress experienced by the parents in 2006, when compared to when they were interviewed in 1990. Gray (2006) stated; "this could be because most of the children had improved to the point where they were significantly easier to live with, even if they retained many autistic symptoms" (p. 973). Gray (2006) also postulated that in 2006, when the children were mostly young adults, the education and treatment centers available for young adults with autism were not as available.

The following section shall provide an overview of the studies identified in the literature search that focus specifically and solely on fathers of children with ASD.

2.6.2. Fathers of children with ASD

Fathers of children diagnosed with Autistic Spectrum Disorder (ASD) are a demographic that seems to be underrepresented and underresearched (Elder, Valcante, Yarandi, White, & Elder, 2005; Flippin & Crais, 2011; Hartley, Seltzer, Head, Abbeduto, 2012). In 1992, researchers Rogrigue, Morgan and Geffken (1992) claimed that, at that time, fathers had been forgotten in terms of research concerning parenthood, and called upon academics to investigate further their lives and experiences. Rogrigue et al. (1992) also held that, at the time, there was more awareness and knowledge regarding the experiences of mothers of children with autism when compared with that of fathers. Such disparity with regards to research on fathers at the time could be a result of the long-standing and deeply rooted cultural norms that saw mothers taking the primary responsibility for everyday childrearing duties, whilst fathers took more of a bread-winner's role (Nye, 1976; Rogrigue et al., 1992; Konstantareas, & Homatidis, 1992).

The lack of research pertaining to the impact of autism on fathers of children diagnosed with the condition is apparent in this literature search. From this search, only 2 focused solely on fathers and their experience of fathering a child with ASD. The first of the two studies, Rogrigue, Morgan and Geffken's (1992), sought to shed light on the psychosocial adaptation of 60 fathers of children with ASD (n=20), Down Syndrome (DS)(n=20) and normal developing children (n=20). Rogrigue et al. (1992) broke down a complex phenomenon - "psychosocial adaption" - into separate component. They divided "psychosocial adaption" into three domains: interpersonal; family; and socio-ecological domains. The research team administered standardized questionnaires in order to obtain quantitative data with regards to the fathers' perceived efficacy and competency as a parent; the fathers' feelings of frustration, anxiety and motivation with regards to parenting; the fathers' coping strategies in response to the difficulties associated with rearing the children; the fathers' perceived levels of family cohesion; the fathers' perception of the impact of raising their child on family finances and planning; and the fathers' perceived level of social support received. Consequently, multivariate analysis of covariance, using the child's chronological age as the covariate, was conducted with measures that were conceptually related.

The resulting analysis of the data collected led researchers to conclude that fathers of children with ASD experienced more disruption in family planning as well as increased financial burden when compared to fathers of developmentally normal children. However, Rodrigue et al. (1992) reported that “levels of perceived parenting competence, marital satisfaction, and social support were similar to those reported by fathers of developmentally normal children” (p. 258). Interestingly enough, findings indicated that ‘information-seeking’ and ‘wish-fulfilling-fantasy’, i.e. wishing that the stressor would disappear, were used mostly as coping strategies by fathers of children with ASD. The findings of the study also indicated that fathers of sons with ASD or DS “perceive parenthood to be more satisfying than fathers of daughters” (Rodrigue et al., 1992, p. 259).

The findings of the research also indicated that the fathers of children with autism did not report many family adjustment problems (Rodrigue et al., 1992). Researchers argued that the fathers’ perceived lack of ‘family adjustment problems’ could be owing to the fact that whilst mothers assume primary responsibility for the care for their children, fathers may have had the perception that their role in their family was to attend to financial matters (Rodrigue et al., 1992). Thus, in terms of their role, as well as in terms of the functions related to their role, some fathers may have perceived no changes to their pre-existing notions of fatherhood and of family relations

The authors of the study insist that the findings should not be extended to fathers with characteristics other than that of their sample: white (Caucasian) American, middle- to upper middle-class fathers, whose average age is 40.3 years. Furthermore, whilst the standardized measures used - questionnaires and checklists - produced results that were statistically valid and relevant, such measures could have in actual fact limited the father’s spontaneity and autonomy vis-à-vis their answers. Thus the participants’ responses might have been limited and denied a realistic and authentic description of the fathers’ experience. Notwithstanding the small sample size, the study did present interesting perspectives regarding a father’s psychosocial adaptation. Nevertheless, the relevance of the findings of a study conducted in the United States in 1992 regarding a socially constructed phenomenon such as psychosocial adaptation may have limited applicability to current thinking.

The second study was conducted 20 years later, in 2012, and was also carried out in the United States of America. Thus, in view of its recency, it could be seen as being more relevant to the current socio-political context. Researchers Hartley, Seltzer, Head and Abbeduto (2012) sought to examine depressive symptoms, pessimism, and coping in fathers of adolescents and young adults with Down syndrome (DS; n=59), ASD (n=135) and Fragile X syndrome (FXS, n=46) and sought to single out the factors contributing to potential group differences. The researchers based their hypothesis on findings of other research studies (e.g. Hartley, Baker, Seltzer & Floyd, 2011) that postulated that parent age, behavior difficulties, as well as the likelihood of having another child with that same condition are factors that make a major contribution to the psychological wellbeing of mothers of children with developmental difficulties. Furthermore, what determined mental wellbeing, according to Hartley, Seltzer, Head and Abbeduto (2012), was a lack of depressive symptoms, a lack of pessimism, and individual coping styles.

Participants for this study were recruited through research projects whose target population were mothers, where psychological wellbeing was being studied. The age-range for the children was 10-22 years of age. The fathers involved in the study all had a college degree and reported an average yearly income of \$75000. The data on paternal psychological wellbeing was gathered through the completion of standardised questionnaires. The data gathered was analysed in phases: first, one-way analyses of covariance were conducted; subsequently, group comparisons of paternal age, child behaviour problems, the presence of additional children with a disability and maternal depressive symptoms were computed and the extent to which these factors accounted for variation in paternal psychological wellbeing was processed using hierarchical linear regressions (Hartley et al., 2012).

This study indicated that fathers of adolescents and young adults with ASD who participated in this study reported more depressive symptoms than fathers belonging to other groups. Fathers of children from the ASD and FXS groups indicated that they experienced more pessimism than the DS group. The ASD and FXS groups reported that their challenges were experienced in a more stressful manner and reported poorer psychological wellbeing when compared with the DS group. The factors of advanced paternal age, child's behavioral difficulties, risk of having other children with a

disability and maternal depressive symptoms were all found to have some bearing on depressive symptoms and pessimism experienced by the fathers (Hartley et al., 2012).

The assumption of the researchers was that adolescents and adults with developmental disabilities such as ASD, FXS and DS often continue to reside with parents. Consequently, the hypothesis was that due to such circumstances, both parents were exposed to unrelenting and elevated levels of responsibilities and stress. This notion seemed to have been substantiated by this study. However, the researchers' notion of psychological wellbeing could be considered reductionist as it was based on research that had been derived from studies concerning mothers and their experiences of their children. The researchers however highlighted this limitation in their write-up and maintained that whilst the father's psychological wellbeing was affected by the child's disability, other diagnostic related variations in paternal wellbeing could have been considered.

An interesting finding in the literature quoted above relates to how fathers' psychosocial adaptation is highly correlated to the spouse's emotional wellbeing and presence (or not) of depressive symptoms. Furthermore, in both of the studies mentioned above, fathers whose own perceived competence as a parent was high reported lower levels of stress. Furthermore, the father's perceived competence was also correlated to both mother and father's perception of the child's difficulties. Consequently, it seems that a father's perceived competence was correlated to their perception of the child's difficulties and thus could be regarded as a relatively accurate predictor of stress levels and overall wellbeing.

Thus, results of the above systematic search seem to indicate that the answer to the question: "are fathers of children with ASD actually underresearched?" is yes. However, the 2 studies referenced above shed light on the psycho-social adaptation, depressive symptoms, pessimism, and coping in fathers of children, adolescents and young adults with ASD, Down syndrome and Fragile X. Yet, they considered those specific aspects of the father's experience alone, and did not look into a father's experience in totality. The studies measured the above-mentioned elements of a father's experience well. However, the idiosyncratic and personal nature of the father's experience was not explored.

2.7. Conclusion

This systematic review of literature sought to shed light on the various aspects of fathering a child with ASD. It also sought to gain a better understanding of how a father, his notions of fatherhood, and his fathering behaviors, are conditioned – both positively and negatively, if conditioned at all - by his interactions with his child/children with ASD.

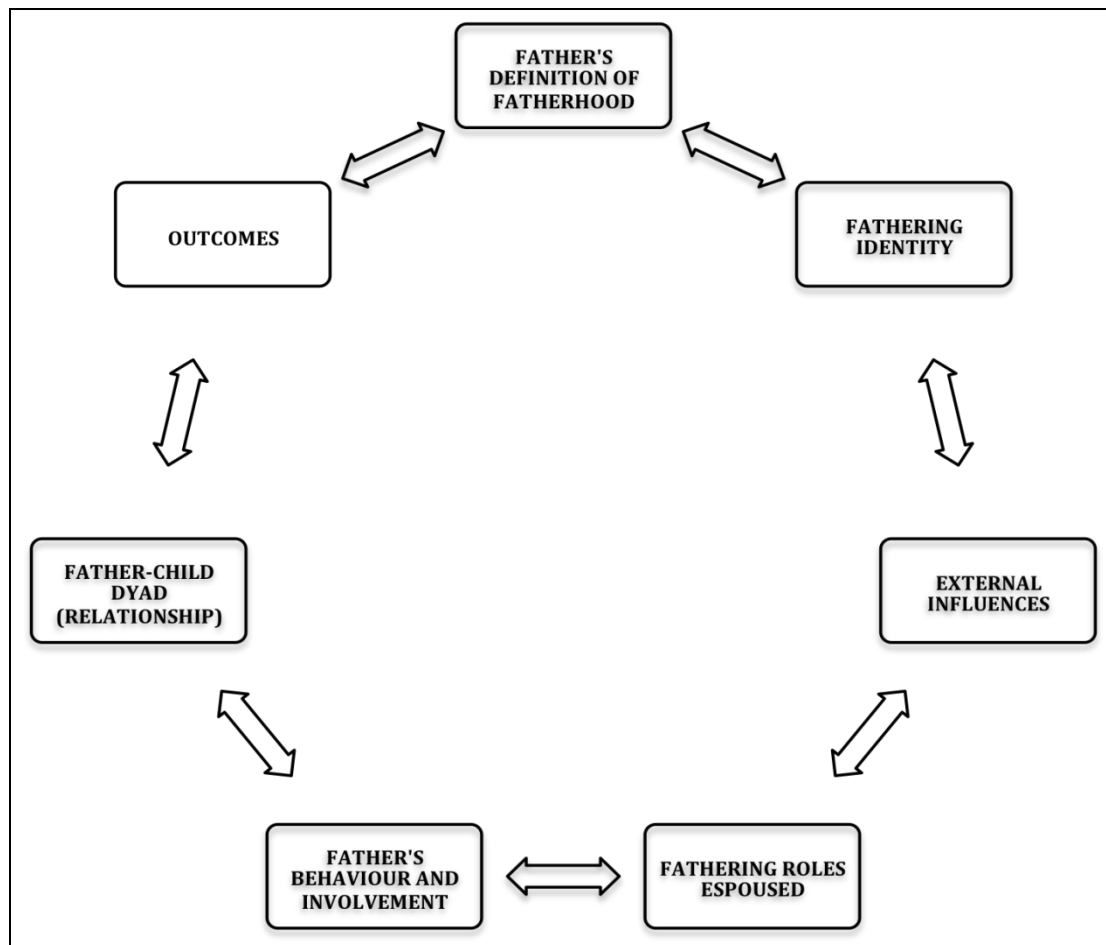


Figure 2.3 – Theoretical model derived from literature review

For this reason, 2 systematic searches of literature were performed (termed SEARCH-1 & SEARCH-2). From these searches, it became apparent that fathers of children with ASD were underrepresented in research literature. However, the literature searches produced various articles that could help understand the effects of a child's diagnosis on fathers. Furthermore, this review of literature underlines the need for this current research.

This review of literature also served to provide theoretical grounding for this study and to contribute towards providing a research based theoretical framework for the research (Figure 2.3). This theoretical model, which is an artifact of the literature identified and critically reviewed in this chapter, proposes that a father's identity is conditioned by various external factors: fathering a child with ASD is one possible factor. External factors could affect the fathering roles that men adopt. Such roles could influence the behavior that men adopt with regards to their children. As a result, the quality and/or quantity of father involvement with their children will impinge on or contribute towards developmental outcomes.

The following chapter will focus on the study's methodology. It will present an overview of the philosophical and theoretical principles that guided this study.

CHAPTER 3 - METHODOLOGY

3.1. Introduction

In this chapter I report on the process of developing the method used to answer the question “What stories do fathers of children with ASD tell about fatherhood and about their fathering experiences?” This chapter shall focus on clarifying issues regarding research aims and purpose, on explaining some of the theoretical aspects of the research design, and on presenting the method used to answer the research questions.

3.2. Every story has a beginning.

The decision as to which method was to be used for this research was a direct consequence of my frustration with the contemporary existing knowledge that focuses on fathers of children with ASD. The literature reviewed in Chapter 2 was predominantly concerned with ‘measuring’ different facets of a father’s experience and with interpreting numbers to gain a better understanding of that experience. It seemed to me that what was being studied, or measured, in many of the studies referenced in the previous chapter was not exactly the fathers’ experience in its totality. Rather, the studies were more concerned about measuring depressive symptoms, family cohesion, psychosocial adaptation, etc.

Whilst such knowledge is definitely useful, and does serve to shed light on various elements and aspects of the participants’ experience, it fails to account for the interaction of such elements and fails to acknowledge the context of the fathers’ experience. In so doing, such information falls short when it comes to understanding a father and his experience in its totality. Nevertheless, such literature does help to fill some of the gaps in the subject. Yet, it still leaves me with the question of “what goes on in the lives of such fathers?”

3.2.1. Formulating the research questions

The identification of what the researcher is out to uncover is similar to the identification of a destination before undertaking a journey. Kumar (1996) postulates:

“The formulation of a research problem is the first and most important step of the research process...it is like the foundation of a building” (p. 35).

Kumar (1996) places the ‘research question’ at the centre of a study. According to Punch (1998) the ‘research question’ is the centerpiece of the research process. He also argues that a well-articulated research question is what determines the route a researcher has to undertake for him/her to answer that question. The ‘gaps’ identified in the area of “Fathers of children with ASD” motivated me to gain further insight into a father’s life. Thus, the lack of eloquent descriptions and qualitative insight into a father’s experience led me to choose research questions that were aimed towards providing rich and in-depth descriptions. Thus, my research questions took the form of inquisitive statements that could help explore a father’s experience of his child’s autism:

- i. *How do fathers of children diagnosed with ASD live and experience their children, and their diagnosis?*
- ii. *What challenges do fathers of children diagnosed with ASD encounter and how do such challenges affect their notions of fatherhood?*
- iii. *What aspirations, hopes, dreams, concerns and reservations do fathers of children diagnosed with ASD have with regards to the future of their children?*

The questions above were aimed at allowing enough flexibility for variation and depth to emerge from the data gathered (Mantzoukas, 2008), and thus were aimed towards helping to answer the most salient of questions:

“What stories do fathers of children with ASD tell about fatherhood and about their fathering experiences?”

3.2.2. Purpose of the research

This study adopts an exploratory design, and is concerned with understanding further a little known and underresearched phenomenon with the purpose of unearthing new insights (Robson 2002). The research questions described previously were aimed at seeking new insights that could, in turn, open new alleys and research opportunities. The research questions identified were aimed at exploring phenomenological

perspectives on a father's hopes, aspirations, fears and concerns about the present and future of his child. In this context, the term 'phenomenological' refers to the study of consciousness and of direct experience.

Thus, the research questions above configured the purpose of the study; which was primarily to gain insight into how fathers experienced their children who have been diagnosed with ASD. Thus, through this study, I strove to search out knowledge that could help me understand better how the diagnosis impacted a father's fathering experience. Furthermore, my objective was to gain a better understanding of how ASD - the diagnosis, the symptoms, and characteristics associated with the condition - could impact a father's selfhood and how this could in turn influence father-child interactions as well as influence other important family dynamics.

3.3. Ontological and epistemological considerations and assumptions

The ontological and epistemological positions I adopted in the course of this study shaped considerably the knowledge and understanding that the research questions above yielded. Ontology is a concept that has to do with one's assumptions about how knowledge is created, and is concerned with the nature of reality. On the other hand, epistemology has to do with one's beliefs about how one might uncover or expose truth or knowledge.

The philosophy that informed my ontological position was that of social constructionism. Such a view rejects the notion of a single objective reality or an absolute truth, and proposes that reality is a product of a conceptual system made of social constructs that define meaning (Shotter, 1993). From this stance, reality is not discovered; rather, it is created (Burr, 2003). Thus, as seen through this philosophical lens, constructs of fathering and fatherhood represent entities of existence, which consist of the language, narratives, and discourses used in a given time and place (Ragin, 1994). Thus, in the context of this study, reality was seen as a product of human consciousness, where concepts such as fatherhood, happiness and stress were not seen solely as quantifiable variables. Rather, in this study, a pluralist position was held with regards to what constitutes truth, where knowledge was seen as being constructed by people who actively engage in its creation (Etherington, 2009).

Social Constructionist assumptions also informed the epistemological platform of this study. Such assumptions required the thorough understanding of the roles fathers played in the creation of their realities and also the acknowledgment of the participant's (father) and observer's (researcher) reflexive and agentic role (Kvale & Brinkman, 2009). Thus, understanding was sought through the analysis of dominant discourses and narratives. Such philosophy is rather different from what Robson (2002) defines as the "standard view of science" (p. 22).

A 'standard', or 'positivist paradigm' takes the view that a real and objective world exists, and this exists independently of human belief, perception, culture and language (Baker, 1994). Kincheloe & Tobin (2009) argue that such a philosophy is concerned with predicting and sees knowledge as invariable and based on universal relationships. Furthermore, this paradigm would have focused on producing causal relationships between variables (Indick, 2002).

Thus, a 'relativist' epistemology and ontology, that interprets particular events (fatherhood and his child's diagnosis), experiences (fatherhood and fathering), and patterns (father-child interactions) in terms of stories and discourses (Cohen, Manion & Morrison, 2007), was used. Social constructionism is in fact an anti-realist and relativist stance (Hammersley, 1992), and it places great emphasis on everyday interactions between people. In light of this paradigm, knowledge was co-created together with the participants (fathers). In this manner, the research participants were recognized as agentic constructors of knowledge who create their own realities through their words (Etherington, 2009).

3.4. Research strategy

Robson (2002) postulates that research must be planned in a way that enables the researcher to gather the data that can best inform the research question (Robson, 2002). Creswell (2009) puts forward three types of strategies or designs; qualitative, quantitative and mixed methods. Qualitative strategies are more appropriate for exploring the meanings individuals or groups ascribe to a phenomenon. Such strategies are more appropriate for a social constructionist worldview. Quantitative strategies are more suitable for testing objective theories by examining relationships among variables and are more fitting for positivistic worldviews. In the middle of this

continuum lies a mixed-methods strategy (Mertens, 2005). This strategy employs a combination of elements from a qualitative and a quantitative design. This design is particularly suited to studies that deal with multiple research questions that require different methods of inquiry to answer (Creswell, 2008).

Due to the idiosyncratic and interpretive phenomenon in question, and due to the fact that I was not in search of causal determination, prediction, and generalization of findings, a qualitative approach to the research was selected as most appropriate. A qualitative research strategy offered a degree of flexibility in terms of data collection procedures as well as analytic practices. It also allowed a greater degree of sensitivity towards symbolic dimensions and social meanings, and provided me with the opportunity for a more in-depth understanding of the phenomenon in question (Bryman, 1984). Qualitative designs are appropriate for exploring the meanings individuals or groups ascribe to a phenomenon (Robson, 2002). Furthermore, the qualitative design that was used did not seek prediction and control; rather, it sought understanding (Glesne & Peshkin, 1992).

Qualitative research supplies the researcher with interpretative tools that are sensitive towards contextual factors, and place the researcher in the midst of the study (Creswell, 2006). These tools are research traditions that offer a degree of flexibility in their design. They also contemporaneously provide the researcher with rigorous data collection procedures and transparent analytic procedures, which lead to valid and trustworthy ‘findings’ (Robson, 2002). In my search for the right tool I took into consideration the following approaches: case study, grounded theory, interpretive phenomenological analysis, and narrative inquiry.

A ‘case study’ approach would have required that I explore a bounded system (a case) over time, using interviews, observations and documents (Creswell, 2006). This would have produced an in-depth understanding of the experiences of fathers of children with ASD through various data collection techniques. A ‘grounded theory’ approach would have entailed that I develop theory by gathering data directly from the field by interacting with the participants who have experienced the phenomenon (Strauss & Corbin, 1998). Thus, the main objective of such a tool would have been to generate theories regarding the processes and experiences that shape the lives of the fathers who participated in my study (Creswell, 2006). ‘Interpretive

phenomenological analysis' (IPA) was also considered as a potential tool, particularly because of its focus on understanding and making sense of a participant's lived experience. This mechanism would have entailed that I attempt to elicit the key experiential themes in the participant's talk and through this, report on the meanings that such experiences hold for the participants (Creswell, 2006).

All of the methods above could have been used to research this particular phenomenon. They all seemed to value context and interpretation and acknowledge the idiosyncratic nature of the participant's experience. However, none of these could have provided me with as much depth as narrative. Narrative inquiry was seen as a mechanism that enabled the construction of detailed stories or experiences of participants (Creswell, 2006). Most importantly, such a tool gave me the opportunity to work with whole stories rather than fragments of experience.

Furthermore, in light of the social constructionist ontological and epistemological position I adopted, which embraces the view that reality is socially constructed and subjectively determined, the means I used to construct and understand individual realities needed to be sensitive to the pluralistic nature of such philosophy. Narrative inquiry was seen as a tool that was fit for the purpose of discovering how the construction of reality came about, and as a tool that would have enabled me to gain insight into the meanings that people ascribed to such realities. The following section will present an overview of the research tool that is 'narrative inquiry'.

3.5. Narrative inquiry

Bleakley (2005) defines 'narrative inquiry' as a qualitative research tool that places stories, or narratives, at the centre of research process. Bleakley (2005) argues that in 'narrative inquiry', stories could be used in two ways: as raw data, which is consequently analyzed, or as the final product of analysis and synthesis of data. Bleakley's definition resonates with Polkinghorne's (1995) definition of 'narrative inquiry'. Polkinghorne (1995) utilizes Bruner's (1986, 1987) notion of "ways of knowing" to describe his view of narrative inquiry.

Bruner (1986) put forward the notion that knowing and thinking could be organized in two ways: paradigmatic and narrative types of thinking. Paradigmatic knowing is

based on the categorization of natural phenomena with regards to their properties and relations (Polkinghorne, 1995). By contrast, narrative knowing is associated with everyday descriptions of human action, usually in the form of stories. Polkinghorne (2010) postulates that narrative knowing reflects a ‘constructed’ world where human agency is what makes things happen.

Thus, Polkinghorne (1995) proposes two general forms of narrative inquiry: paradigmatic analysis of narrative and narrative analysis. Paradigmatic analysis of narrative requires stories to be collected as data and analyzed in terms of categories and themes that cut across the stories (Kramp, 2004). The second form of narrative inquiry, narrative analysis, is somewhat different from paradigmatic analysis. In narrative analysis, the main outcome is actually a narrative (Polkinghorne, 1995; Oliver, 1998; Creswell, 2006).

Whichever definition of ‘narrative inquiry’ is utilized, researchers praise the ability of this research tool to use stories as windows onto plural ‘knowable’ realities (Etherington, 2008). However, unlike the qualitative methods mentioned previously, which provided systematic steps for undertaking the research process, narrative inquiry lacks a clear definition. Hardy, Gregory and Ramjeet (2009) argue, “for any potential narrative analyst, searching for a precise definition and outline of how narratives are to be used in research, or for a clear process and method of analysis, often proves problematic and confusing” (p. 7).

Riessman (1993) argues; “whilst some types of qualitative analysis have a standard set of procedures, narrative research does not” (p. 54). Because of this, narrative could be considered as being a contested, complex, transitional and developing field (Chase, 2005). However, the lack of a clear and systematic procedure is not necessarily a limitation. Riessmann & Speedy (2007) argue that ‘narrative inquiry’ is cross-disciplinary, and is flexible enough to resist the boundaries of any single scholarly field. Thus, the lack of a methodical procedure could empower researchers by enabling them to be further engaged with their research.

3.5.1. Notions and applications of narrative inquiry

Various notions and applications of narrative inquiry could be seen in the works of Clandinin and Connelly (2000), Shacklock and Thorp (2005), Reissman (2008), Gee (1985, 1991, 2000), and Bignold (2011). These notions were deemed to be relevant for the study's research design and are thus discussed further below.

Clandinin and Connelly (2000) base their approach of narrative inquiry on John Dewey's philosophy of experience. Dewey (as cited in Clandinin & Connelly, 2000) argues that "individuals should be understood in terms of their individuality but also in a social context" (p. 2). Furthermore, Dewey considered 'continuity' as being central to the notion of experience. He argues that experiences grow out of other experiences, and experiences grow out of further experiences (Clandinin & Connelly, 2000). Thus, Clandinin and Connelly (2000) propose what they term a "three-dimensional-space" approach. They propose that a narrative inquirer reads and reread data, considers interaction, continuity, and situation. Consequently, the researcher moves away from the actual transcript and seeks to produce a story that highlights the themes, tensions and patterns of the individual's story (Ollerenshaw & Creswell, 2002).

Shacklock and Thorp's (2005) notion of narrative inquiry focuses on "the production, interpretation and representation of storied accounts of lived experience" (p. 156). Shacklock and Thorp (2005) see narrative inquiry as a "historical inquiry into lived experience" (p. 157). They define it as "a dialogic event where participants act together in an ongoing, non-linear process that leads towards the construction of an account" (Shacklock & Thorp, 2005, p. 157). Their notion of narrative inquiry is based on dialogues between the inquirer and the participant that produce stories consisting of both personal and collective aspects.

Reissman (2008) described four models or methods for interpreting texts that have a storied form in common, and labeled such methods as narrative analysis. One could argue that Reissman's (2008) view of narrative inquiry bears resemblance to what Polkinghorne (1995) referred to as paradigmatic methods of analysis. Reissman (2008) proposes thematic analysis, structural analysis, dialogic/performance analysis and visual analysis as methods that can be used to analyze stories. She argues that

these methods are “not mutually exclusive; they can be adapted and combined” (Reissman, 2008, p. 18). In her description of thematic analysis, Reissman (2008) argues that the focus is on “theorizing across a number of cases by identifying common thematic elements across research participants” (p. 74). In trying to illustrate the ‘structural analysis’ typology, Reissman (2008) refers to William Labov’s (1972, 1982, as cited in Reissman, 2008) “Attention to the Function of Clauses” (p. 81) approach and Gee’s (1985, 1989, 2000, as cited in Reissman, 2008) “Attention to the Units of Discourse” (p. 93) approach. Labov (1972, 1982) assumed that narratives have five formal elements (i.e. orientation, complication, evaluation, resolution, and coda), and that each of these has a function.

Gee (2000) on the other hand constructed parts of a narrative inductively and did not assume that any piece of narrative contained presupposed sections. Gee (2000) uses the term ‘reflexivity’ to explain the reciprocity between language and ‘reality’. He argues that while using language, individuals simultaneously build on six areas of ‘reality’. These areas are: the meaning and values of aspects of the material world, activities, identities and relationships, politics, connections and semiotics. Gee (2000) dissected discourse into what he called ‘small spurts’ (Tsai, 2007). Each piece of information in a spurt is termed ‘line’, which is the basic unit of analysis. A group of lines concerning a single topic or theme constitutes a ‘stanza’. This structure revealed his assumption on how people’s mind worked in using language. Reissman (2008) describes dialogic/performance approach as a broad and varied interpretive approach that draws on elements from both thematic and structural methodologies, whilst further adding a contextual dimension. On the other hand, Reissman (2008) defines visual analysis as a typology that makes use of photographs, paintings and drawing, as primary data. Consequently, such data is analyzed by asking interpretative questions such as “how and why the images were produced” (Reissman, 2008, p. 142).

Bignold (2011) builds on the work of Sparkes (2002), Clough (2002), Conle (2001), as well as Barone (2000) and proposes the use of ‘creative non-fiction’ in narrative inquiry. Gutkind (2007) defines ‘creative non-fiction’ as a factually accurate account, or story, that conveys information whilst reading like fiction. Clough (2002) and Barone (2000) define ‘creative non-fiction’ as contemporary writing that uses non-fictional storytelling to aid in the understanding of experience. This ‘storying’ procedure consists of using fictional techniques to ‘weave’ real facts and real lived

events into real stories (Sparkes, 2002; Conle, 2011). Furthermore, according to Cone (2011), narrative inquiry is concerned with the presentation of data, in the form of a narrative, which is gathered through ‘dialectic communication’. Thus, Bignold (2011) defines ‘narrative inquiry’ as the production of stories that are “based on actual events” (p. 25) and experiences. These stories, according to Bignold (2011) are truthful and honest and could be based on data gathered using various techniques.

3.5.2. Narratives in narrative inquiry

The term ‘narrative’ has been understood in different ways by researchers who use qualitative research designs (Polkinghorne, 1995). Barthes (as cited in Reissman, 2008) argues that ‘narrative’ is a universal and all-pervading phenomenon that is present in a variety of forms, such as “myth, legend, fable, history, tragedy, drama, comedy, art form, news items and conversation” (Reissman, 2008, p. 4). Barthes (1975, as cited in Reissman, 2008) maintains that there has never been a people, or an individual without a ‘narrative’.

Resimann (2008), however, warns that notwithstanding the fact that narrative is indeed an all-pervading phenomenon, “not everything could be considered to be narrative” (p. 4). According to Reissman (2008), ‘narrative’ involves an ordered and meaningful arrangement of events, as well as a particular style of language. She also argues that ‘narrative’ consist of developed characters and contexts, and is, above all, used to communicate a message. If seen from a socio-linguistic perspective, narrative could be defined as a discrete unit of discourse. From an anthropological perspective, it usually refers to an entire life story. From a psychosocial perspective, ‘narrative’ refers to a long conversation aimed towards making sense of experiences, which consequently contribute to the formation of accounts of lives (Reissman, 2008). From the latter viewpoint, ‘narratives’ are seen as universal mirrors that reflect an individual’s perception of the truth; they reveal who people are and why they do what they do. In this study, ‘narrative’ was not seen as a history of objective facts about an event or about an individual. Rather, it was understood as being a ‘report’, which includes insights and interpretations of an individual’s version of experience. The term ‘narrative’ was understood as being a story or account, consisting of a series of episodes or stages, told in a particular situation with a particular purpose (Polkinghorne, 1995; Reissman, 2008).

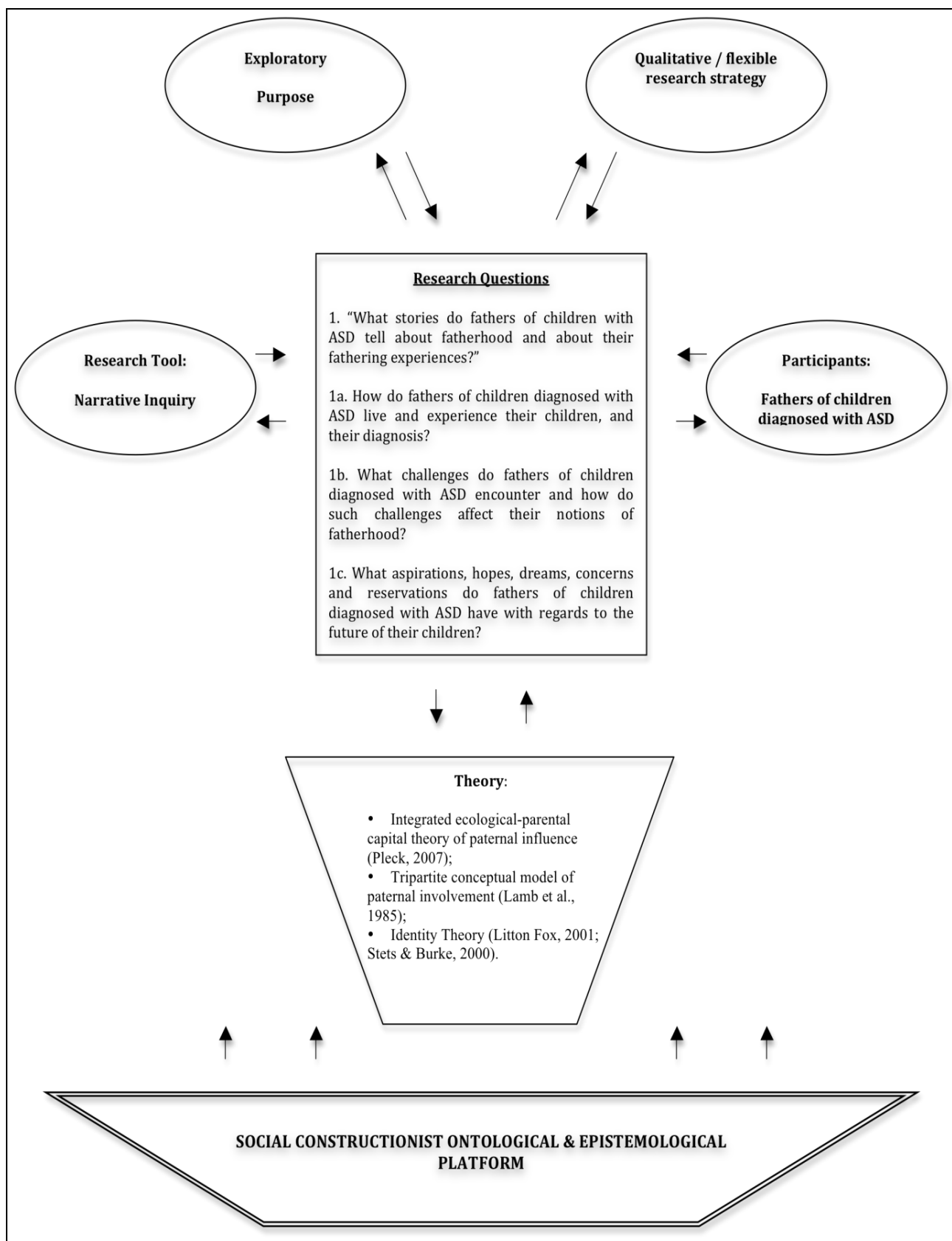


Figure 3.1: Overview of research design

3.6. The Research Design

Thus, from an array of qualitative research methods, narrative inquiry was used as it seemed to offer the best way to understand the phenomenon and experience being researched. In this way, such a methodology appeared to place me in the best possible position to be able to answer my research questions.

Narrative Inquiry also enabled me to prioritize stories over general themes and fragmented forms of knowledge, and also enabled me to gain a better understanding of a father's life, as told by the fathers themselves (Etherington, 2004). Most importantly, narrative inquiry enabled me to be engaged in my research by helping fathers construct their stories. The research design utilized in this study is summarized in Figure 3.1. (p. 46).

3.6.1. The stories' owners: the participants

Due to the qualitative nature of this study, and due to the fact that the study's aim was not to achieve representativeness, rather uniqueness and subjectivity, a purposive sampling method (Robson, 2002) was used to recruit participants. This sort of 'deliberate' recruitment process enabled me to satisfy the specific needs of the study by gaining appropriate answers to the research questions. The participants in this study were all males, aged between the ages of 35 and 44, and were all fathers of children who had been given a diagnosis of ASD. All were Maltese nationals with a minimum level of education that was 'post-secondary non-tertiary'.

3.6.2. Recruitment of the participants

The sample used in this study consisted of 10 fathers. The recruitment of the participants started in March 2012, by sending 'Information Letters' (Appendix 4, p. 148) to organizations in Malta who might have data regarding the demographic in question. These organizations were: Autism Parents Association - Malta (APA); Structured Training and Education Programme (STEP); Equal Partners Malta; and Department for Student Services (DSS). APA-Malta is a non-governmental organization that aims to help families with children affected by Autism. STEP is a

specialized programme for children and adolescents on the autistic spectrum. This is also a programme that aims to work with individuals with disabilities, their families and the community through partnerships. (DSS) - DSS is a governmental organization that provides numerous services that cater for students with learning or developmental difficulties, including ASD.

This information letter provided the organizations with an overview of the research study, whilst also asking for help with finding participants for the study. Subsequent to this, I proceeded to ask the organizations to distribute 'Participation Forms' (see Appendix 5, p. 152). These forms provided the potential participant with a summary of the study whilst also giving information on what would be expected of him if he were to participate.

Thus, these forms were given to the organizations and were asked to distribute them to fathers who were affiliated with their organization and who had a child diagnosed with ASD. These participation forms were sent to the fathers by post. Together with these letters, the fathers also received a stamped and self-addressed envelope, as well as a note that stated that the letter was sent by the organization. The intention of the note was to reassure the organization's clients that their privacy was respected and that no personal information was divulged to any third parties. Fathers who were willing to participate were requested to return the forms to the address specified. Subsequently, the fathers signed consent forms (see Appendix 6, p. 156) during our first meetings.

3.6.3. Collecting and recording of the participant's stories.

A very important element of the study was the task of collecting the participants' stories. The word 'collecting', in this context, is used in a very loose manner as it refers to the manner in which stories are generated, gathered and 'extracted' from the field (Clandinin & Connelly, 2000). Mishler (1986, 1991) argues that in narrative inquiry, a researcher does not find narratives but instead participates in their creation.

Initially my plan was to channel the conversations by using a 'semi-structured' interview agenda (see Appendix 7, p. 158). However, after piloting the interviews, I felt that such a semi-structured approach seemed to reduce the interview to dry and

condensed answers to questions. Thus, for gathering the study's data I used an unstructured interviewing technique (Robson 2002). In this regard, Hollway and Jefferson (2000) postulate that in such style of interviewing, "the agenda is open to development and change, depending on the narrator's experiences" (p. 31).

The pilot interviews were done with 2 volunteers who met the criteria to participate in the study – biological fathers of a child diagnosed with ASD, whose diagnosis was identified more than 2 years ago – but were not recruited through the recruitment process described earlier. Rather, the two participants were fathers whose children I had worked with, who agreed to participate in the piloting phase of the study. The pilot phase was very important, particularly because it highlighted some issues with regards to the interviewing process: namely, the issue concerning the semi-structured interviewing agenda, the negotiation of my position, and my relationship and purpose with the interviewee. All of the interviews, including the pilot interviews, required negotiating my position in the data collection process. This researcher-participant relationship was negotiated throughout the interview process, and was introduced and explained by the 'Participation Letter' that was distributed. Furthermore, the relationship and purpose of the research were clarified before the interviews were carried out.

The conversations were mostly carried out using both English and Maltese languages. This is due to the Maltese population's bilingual manner of communication, in which a person is constantly switching from one language to another. Thus, Maltese words and dialogue were present in abundance in the interviews. Thus, the interviews were recorded using an electronic device to aid memory and to facilitate translation and transcription to English. Interviews approximately spanned from an hour to one and a half hours, and were mostly held at the fathers' residences. For the participants who demonstrated other preferences, individual arrangements were made. Such arrangements were made as long as the location of the interview did not negatively impact the outcome of the interview. The criterion for an appropriate location for the interview was a quiet place that could allow adequate time and space for the interview to be completed and recorded. For sufficient data to be gathered, a maximum of two interviews with each participant were scheduled. Consequently, the interviews were transcribed and storied into narrative form. I will be explaining this further in the next section.

In this study, photographs were also used alongside conversation. Photographs were used to aid the interviewee by triggering memories that could help in the creation of narratives. Photographs mark a special memory in a person's mind; a memory around which a story is associated (Ketelle, 2010). Thus, by combining a visual methodology with a qualitative data collection method such as narrative inquiry, richer and broader angles could be perceived (Kingsley, 2009).

The photographs that were used were photographs that had been in existence prior to the interviews, and had not been taken with the research in mind. These were photos that the participants provided and that were representative of their fathering experience. These photographs were selected by the participants and were discussed during the process of the interviews. The photographs were not included in the write-up of the study. Rather, they served as artifacts that were aimed at aiding the interviewing process. The use of photographs was explained to the participants at different points, including: the participation letter, the first time I got in touch by phone, and also at the beginning of every interview conducted.

After the interviews, the transcription, and storying processes were completed, I 'checked back' with each participant. These 'check-backs' were short meetings and were done to verify, with the fathers, the adequateness, authenticity and validity of the narratives produced. These meetings were around 45 minutes in duration.

3.6.4. From the field to text: the transcription process

The data gathered through the interviews consisted of a number of conversations that were recorded on an electronic device. Davidson (2009) argues that it is very difficult to capture all of the features of a conversation from recordings and transform them into text. In this study, I took a decision to include some utterances and non-verbals, but at the same time produce text that was 'clean' and more readable (Kvale, 1996). In the transcripts the interview noise, such as stutters and pauses, were removed (Oliver, Serovich & Mason, 2005). While staying truthful and loyal to the participants' words, I focused more on the meaning and perception of the language used – on the substance of the interview – rather than merely on the accurate reproduction of the language used (Oliver et al., 2005).

The reason for using such a method was also a matter of necessity, particularly in light of the bilingual mode of communication of the fathers participating in the study. In fact, most of the interviewees used both English and Maltese words. In some instances, participants spoke exclusively in Maltese. Thus, the actual process of transcription consisted of listening and re-listening to the recorded interviews to gain a good understanding of the message the interviewees were trying to convey.

Furthermore, the process consisted of constantly shifting my focus from the written data to the recorded oral data. The translation and the transcription of the audio in text were done contemporaneously. I am fluent in both the Maltese and English languages, and thus completed the translation and transcriptions. This was a very time consuming process that involved a lot of deliberation and reflection. However, it helped me to immerse myself in the data. This aided considerably the process of “storying”. To help me in this translation and transcription I also used transcription software. This software helped to reduce the speed of the recorded data to a speed that was more adequate for me to recognize and comprehend the language used. An overview of the timeline of the research process can be found in Appendix 8 (p. 159).

3.7. The storying phase

The objective of this phase of analysis was to turn the data obtained from the translation and transcription of the interviews into a type of discourse composition. These discourses drew together each participant’s perception of events and happenings together with their thoughts and emotions (Polkinghorne, 1995). Polkinghorne (1995) argues, “because the meaning of the term analysis has been extended in qualitative research to cover any treatment of data, I retain analysis when referring to the configuration of the data into a coherent whole” (p.15).

By “narrative analysis” Polkinghorne (1995) referred to the configuration of the data in chronological order. This process, according to Polkinghorne (1995), consists of integrating and synthesizing data into a plot, and is aimed towards producing a final narrative. This provided me with a good starting point for my own analysis. Nonetheless, I felt that such a description, whilst providing me with direction, lacked the element of forward thinking. Polkinghorne (1995) seemed to focus more on a

retrospective description of events. Polkinghorne (1995) argues, “the result of a narrative analysis is an explanation that is retrospective, having linked past events together to account for how a final outcome might have come about” (p.16).

Thus, this storying phase of the study drew upon Clandinin and Connelly’s (2000) concept of human experience, which is defined in terms of three axes: Interaction, Continuity and Situation. I felt that this framework could better capture a story’s dimensions of time: past, present and future (Figure 3.2).

Clandinin and Connelly (2000) argue that in narrative terms, individuals cannot be understood only as individuals, and that past experiences and future prospects contribute to an individual’s contemporary perspectives, truths and realities. They also put forward the idea that experience grows out of other experiences, and consequently, experiences lead to further experiences. Finally, they claim that an individual’s experience occurs in a particular landscape, location or context (Clandinin and Connelly, 2000). This conception of “experience” (Table 3.2) was pivotal in this research study, as it provided a foundational framework for thinking about a father’s story. Examples of how this framework was actually used can be found in Appendix 9 (p. 160).

INTERACTION		CONTINUITY			SITUATION
PERSONAL	SOCIAL	PAST	PRESENT	FUTURE	PLACE/CONTEXT
<u>Inner state of affairs;</u> e.g. feelings, hopes, moral dispositions.	<u>Exterior existential conditions in the environment</u> with other people and their intentions, purposes, assumptions, and points of view.	<u>Backward:</u> remembered experiences, feelings, and stories from earlier times.	<u>Now:</u> Current experiences, feelings, and stories relating to actions of an event	<u>Forward:</u> Implied and possible experiences and plot lines.	<u>Context, time, and place:</u> space situated in a physical landscape or setting with topological and spatial boundaries with characters’ intentions, purposes, and different points of view.

Figure 3.2: Clandinin and Connelly’s (2000) 3D Analytic Framework - Adapted from Ollerenshaw & Creswell (2002) and Clandinin & Connelly (2000)

Thus, the translated and transcribed interviews were read and re-read and ‘analyzed’ in terms of Clandinin and Connelly’s (2000) 3D Analytic Framework. Consequently, various excerpts of the transcript were organized in thematic units or ‘stanzas’ that demarcated transition from one narrated event to the other. The objective was to group various excerpts into stanzas that were more meaningful, and that concerned similar subjects or themes. This ‘re-arranging’ was carried out to make better sense of the participant’s speech, which, due to the spontaneous nature of the interviews, resulted in the ‘narrating’ of experience being somewhat disorganized. This resulted in the ‘creation’ of ‘interim narratives’ that focused on the re-organizing of the data collected during interviews. This narrative ‘style’ was based on Gee’s (1991, 2000) notion of narrative inquiry. In his approach, Gee (1991, 2000) used the concept of ‘thematic stanzas’ (Reissman, 2008), to inform narrative transcription. According to Reissman (2008), this made the stories more readable and more accessible.

These ‘interim narratives’ (see Appendix 10, p. 165) consequently served as the founding blueprint that guided the ‘creation’ of the fathers’ narratives. At this stage, storying techniques were used to turn the ‘interim narrative’, consisting of excerpts from the original transcripts arranged in a more meaningful way, into storied accounts of the fathers’ lived experiences (Table 3.3. p. 54).

This is a process that Bignold (2011), Sparkes (2002) and Conle (2001) define as the creation of ‘creative non-fiction’. However, in this case, the term ‘creative nonfiction’ could be somewhat misleading, as it could imply that the story could be fictitious. However, the stories are real and are products of the dialectic process that occurred between the fathers and myself. The final narratives were in fact ‘fashioned’ using real data that was obtained from real interviews with real people. Yet, various elements of ‘creative non-fictional’ writing, such as characters (representing real people), symbolism, metaphors, character development, plot (including a temporal element), and events were used to develop a father’s narrative.

The resulting narratives were written in the ‘third-person-omniscient’. By using this style of writing I intended to show the thoughts and actions of the main character of the story, the father, as seen from a narrator’s perspective. The reason for not writing the stories in the first-person was to create a certain degree of distance from the

fathers and also from myself. This was because the stories are not reproductions of the participant's, or my own, exact words. Rather, they are 'assemblages' that are comprised from data gathered from the interviews (transcripts of interviews written in the first person); from the pictures that were used during the data-gathering phase; from my own experience of the fathers; and from my observation interpretation and experience of the interviews. Thus, these stories were, from start to finish, co-constructions. Thus, the narrator, from 'his' overarching point of view, narrates a 'collective utterance'. Similarly to Mercieca (2013), "I want to think of the stories as blocks of sensations, a compound of percepts and affects, that can stand on their own" (p. 53).

<u>Interim Narratives</u>	<u>Final Narratives</u>
<p><u>Foresight</u> <i>[thematic stanza]</i></p> <p>Once I read an article about a long distance trailers company. Some of the drivers were having frequent accidents. Others did not. They then tried to see how one of these drivers, who did not have a lot of accidents, actually was able to do such a thing. They noticed that the driver always thought in advance about what could go wrong. He also thought of what he could do to avoid accidents. He used to think in advance. That is why he didn't have so many accidents. (2, 276).</p> <p>That is my mindset: Sometime there are times when something hits me and I am not expecting it. But I try to cover all my basis. (2, 277).</p> <p>No nothing at all. It was something unexpected, and unanticipated. In fact the first indication came from my wife. This was when my daughter, could not even walk. This is when my wife mentioned something. (1, 6).</p>	<p><u>Foresight</u> <i>[thematic stanza]</i></p> <p>Rupert is a person who likes to anticipate things before they actually happen. He anticipates problems just like truck drivers do. This analogy is one Rupert took out of a research he read that argued that the truck drivers that were mindful of the accidents that could occur and who tried to identify potential causes of accidents actually had a lower accident rate. Rupert however could never anticipate the condition of autism. He could not see it coming. Before his wife mentioned that she was concerned about their daughter's behaviors and mentioned it to him, he knew nothing about the condition.</p>

***Table 3.3: The 'storying' of the 'interim narratives' into 'narratives'.
The numbers in brackets, e.g. (2, 227), refer to the interview number and the
'transcript line number' of the excerpt.***

As mentioned previously, the resulting narratives were presented back to the owners of the stories, the fathers, during the 'check-backs'. As the owners of the stories, the fathers were consulted about the authenticity and validity of the narratives. The fathers gave their feedback, and commented on how they felt as they read their

narratives. This discussion sometimes also led to some minor amendments to the story and led towards the final narratives. The fathers were also asked to give their story a title. Some of the fathers gave a title whilst some fathers were more comfortable to leave the story without a title. An example of one of the completed stories is presented in the following chapter, and the remainder in Appendix 11 (p. 168).

3.8. The commentary phase

This phase of analysis was characterized by a search for ‘storylines’ and ‘plots’ that were common across the 10 stories. In this part of the inquiry the fathers’ stories were further explored with the intention of finding shared narratives and thus to help answer the main research question: “What stories do fathers of children with ASD tell about fatherhood and about their fathering experiences?”

The objective here was not to identify or hypothesise causal relationships, rather it was to locate specific ‘storylines’ in each narrative and consequently obtain descriptions of common events that could be found across the narratives. In this way, my intention was to come up with a wide, yet authentic ‘overview’ of the fathers’ stories. My hope was that through this I could answer the question “what stories do fathers tell...” more thoroughly.

This phase drew upon various qualitative methodologies such as ‘thematic analysis’, ‘IPA’, and ‘content analysis’. As presented in the forthcoming chapter the commentary produced common ‘thematic stanzas’ (that resemble the concept of themes common in thematic analysis), described and made inferences about the antecedents of a communication (content analysis), and also aimed to analyze how a father whose child is diagnosed with ASD in making sense of his experience (IPA). However, notwithstanding the fact that this commentary utilises elements usually associated with various methods of analysis, and could thus allude to one or more of these methods, it cannot and should not be solely pigeonholed in one particular research category.

Reissman (2008) labels the qualitative research methods, such as the ones identified previously as “category-centred methods of analysis”, in which “long accounts are distilled into coding units or themes” (Reissman, 2008, p. 12). She argues that each

approach provides a unique way to analyse data, which in turn produces different insights and information. She however does not limit her notion of ‘narrative analysis’ to the use of distinct methodologies. Rather, she argues that an amalgamation or combination of such methods could serve well to analyse the ‘unique’ form of data that is produced in narrative inquiry. The ‘category-centred methods of analysis’ described by Reissman (2008) would entail a ‘deconstruction’ of data, if used separately. However, the commentary produced in this study was not aimed to deconstruct or de-contextualize the fathers’ narratives. Rather, it was aimed to utilize the diachronic data produced in the ‘storying phase’ to provide insight into a father’s narrative whilst maintaining contextual aspects of the stories. This phase of the study is described further in Chapter 5 (pp. 63-64).

3.9. Ethical issues

The British Psychological Society's Code of Ethics and Conduct (BPS, 2009) provided guidance on the general ethical principles embraced in the course of this research. Before the study began, Ethical clearances (see Appendix 13) were obtained from the University of East London, School of Psychology Ethics Sub-Committee, as well as from the University of Malta Research Ethics Committee. Furthermore, before the start of the data collection, I outlined to the fathers what the research was about, and consequently asked their consent to take part. The information that I provided to the fathers included: information regarding the purpose of the research; the procedures involved in the research; what I, as the researcher, was researching; and their place within the project.

Also, before the research commenced, the fathers were informed of their right to withdraw from the study whenever they wished to. Furthermore, throughout the research, an effort was made to protect the identity of the participants. Thus, actual names were omitted from all parts of the research. Instead, pseudonyms were used when referring to fathers. Furthermore, I also made sure that the narratives storied from the data did not reveal the fathers’ identities. Thus, I purposefully removed certain details of the narratives that could have revealed the fathers’ identities.

The biggest ethical issue was that of “whose story was it?” Even though one could consider the narratives as being co-constructed, I acknowledged the fact that the

participants owned the narratives. These were their stories, and consisted of their lives, their thoughts, and their feelings. This study would not even exist if it were not for them. However, whilst writing the research I realised how the ownership was transferred the instant I pressed the record button on my audio recorder. At that instance, I felt that I became responsible for the fathers stories. In reality, I felt more of a custodian than an owner, and felt the responsibility of giving the fathers a voice, whilst also protecting their story, their privacy and their dignity.

Thus, throughout the study I was aware of the responsibility of being the custodian of a story. Even though the stories were co-constructed, this did not change the fact that the stories were the participants' lived experiences and not my own. For this reason it was always my responsibility, throughout the research, not to cause harm to the participant fathers or anyone else who was not directly involved in the study (e.g. spouse, or children). During the process of the interviews, I did my utmost to make certain that those involved in the research were not caused distress. Furthermore, throughout the 'storying' and 'commentary phases', I was thoughtful of the fathers and their families and kept in mind that they were in fact my most important audience. Throughout the study I remained respectful to fathers and to their families, as it was to them that I was primarily responsible. For this reason I was extremely careful not to compose texts that damaged the various life stories that supported them (Reissman, 2008).

CHAPTER 4 – FINDINGS

4.1. Introduction

In this chapter, I will be presenting one of the narratives storied in the ‘storying phase’ of the study. Subsequently, I shall be presenting the commentary on the narratives that provides a description of the connectedness between various ‘thematic stanzas’ of the 10 narratives storied.

4.2. Rupert’s Story: Is there anybody in there?

Becoming a father

One morning, whilst lying in bed with his wife, Rupert put his ear next to her belly and asked, “Hello, is there anybody in there?” Later that day, she had an appointment with her gynaecologist to try to determine why, after 2 years of trying, they had not been able to conceive. Later that day, during a meeting, he received a text message that read: “There is someone in there!” This is how Rupert found out that he was going to be a father. The message was totally unexpected. However, after receiving it, he started preparing emotionally for the sleepless nights that were to come. After the birth of his first child things changed for Rupert, but not as much as he was expecting. Things changed further after his second child was born, as he, together with his wife, had more responsibilities. It was hard for the couple to go out with two children. Thus, they chose to spend more time at home.

Foresight

Rupert is a person who likes to anticipate things before they actually happen. He anticipates problems just like truck drivers do. This analogy is one Rupert took out of a research he had read that argued that the truck drivers that were mindful of the accidents that could occur and who tried to identify potential causes of accidents actually had a lower accident rate. Rupert however could never have anticipated the condition of autism. He could not have seen it coming. Before his wife mentioned that she was concerned about their daughter’s behaviours and mentioned it to him, he knew nothing about the condition.

The denial phase

His wife got worried when she noticed that their eldest child manifested difficulties with walking. Rupert’s first reaction was denial. At the time he insisted that everything was ok. He also went as far as to identify and print out indicators describing the symptoms of autism and the developmental milestones just to prove his wife wrong. By doing this, he felt that he went

as far as to prove that his daughter did not have autism. At the time he believed that his wife was fussing over nothing. He wanted to prove that his children were normal. He wanted them to be normal. Furthermore, he didn't want any label of any sort.

When his daughter started attending playschool, one of the carers pointed out her difficulty with speech, and the fact that her peers were communicating verbally whilst she was not. At this time Rupert noticed that she was not interested in toys and that she was more interested in stacking books. An avid reader himself, he instantly made the comparison and argued that this was an indication that she would emulate him one day. As she started attending Kindergarten, his daughter's behaviour caught the eye of the Kindergarten Assistant. She immediately informed Rupert and his wife that their daughter was presenting difficulties in play and in communication.

At the time, tantrums were occurring more frequently at school, but never at home. Initially Rupert interpreted the attention that his daughter was getting as being an obsession or fixation from the teacher's part and he dismissed it as such.

The search for answers

After around a month of Kindergarten, Rupert was 'summoned' by this teacher and by the Head of School, who recommend that he and his wife seek the advice of a specialist. Rupert took this recommendation to heart and did what the head of school had recommended. After three sessions with a specialist, Rupert demanded to know the truth. This is when the specialist broke the news to Rupert and his wife; the symptoms evidenced were indicative of autism. From then on, Rupert started researching the subject thoroughly and passionately. This is when he also noticed that his younger son, who was a year and half younger than his daughter, was also presenting similar symptoms.

Perceptions of autism

Rupert previously associated the word Autism with disability; which brought about painful images of wheel chairs and of stigmatisation. However, the word also brought another image to mind, that of Dustin Hoffman and 'Rain Man'. This did give a sort of positive twist to the situation, which was initially looking dim, as it hinted towards the notion of a different but special ability.

The journey towards acceptance

Through good information, explanation of the facts, and extensive and thorough research, Rupert gradually came to accept the diagnosis. Nevertheless, deep down, he did hope and wish that someone would tell him that there had been a mistake, and that his children did not have autism. However, his last hopes were dashed when Rupert, together with his wife, attended the 'case conference' at the Child Development Assessment Unit at hospital, where the diagnosis was confirmed. On this occasion, Rupert did not hear what he was hoping to hear, and any thoughts of there being a mistake with the diagnosis were completely expelled. This was the moment when he actually accepted the diagnosis.

Thus, from then on, “this was the situation”, and he was going to do what he always did: look for solutions.

Looking for solutions

Rupert is by nature a problem solver. He is a proactive individual, and rather than mulling on a problem, he likes to seek for solutions. His philosophy is: “lets get on with it and solve the problem”. This is his ethos in every aspect of his life. His wish is to, one day, see a solution to the puzzle of autism. He acknowledges the improbability of this, but he is not one who gives up easily.

His tendency to problem-solve, and his yearning to ‘solve’ autism has also driven him to explore routes that he describes as being somewhat controversial. He takes what he deems are calculated risks that occasionally go against Maltese doctors’ advice. An example of this is BioMeds, which he has been administering to his children for some time now. A DAN (Defeat Autism Now) Doctor (who is also registered on the Malta Medical Register), who he bumped into some years back, introduced him to BioMeds. He is aware that the medical authorities are very conservative and they have not as yet approved or accepted such intervention. Nevertheless, he feels that he is not in a position to wait for ten years for the authorities to accept such intervention and feels that he is driven by a sense of urgency to help his children.

Today Rupert states that he continues to keep himself informed on all aspects and matters related to Autism. He is sceptical about some forms of ‘alternative’ therapies such as the Hyperbaric Oxygen Therapy (HBOT). However he is hopeful; particularly in light of the feedback he gets from other fathers whose children were exposed to such a therapy.

Fatherhood

Rupert’s notion of fatherhood is one in which he sees himself being present in his children’s lives on a daily basis. However, because of the long hours his job requires, he is not always able to do so. For this reason, rather than quantity, his focus is on spending good quality time with his family.

Rupert wakes up early in the morning to prepare the medications for his children. Before going to work, he takes one of the children to school, whilst his wife takes the other child to school. In the evening Rupert enjoys playing with both his children. He tries to play educational games. He also enjoys monkeying around with them and enjoys rough-and-tumble play.

Difficulties related to autism

Rupert experiences the difficulties related to autism in different degrees. This is because of the diverse and distinct characteristics of both his children. Whilst both were diagnosed as being on the spectrum, his daughter communicates well, whereas his son presents a limited verbal vocabulary but good receptive language skills. His son is relatively rigid and is demanding and adamant with regards to his routines. If his son decides that he requires something or that he wants to go somewhere, he is usually adamant about his request, and gets very frustrated if he doesn’t get what he wants.

The why me question

At various instances, Rupert experiences an array of feelings. These include: joy; pride; love; anger; and also worry. Anger is mostly experienced when he sees his son throwing a tantrum. In such instances, Rupert becomes angry, though he makes it a point that his anger is at the situation, rather than at his son. Occasionally he finds himself asking the question “why me?” In other instances Rupert finds himself pitying himself and wishing that he did not have to face such difficulties. Rupert has also been through some difficult and upsetting situations. One of these was at a public entertainment venue, where his daughter was jumping on a trampoline. When it was time for her to stop and step out of the play area she did not want to budge. To the supervisor, it seemed that she was giving her the cold shoulder. This annoyed the supervisor considerably, who, not knowing about the condition, was somewhat rough in the way she handled the girl. This situation was the cause of a lot of anger and frustration for Rupert.

Learning from experience

Notwithstanding all this, Rupert has learnt how to cope with his children’s difficulties. Together with his wife, he prepares his children well before any activity. Rupert also tries to anticipate what could go wrong, and takes appropriate preventive action. Preparation is crucial according to him. By preparing their children well, Rupert and his wife, on more than one occasion, have also gone abroad on family holidays. Today Rupert looks upon his children’s difficulties from a different standpoint. He is thankful that his children have improved as much as they did in various areas, and empathises with other fathers whose children’s difficulties could be similar or greater than his own. He is thrilled to be able to communicate well with his daughter. Also, the fact that his son understands him as well as he does is also a source of pleasure and satisfaction.

Life besides autism

Rupert is a man with a lot of distractions, and this does help him to cope with the various stressors of life. Work takes a lot out of him and requires a lot of concentration. Whilst at work he tends to forget about everything else that could be worrying him. He is also very keen on a particular hobby; a hobby that requires that he weekly spends time outside the home. He has also turned this hobby into a part time job. Rupert is adamant that his dedication to his work and his passion for his hobby is not a form of escapism from the world of autism. Rather, if anything it is a break from all and everything. For him, autism is just another element in his life which requires as much time and effort as other elements. However, he has the ability to focus on the one thing he is performing at the current time, and exclude other variables that could interfere with what he would be doing.

The husband and the father

For Rupert, quality time with his wife is as important as quality time with his children. On Fridays, his wife and himself have a ‘no children day’. Both Rupert’s and his wife’s parents help them out with this by supervising

their children. This enables them to go out and find time to nurture their relationship. Rupert is the breadwinner of the family. The decision for him to work and his wife to stop working was financially driven. This is why he occasionally spends less time than he would ideally spend with his family. However in light of his family's current financial situation, it would be impossible for him to have it otherwise. Nevertheless, for him, his career is not important. His job is important only because it brings the money that his family needs. He is thankful that he has a job that enables him to provide well for the family.

Autism and society

Today Rupert is very comfortable with talking about his children's autism. Most of his friends know about his children's condition. He feels that there is nothing wrong with talking about it. There is no shame or guilt involved, particularly because he has done nothing wrong that could have contributed towards their condition. Furthermore, he reasons that people need to be aware of his children's condition, so that if something happens, such as a tantrum, they would understand better why it occurs.

Some members of his extended family do not agree with this. They do not understand why he is comfortable to talk about his children's condition openly with friends and with acquaintances. Rupert reasons that for there to be more and better understanding about autism, there should be more awareness. Furthermore, for there to be more awareness there must be more openness. However, he appreciates the fact that other people could have other opinions about this.

The future

Rupert sees himself primarily as a father, and not as a father of a child with autism. He describes fatherhood as consisting of a lot of hard work and sacrifice. However he enjoys the role of provider of love – of the unconditional kind – and protection. He hopes that by the time his children grow up they will be independent and self-sufficient. However, as always, he is also thinking about what could go wrong. Thus, he is making sure to save enough money for them to receive the care that they would need, should they still need someone to care for them when they grow up. In the mean time he is not giving up hope. His wishes, his hopes, and his goals are to be able to continue to provide for his family and ensure their quality of life and their happiness.

Note to reader:

The narratives that were storied in the research are central to this study. It is through these stories that the reader can gain real insight into the fathers' experience. The other 9 narratives storied are found in Appendix 12 (pp. 171-230).

4.3. Identification of common storylines, events and elements

The process of the identification of common storylines consisted of analysing the headings of the ‘thematic stanzas’ that composed the 10 narratives. The stanzas that were seen to have common or similar elements were gathered under the heading ‘Events’. An ‘Event’ was not necessarily composed of one ‘thematic stanza’ alone. Rather, it consisted of a cluster of stanzas that focused on a similar experience. An overview of this ‘clustering’ process can be found in Appendix 14 (pp. 234-236), Tables 1 and 2. Table 1 (Appendix 14) provides a general outline of the 10 stories in terms of their composing thematic stanzas. The ‘thematic stanzas’ are grouped together and identified using color and a number-code. Table 2 (Appendix 14) provides an overview of the ‘Events’ identified as well as a ‘Key’ that helps identify the colored clusters in Table 1 (Appendix 14).

The ‘Events’ identified are illustrated in Table 4.1 (p. 68). This table presents an overview of the ‘Events’ as well as their constituent ‘Elements’. ‘Elements’ are particular experiences or sub-themes that contribute towards the formation of the ‘Events’. Some of the ‘Elements’ identified consisted of experiences that many father shared in their stories, whilst others elements were less common across the stories. ‘Elements’ also illustrate how the “Events” in the father’s life could have been distinctively experienced. Tables 1 and 2 (Appendix 14) illustrate how the ‘Events’ and ‘Elements’ of the stories were identified.

The headings used to describe the ‘Events’ and ‘Elements’ identified were elicited using a bottom-up (data driven) and also a top-down (theory driven) approach. The ‘Events’ and ‘Elements’ identified in this study will be discussed further in the commentary in the next sections. This commentary will consist of an overview of the ‘Events’ and the ‘Elements’ and will also consist of excerpts from the various stories, in the third-person-omniscient. These excerpts are in the third person as this commentary is about the narratives that were storied, which were in fact written in the third person. The commentary should also elucidate further the headings used as Events and Elements.

<u>Events</u>		<u>Elements</u>
1	First concerns/regression	<ul style="list-style-type: none"> • Denial
2	The diagnosis	<ul style="list-style-type: none"> • A lack of regard and sensitivity • Uncertainty • Frustration and unanswered questions
3	Search for solutions	<ul style="list-style-type: none"> • The interventions sought • Early intervention
4	The issue of communication	<ul style="list-style-type: none"> • Communication impinging on learning
5	Difficulties contributing to stress	<ul style="list-style-type: none"> • Lack of sustained progress or development • Difficulties related to schooling • Difficulties related to finances
6	Fatherhood	
7	Relationship with the child	<ul style="list-style-type: none"> • Working hard to see progress
8	Coping and coming to terms with their children's condition	<ul style="list-style-type: none"> • The question of "why me?" • The question of "what caused autism?"
9	Affects of autism on fatherhood	<ul style="list-style-type: none"> • Positive effects of the diagnosis • Thoughts on having other children
10	Relationship with spouse	
11	Society and autism	<ul style="list-style-type: none"> • Negative social experiences
12	The future	<ul style="list-style-type: none"> • Hopes and dreams

Table 4.1: Overview of Events and Elements

4.3. The first concerns (Event)

Research seems to indicate that there are no reliable predictors of autism in infancy (Elsabbagh et al., 2012). However, Goin & Myers (2004) suggest that there could be developmental anomalies, which could be present during the first year, which might be indicative of ASD. Characteristics that could be early indicators include a lack of eye contact (Elsabbagh et al., 2012), “lack of affection and social skills, lack of imitative skills and joint attention behaviours, postural/motoric/gestural differences, unresponsiveness towards one’s name, solitary or unusual play patterns, and communication delays” (Goin & Myers, 2004, p. 11).

The stories collected all consisted of an event where an aspect of their children’s development drew the fathers’ attention. This was usually related to an uncharacteristic developmental issue that seemed to cause them concern. Fathers observed their children presenting behaviours such as: flapping; poor eye contact; lack of reciprocity; sensory issues; and delay in communication. In some of the stories, fathers were hesitant to label as different or abnormal the observed behaviors, particularly because of their children’s very young age. However, when the behaviors persevered, and also when they compared such behaviours to other children their sons’ or daughter’s age, they noticed that there was something unique about their children’s behavior.

In some instances the fathers were not the ones who noticed the behaviours. Rather, it was their spouses who were the first to remark on such behaviors. This was the case for Alan:

“...the various encounters that his wife had with many parents and their children made her ask some questions about her daughter’s development, who appeared to be different from other children’s development. She noticed that many children were different from her daughter.” (p. 195)

In Luke’s case, his wife’s concerns started when their son was 8 months of age. At the time Luke’s wife felt that he did not always take notice of her:

“She thought that this was rather strange. She also noticed that he did not answer when his name was called”. Later “Luke also noticed this occurrence and recalls that it was a while before he answered to his name. It also took a while before he could see him sitting down on his own. Luke and his wife also noticed other things such as a lack of social reciprocity, particularly when they used to compare his development to that of his brother.” (p. 216).

Jesmond’s story also included a similar event. Jesmond and his wife were concerned about their son ever since he was very young:

“Jesmond remembers that his wife used to be concerned about [their son] Aaron even when she was breast-feeding him, as he would not react when she called him. She used to tell Jesmond that she sensed something different when compared to their elder son. Jesmond also remembers that when he was young Aaron did not cry or make any eye contact with him or his wife. Initially Jesmond and his wife thought that he was deaf. They also suspected that he could have had a speech delay. Jesmond initially had assumed that it was something typical, as he himself had a speech delay when he was young. Nevertheless Jesmond and his wife together decided to carry out the relevant tests to see if there was anything wrong with Aaron’s development” (p. 209).

On the other hand, William’s concern started when his son approached the age of two years:

“William started to notice him flapping. Initially William thought that the flapping was a game that his son played. As time passed, it became harder for William to take a photo of him, as his son started displaying poor eye contact. He started biting his hands, touching his private parts, licking the wall, and feeling the texture of labels. As he grew older he also started manifesting severe tantrums”(p. 224).

Oliver started to suspect that something was wrong with his son’s development when his son Larry appeared to be disregarding him and his wife, even when he was sitting right beside them. At this point Oliver assumed that he was hearing impaired:

“...when Larry [Oliver’s son] overheard the jingle of a commercial he liked, from the other end of the house, he would immediately run towards the telly.” (p. 185).

Frank on the other hand had realised early on that his son was different, as he used to express himself in a rather peculiar way:

“He used to put his hands up and stand on things and also go through rather odd routines. Initially, his ‘odd ways’ were seen as funny and quirky; so Frank wasn’t too worried. However, an incidental meeting with another child his son’s age during a particular public event changed all that... Frank noticed this boy standing on a chair, and behaving just like his son... That just hit him like a log; that there was something that was unique. There was something that was causing this boy to do exactly the same thing. This prompted Frank and his wife to look for professional advice” (p. 171).

4.3.1. Denial (Element)

The stories also illustrate how many of the fathers initially met their spouses’ and their own concerns with doubt, scepticism, and occasionally denial:

“Alan went through a three month ‘denial phase’ where he tried all he could to find evidence that contradicted the hypothesis of autism. That went on until he realised that his daughter was behaving totally differently from other kids” (p. 197).

In Rupert’s case, his first reaction to his wife’s concerns regarding their daughter’s difficulties was denial:

“At the time he [Rupert] insisted that everything was ok. He also went as far as to identify and print out indicators describing the symptoms of autism and developmental milestones just to prove his wife wrong. By doing this, he felt that he proved that his daughter did not have autism... He wanted to prove that his children were normal. He wanted them to be normal. Furthermore, he didn’t want any label of any sort” (p. 58).

4.4. The diagnosis (Event)

A parent’s reaction to learning about their child’s diagnosis of autism varies from one individual to another (Andeica-Săndică et al., 2011). Parents may display feelings such as “disbelief, anger, guilt, helplessness, devastation, surprise, or even rejection of the child, to understanding and relief when finally the parents have an explanation for their child’s behaviours” (Andeica-Săndică et al., 2011, p. 478). This was the case for many of the participants in this study. The stories indicate that the diagnosis of ASD was met by a variety of feelings, which included feeling shocked (Fred), traumatized

(Jesmond), distraught and discouraged (Oliver), and feeling shattered (Isaac). In the cases of the father's who participated in this study, the official diagnosis was made either by a Clinical Psychologist, an Educational Psychologist or a Paediatrician. The moment, when the fathers learnt of their children's diagnosis, is present and clearly featured in all of their stories:

"The moment when Isaac got the news, that his son could be on the autistic spectrum, is clearly imprinted in his mind. It was three o'clock in the afternoon, and it was a moment that he can never ever forget. His wife immediately started crying when the psychologist confirmed the news. Isaac put up a strong front to support his wife. However, emotions ran high that day, and he broke down in tears soon after leaving the psychologist's office. He was shattered. It was then when he felt that he had touched rock bottom". [Isaac] (p. 178)

"The diagnosis was officially given by the paediatrician and the clinical psychologist at CDAU, and it changed William's life completely, from day to night". [William] (p. 224)

"It was the psychologist who told them [Fred and his wife] that it was ASD. That is when they realized that they had to start learning about the condition. From that point on Fred's life changed again. He initially was heading towards one direction. Very abruptly, from the next moment, he had to make a change of plans". [Fred] (p. 205)

4.4.1. A lack of regard and sensitivity (Element)

An element that was common in some of the stories was the manner in which the diagnosis was made or divulged by the professionals who assessed their children. Some fathers felt disrespected, felt upset and even hurt by the way the diagnosis was communicated. Oliver's story provides a description of the first time an expert in child development assessed his son. The expert immediately remarked that his son had autism:

"Oliver was shocked and even scandalized by the way that the professional, quite coldly, informed them [him and his wife] that their son was on the autistic spectrum. Oliver remembers how it felt when he heard the news: like this was the end for his son, and like there was no way out what so ever" (p. 185).

Jesmond's experience resembles Oliver's who also commented on the manner in which he learnt about his son's diagnosis.

In his case, as he looked back at "the way that he was given the news about his son's diagnosis, Jesmond feels disappointed, and does not approve of the method used by the professional to break the news" (p. 210).

Similarly, Luke's story tells about how he felt that the manner in which his son was assessed and diagnosed was not done in a professional manner.

"At the time of the diagnosis, and also to this very day, Luke is uncomfortable with how the assessment actually unfolded. One of the professionals who first mentioned the word autism presented Alex [his son] with a board with objects that turned or spun. Alex was then observed spinning the wheels that he was presented with" (p. 217).

According to Luke, this is what spurred the professional to conclude that it was ASD:

"The manner, in which the diagnosis was done, rather than the diagnosis itself, is what really annoyed Luke" (p. 217).

4.4.2. Uncertainty (Element)

After the shock of the diagnosis, some of the fathers were left with a label, but also with a lack of understanding of what that label actually meant:

"The diagnosis of ASD brought about a lot of uncertainty and also a lot of questions...when he heard for the first time his son's diagnosis, he was initially shocked and frightened. What exactly was autism, he asked? [Luke] (p. 217)

"Oliver found it difficult to come to terms with the news. He felt puzzled and confused". [Oliver] (p. 186)

Some of the stories collected in this study illustrate the uncertainty that was brought about by the diagnosis. Furthermore, the numerous unanswered questions left the fathers guessing on what would be happening from that moment on. This was evident

in Luke's story, as the diagnosis brought about a lot of hazy yet daunting information, such as:

"...autistic children do not speak; some are intelligent whilst others are not; some have certain skills whilst others have other skills; some even are isolated and refuse to have any contact with people. As Luke heard these things he asked himself: "ow, my...what is coming my way?" Was he not going to be able to hug his son anymore? Was [his son] Alex not going to ever hug him?" (p. 217)

The situation was similar for Isaac. The first thing that came to Isaac's mind when he heard about the diagnosis was:

"...what am I going to do now? The questions that came to mind were many. On the other hand the answers to those questions were lacking. Isaac asked himself what was going to happen to his child" (p. 179).

Similarly, when Oliver learned about the diagnosis, he did not even have a clue on where to start, or where to search for help:

"What should he do now? How could he help his son? The lack of information regarding autism made him feel helpless" (p. 185).

4.4.4. Frustration and unanswered questions (Element)

Oliver's story sheds light on the lack of information that he was supplied with and on the lack of support that the professionals working with him and his family displayed when communicating the diagnosis:

"The way autism was depicted and described by this particular professional left Oliver in a state of shock. He was traumatised and was very emotional. He had hoped that he would have encountered an individual who empathised with him and who would have encouraged him. Nevertheless, this was not to be, and Oliver was left emotionally unwell whilst trying to make sense of the new piece of information that had shocked his life" (p. 186).

Similarly, Frank's story highlights how the professionals working with him left him with a lot of unanswered questions, as well as a lot of added frustration:

“He has autism. But for crying out loud, tell me how bad it is!? Is he going to speak? Is it severe? These were questions that remained unanswered” (p. 172).

Frank’s story however seems to indicate that, unlike many fathers’ who felt let down by the professionals’ attitude towards them and their child’s difficulties, the professionals working with his son were sensitive to his situation:

“The professionals who broke the news were understanding and sensitive to the situation. However, they were unable to answer Frank’s main question: what the hell do you do now?” (p. 172).

However, in his case, whilst longing to have his questions answered, he was also conscious of the possibility that such questions were probably unanswerable:

“...there was a part of him that was saying that these people couldn’t give him the answers to his questions. Then there was an emotional side of him that was yearning for answers: ‘give me something...anything’. He was not asking anyone to lie to him, but he wanted someone to throw him a rope, and tell him at least if there even was a ten percent chance of him talking. Yet, this was not to be” (p. 172).

4.5. Search for solutions (Event)

Many of the fathers’ stories involved a search for a treatment or therapy that could help their children with their difficulties. The steadfast commitment towards a search for solutions or possibilities that could help their children was evident throughout all of the fathers’ stories:

“After the initial shock of the diagnosis Isaac got himself together and started looking for ways forward. He reasoned, that what had to be done just had to be done (12)...he embarked on a voyage to help his son ‘control’ the symptoms of autism” [Isaac] (p. 179).

“The first thing that Ian did upon hearing the news was to try to find out about the options or possibilities that could help his son” [Ian] (p. 190).

“Luke’s first priority has always been to help Alex reach his potential. Luke has worked towards this by searching for treatments and therapies that could help Alex [his son] maximize his potential” [Luke](p. 219).

Evident in many of the fathers' stories was the great sense of urgency as well as the strong sense of purpose with which they approached their search for solutions. Some of the fathers were even hoping to find a cure for autism. The urge, or need, to help their children progress also pushed some of the fathers to explore unconventional interventions:

"He takes what he deems are calculated risks that occasionally go against Maltese doctors' advice. An example of this is BioMeds...He is aware that the medical authorities are very conservative and they have not as yet approved or accepted such intervention. Nevertheless, he feels that he is not in a position to wait for ten years for the authorities to accept such intervention and feels that he is driven by a sense of urgency to help his children" [Rupert] (p. 60).

4.5.1. The interventions sought (Element)

A large number of parents every year, as a result of wanting to help their children, look to find interventions or treatments that might help their 'autistic' children (Nancy, 2010). The fathers' stories shed light on the numerous strategies and interventions that they came across and also chose to try. As mentioned earlier some of these were controversial, whilst the evidence base of certain interventions was contentious. Some of the therapies that were sought were: Speech Therapy, Occupational Therapy and Structured Teaching (TEACCH). Therapies that were less popular were: Hyperbaric Oxygen Therapy (HBOT), BioMeds, the Son-Rise Programme, gluten-free and casein-free diet (GFCF), and Stem Cell Therapy. The fathers' stories show how fathers utilised one or more of the interventions/therapies mentioned previously. They also present results or outcomes that were very dissimilar:

"A strategy that Oliver and his wife tried, with the hope of reducing the effects of autism on their children, was that of a gluten free diet. They also consulted with a foreign doctor who prescribed various supplements, vitamins and other remedies that could help his children. They tried every possible thing. They also took up the suggestion of the foreign doctor who suggested exposure in the hyperbolic chamber. Thus, they travelled to the UK where they underwent hyperbaric oxygen therapy" [Oliver] (p. 188).

“Ian also opted to try BioMeds and decided to purchase vials of vitamin B from the United States. However, after attempting this, he felt that the treatment was not as successful as he had initially hoped. There was a point where he decided that it was not worth the hassle or the money, especially since nothing he was trying was actually proven” [Ian] (p. 190).

“...besides the nutritional and supplementation advice, this doctor also suggested ‘hyperbaric oxygen therapy’. In Luke’s opinion this was a very good suggestion” [Luke] (p. 219).

An important aspect of these interventions was that of their cost, which varied from €12 for a session of HBOT, €30 for an hour of speech therapy, and €10,000 for stem cell therapy.

4.5.2. Early intervention (Element)

Many of the stories were characterised by the fathers’ eagerness to provide their children with therapy as early as possible. ‘Early intervention’ was described by some of the fathers as an important aspect of education that produced positive outcomes:

“...if he and his wife had not worked with John [his son] early on, he is two hundred percent sure that John would not have reached this level. For Ian early intervention was key to his son’s development and to the progress that is evident today” [Isaac] (p. 182)

“One of the things that worked best for Mary [his daughter] was early intervention” [Alan] (p. 196).

Research seems to support the fathers’ notion that early intervention is useful to help their children cope better with their difficulties. Furthermore, research seems to indicate that ‘early intervention’ could also reduce the possibility of future difficulties (Paynter, Scott, Beamish, Duhig, & Heussler, 2012). A study completed by Wong and Kwan (2010) also seems to indicate that parents of an ‘intervention’ group perceived significant improvement in their children’s language, social interaction, and their own stress level when compared to a control group.

4.6. The issue of communication (Event)

Donaldson, Elder, Self and Christie's (2011) study, on fathers' perception of their roles with their children with autism during 'In-Home Training', seems to indicate that communication is perceived to be very important for fathers. This study also suggests that communication influences the fathers' relationships with their children to some degree, and also contributes greatly towards the father's wellbeing. The fathers' stories seem to corroborate Donaldson et al.'s (2011) findings. However, whilst some of the fathers were happy with their children's communication, both expressive and receptive, some were unhappy with the lack of quality communication presented by their children. The stories illustrate how the children's ability to communicate is seen as central for fathers who participated in this study:

"The issue with communication is very stressful for Frank. The hardest thing to deal with, for him, is the fact that his son has never spoken to him. Frank gets emotional every time he sees a child his son's age talk. He yearns for his son to one day look at him and tell him what he needs, rather than having to figure his son's need for himself" [Frank] (p. 172).

"...at this stage Alan sees the development of speech as one of the most important things.... Alan dreams that one day she would be able to talk to him and have a conversation with him... the lack of communication upsets and saddens Alan" [Alan] (p. 199).

"Alex's [Luke's son] lack of communication occasionally is also a cause of stress. However, this is not because he does not talk to Luke. Rather, it is because there are times when Alex is hungry, thirsty, sick, or in pain and unable to express himself in a verbal or nonverbal manner" [Luke] (p. 218).

"Communication is an issue that frustrates Ian somewhat...what frustrates Ian is the fact that he cannot have a conversation with him [his son Franco]... With him it is a one-way relationship. Whilst Ian tries his best to engage him, and also see to all of his needs, he does not get any type of feedback in return. Ian would really like to get a reply from his son; a simple yes or no when he asks him if he wants a drink" [Ian] (p. 191).

As evident in the parts of the stories cited above, difficulties in communication seem to be the cause for a lot of frustration, stress and also sadness. One of the main causes of stress and sadness seems to be the fact that some fathers have never or have rarely

heard their children verbally express their love or affection towards them. This issue is very eloquently described in Isaac's story:

"For Isaac, communication is a very important aspect in development and also to the father-son relationship. If [his son's] communication did not develop as it did that would have been heart breaking for Isaac... Isaac explains; 'I do not wish my worst enemy to have a child who does not tell him that he loves him and does not communicate with him' [Isaac] (p. 182).

4.6.1. Communication impinging on learning (Element)

Apart from frustration and sadness, some of the stories illustrate how some of the fathers feel that a lack of communication, and particularly a lack of speech, is impinging on the children's development and on their learning. This was the case for William:

"For William communication is very important. In his opinion, before he starts speaking his son will not improve" [William] (p. 227).

In Alan's story it was evident how his daughter's lack of communication impinged on her learning by making it difficult for him to understand what her interests were:

"Alan also feels that 'speech' would also allow him to teach her many more things. It would also enable her to tell Alan what she enjoys and what annoys her. An instance where speech would have been useful is when Alan used to take Mary [his daughter] to piano lessons. At one point she didn't want to go anymore, however she did not tell him what she did not like about piano lessons. If she had told him what annoyed her he would have been able to help her. But she doesn't and can't tell Alan" [Alan] (p. 199).

4.7. Difficulties contributing to stress (Event)

The research identified in the literature review seems to indicate that parents of children with ASD report significantly elevated levels of stress in comparison with parents of typically developing children (Baker-Ericzen et al., 2005). The stress could be a result of various factors, including behavior problems and lack of prosocial behaviour (Lecavalier et al., 2006). The stories seem to corroborate such findings by

illustrating how behavior difficulties, such as rigidity, tantrums and oppositionality, were major causes of stress:

“[Fred] has had to adapt and cope with situations when Mary [his daughter] has had a tantrum. When she did have a tantrum, she usually lied down on the floor screaming and shouting and banging her hands. In such cases, she also threw the first things that she found close to her. During tantrums she was also noticed twisting and turning on the floor. Furthermore, Fred feels that the more attention he gave her, the worse things became. Sometimes tantrums like these even spanned over 5 minutes. In some occasions Mary screamed so much that she started sweating” [Fred] (p. 205).

“His son is relatively rigid and is demanding and adamant with regards to his routines. If his son decides that he requires something or that he wants to go somewhere, he is usually adamant about his request, and gets very frustrated if he doesn’t get what he wants” [Rupert] (p. 60)

The stories also illustrate how the children’s difficulties in social relatedness and also the care responsibilities placed on the fathers are causes of stress:

“...on one occasion whilst on a family outing at the beach Jesmond nearly had the fright of his life when Aaron [his son] seemed to have disappeared. Jesmond and all the family had only placed their belongings on the ground, when Jesmond noticed that Aaron was nowhere to be seen. The whole family immediately thought that the worst had happened. They immediately started searching for him. They soon found him swimming in an area that they had frequented on previous occasions” [Jesmond] (p. 212).

“On one occasion, Ian and his family all went to Disneyland for a holiday. However this holiday was more stressful than it was relaxing for Ian... Ian vividly recollects a moment during that ‘holiday’ when Franco ran away and nearly got run over by a car. This happened because he had seen something that interested him and just decided to run and cross the street” [Ian] (p. 192).

Apart from identifying some of the difficulties and causes of stress, the stories also shed light on the resulting emotive and cognitive processes some of the fathers go through as a result of such stressors:

“William sometimes finds himself thinking of parents that are at the seaside with their children, whilst he is having an occupational therapy session” [William] (p. 226).

Frank’s story quite vividly highlights the emotional turmoil that could be present in a father’s life, particularly in times of high stress:

“In another stressful moment Frank thought about the people who were reported on the news to have abandoned their child at the airport. He argues: “as a parent, you completely understand it. You ‘lose it’ a little bit. You are sleep deprived. You are nervous and afraid. You can imagine coming out of that then you have a child who has very little communication. You got the tantrums. You got the not going to sleep and all of the things related with autism”. Whilst dismissing such thoughts as crazy and senseless, he talks about such feelings with a lot of guilt. He is adamant and utterly convinced that he would never ever dream of putting his child in harm’s way. Yet, he finds it very hard to accept that even in his darkest hour, such crazy thoughts lurk in his head” [Frank] (p. 173).

4.7.1. Lack of sustained progress or development (Element)

Another stressor that is present in some of the fathers’ stories is that of the children’s lack of progress. Luke’s story depicts the sadness that he feels when he sees his son’s ‘slow’ development:

“Caring for a child with autism is very tiring, and at times the lack of progress is saddening. In fact in some moments Luke felt extreme sadness and helplessness” [Luke] (p. 218).

Frank’s story also illustrates the frustration that he experiences when confronted with the absence of his child’s sustained development:

“Frank is frustrated by the absence of normal and sustained progress seen in autism. Furthermore, with all the uncertainty surrounding autism and development, he often forgets to enjoy the little progress observed. He is sometimes envious of other parents who normally have the opportunity to see their child develop naturally. He feels that whilst neurotypical children’s mental faculties advance naturally, in autism this process is not as natural... With children with autism, such development occurs but in a rather artificial manner.” [Frank] (p. 172).

Jesmond's story also consists of accounts in which he was frustrated with the 'slow' development of his son's skills. However, what stressed and frustrated Jesmond mostly was his son's difficulties with 'displaying' the skills that he had learnt:

"Jesmond is angry when he is sure that Aaron is capable of doing something and refuses to do it. He feels even more frustrated when he considers all the time, energy, and money spent on therapy sessions for him to improve. Consequently, when he fails to show his progress it makes Jesmond feel frustrated, angry and upset" [Jesmond] (p. 212).

4.7.2. Difficulties related to schooling (Element)

Another difficulty that is common in many of the fathers' stories is that of schooling. In some cases the difficulty consists of what the fathers perceive as a lack of support from the educational authorities and from the school:

"One of the difficulties William encountered was that of obtaining an LSA (Learning Support Assistant) for his son. The statementing panel was hesitant to assign James an LSA on a one-to-one basis..." [William] (p. 224).

A difficulty that William seems to have come across is the lack of preparation of some of the programmes or institutions that his child attends:

"At this particular summer school William again found an ill prepared LSA as well as an ill prepared programme. There was no structure and no consistency. James used to come back home covered in urine with his packed lunch still intact, as staff at the summer school did not give him time to eat" [William] (p. 225).

Isaac's story illustrates how frustration and stress is a result of the attitude with which some of the members of staff in particular institutions approach the condition of autism:

"On one occasion Isaac had a near meltdown at school when John's LSA blamed his lack of progress on his condition.... Isaac was anything but pleased with this as he was of the opinion that such an attitude was keeping [his son] John from learning as much as he could have been learning. The condition or the label should not be a way to excuse John, he believed. Furthermore, a diagnosis should not be there to limit a

child, but should be a channel to get that child somewhere” [Isaac] (p. 180).

A difficulty that stresses Fred is that of inclusion. His story illustrates how the school that his daughter attends does not help much to make her feel included:

“...schools did not always help a lot with including Mary in mainstream education. For Fred it is important that his daughter is included in school; is supported; and also understood. However, in the past, this did not always occur.” [Fred] (p. 207).

4.7.3. Difficulties related to finances (Element)

An issue that many of the fathers’ stories include is that of finances.

“William also experiences frustrations brought about by financial burdens linked to autism. He used to employ a professional to work with James individually at home. This service used to cost him 10 euro an hour. [His son] James also attends O.T. sessions, which cost 20 euro an hour... These sessions are not free of charge. All of these fees, as well as that of the private school [James attends], are a burden on William and his family, and are also extremely anxiety provoking” [William] (p. 227).

What is noteworthy in this case is the fact that whilst some of the stories unequivocally include this issue as an individual event, other stories referred to ‘finances’ indirectly. The issue of ‘finances’ is an issue that many fathers’ seem to come across, particularly whilst searching for ‘solutions’ for their children’s difficulties. However, in many instances, their commitment towards the children’s wellbeing outweighs the financial burden of such interventions. This however does come at a price, as is clearly illustrated in Oliver’s story:

“The increased financial demands and consequent increased workload made it difficult for Oliver to find time to spend with his family. The amount of time he spent away from home, because of his work commitments, afflicted Oliver” [Oliver] (p. 186).

4.8. Fatherhood (Event)

In the review of literature completed, and summarized in the previous chapters, the lack of evidence regarding the notions of fatherhood of fathers of ‘atypically developing children’ was evident. Nevertheless, the review shed light on certain concepts that fathers of children of typically developing children felt were central to their construct of fatherhood. Some of the concepts consisted of providing a stable environment consisting of both emotional and physical stability, teaching, physical interaction in the form of play and care giving, and providing emotional support and building self-esteem (Summers, Boller, Schiffman & Raikes, 2006).

Very similar concepts are present in many of the fathers’ stories. However the fathers’ notions of fatherhood seem to be re-dimensioned, to a certain degree, by their experience of fathering a child with particular difficulties. The ‘re-dimensioning’ seems to support Goodsell et al.’s (2010) suggestion that notions of fatherhood are greatly conditioned by the situation of the observer (father) and are thus very subjective.

The stories of the fathers who participated in this study include various views and experiences of what fatherhood consists of and means for fathers of children with ASD. In some of the stories, fatherhood is described as a battle. This is the case for William and Frank:

“William believes that in moments like these, as a father he has to step up and fight for his son. He has to be like a fighting lion... He goes further and called his experience a constant battle and a relentless upstream struggle” [William] (p. 226).

“For Frank being a father also entails a certain amount of fight: fighting for his son. The fight is against bureaucracy at times, and is about trying to get the right support for him at school. From an emotional point of view, he sometimes feels like actually punching people. Even though this has never happened, being a father, for Frank, means that he has to be ready to get up and fight for his son” [Frank] (p. 176).

Other elements of fatherhood that the stories present are:

“...providing and putting food on the table”; [being a] “breadwinner”; “keep[ing] everything out and keep[ing] him [his son] and his wife as happy for as long as possible”; “knowing that he is being useful to his family, and that his actions are contributing to his family’s happiness, contributes towards his father identity” [Frank] (p. 175).

“...fatherhood means immense love”; “fatherhood means responsibility and sacrifice”; [fatherhood entails] “to provide his son, who suffers with autism with better development opportunities so he hopefully recovers” [William] (p. 229).

...[fatherhood means] “responsibility, love and economic stability” [Oliver] (p. 187).

“...his role as a father requires him to be supportive. His desire is to provide his children with help and guidance. But most importantly Isaac feels that he is his children’s safety net: the person they fall back on when in need. With regards to John, Isaac feels that there are times when he needs help and support with everyday things. Particularly in view of his difficulties, Isaac strives to help him as much as he can and strives to provide John with the right support and guidance he requires to overcome his obstacles” [Isaac] (p. 180).

“For Alan fatherhood is a challenging but important role”; “According to him this is something that all fathers do: they give their children direction”; “he would like to be a mentor for his daughter” [Alan] (p. 197).

“Ian’s notion of fatherhood today comprises a lot of self-sacrifice” [Ian] (p. 192).

Fred put forward an interesting aspect regarding fatherhood; his story illustrates how his notion of fatherhood is influenced by his child’s difficulties:

“Fred strongly feels that his role is to help his daughter to feel loved... For him to carry out his duties as a father he feels that he requires a lot of time, a lot of patience and a lot of sacrifice. He feels that he probably requires more time, patience and sacrifice than a father whose child is more independent and who has better developed self-help skills” [Fred] (p. 208).

4.9. Relationship with the child (Event)

The stories gathered shed light on the varying relationships that exist between the fathers and their children. The father-child relationships all vary from one to the other to some degree but all include elements of rough-and-tumble play. All of the fathers seem to enjoy spending time with their children and all seem to enjoy the physical and playful aspect of their relationship with their children:

“William enjoys doing activities with his son [James] such as wrestling, which James also seems to enjoy. James also enjoys it when William carries him on his back and plays horse... William plays with James and enjoys tickling him and enjoys roaming around the house with him” [William] (p. 227).

“Frank describes his relationship with his son as a very affectionate and emotional one. His son enjoys hugging and kissing his father, who in turn reciprocates keenly” [Frank] (p. 174).

“Luke feels that he has an excellent relationship with his son... When he is with Luke, [his son] Alex seems to be very happy... Sometimes, in a very spontaneous manner, Alex approaches Luke to hug and kiss him. These are the moments that Luke enjoys the most: the moments when his son is affectionate towards him. Moments like these are the ones that Luke really treasures” [Luke] (p. 220).

“In the evening Rupert enjoys playing with both his children. He tries to play educational games. He also enjoys monkeying around with them and enjoys rough-and-tumble play” [Rupert] (p. 60).

4.9.1. Working hard to see progress (Element)

Besides what some fathers define as ‘monkeying around’, that refers to physical play, many fathers also seem to have taken up the role of “mentors for their children”. The stories illustrate how some of the fathers have engaged in various educational activities and spent time working with their children trying to teach them new skills:

“When with his father, [his son] Alex is encouraged to do educational exercises like matching and sorting. Luke enjoys working with his son and would like to find time to do more of this kind of work with him” [Luke] (p. 220).

This educational element of the father-child relationship occasionally seems to have required the fathers to take up an authoritarian parental disposition:

“Isaac’s drive to help his son progress has led him to spend a lot of time working with his son. [His son] John used to work a lot with his father as he was, and still is, strict, assertive and stubborn. Isaac also considers himself to be very persistent... these characteristics were very important when working with John” [Isaac] (p. 180).

4.10. Coping and coming to terms with their children’s condition (Event)

Research concerning the strategies parents of children with autism use to cope with their children’s difficulties indicate that parents use avoidance coping, problem-focused coping, positive coping, emotion-focused coping, and religious coping (Hastings et al., 2005). Furthermore, research also seems to indicate that the coping strategies used could change over time (Gray, 2006). The fathers’ stories illustrate how various coping strategies were used at various moments in their lives. The stories also shed light on how the fathers made sense of their experiences and how they tried to come to terms with their children’s conditions.

Isaac’s story illustrates how difficult it was for him to come to terms with the condition of autism:

“What was very difficult to accept was the fact that his son was suffering from a condition. It was and still is hard to digest for Isaac: “everyone wants his child to be perfect...” [Isaac] (p. 179).

Alan’s story illustrates how he used various coping strategies at different times. He initially used a problem-focused coping and then used a positive reframing and emotion-focused coping strategy:

“Acceptance of the condition provided him with the impetus he needed for him to start problem solving” [Alan] (p. 197).

“Alan states that as a father he initially started to hope, at least at first and until he got grounded, that after a few years or months everything would be normal. He hoped that his daughter would be living a normal life, without problems associated with autism. Then, as time passed by,

he started to realize that autism was here to stay. However, autism is what made his daughter who she is... For him, [his daughter] Mary is Mary also because she is autistic, and loves her just for what she is: his daughter” [Alan] (p. 201).

Similarly, Rupert’s story also sheds light on the use of more than one coping strategy. His story illustrates how he initially also used denial or avoidance strategies to cope with the news of his child’s diagnosis. Eventually Rupert used more of a solution-focused coping strategy, which seems to have been very effective for him:

“Through good information, explanation of the facts, and extensive and thorough research, Rupert gradually came to accept the diagnosis” [Rupert] (p. 59).

Ian’s story, on the other hand, illustrates more of a positive reframing coping strategy where he saw the fact that he had children, in the first place, prevailed over any difficulties that his child manifested:

“Having a child meant a lot for Ian: becoming a father made him a very happy man. Ian feels that he was angrier at that time, when he thought that he could not have children, than when he found out that two of his children were on the autistic spectrum. He was happy regardless of their condition. Then again, he feels that if god were here “right now”, he would still ask him to make his son a normal boy... Today Ian is not angry, but he feels upset and sad... There were times when Ian used to cry when he thought about his situation, but nowadays it doesn’t happen that often. He still feels upset when he talks about his current situation and about the problems he and his children are encountering” [Ian] (p. 193).

Luke also used a solution-focused coping strategy. His story illustrates how his search for solutions served as a coping mechanism for Luke:

“Looking back at his son’s past, Luke would never want to say that he did not try all he could to help his son... If he didn’t try it then Luke would have always had that difficult question at the back of his mind: “what if?” Like that Luke feels that he and his wife have tried all that is in their power to help their son” [Luke] (p. 223).

Even though not explicitly stated in all of the stories, the narratives seem to suggest that “coming to terms” with the condition of ASD was rather difficult, if not elusive,

for the fathers that participated in this study. Frank's story illustrates how 'acceptance' of their children's difficulties eluded him:

"Frank has been on a journey for acceptance ever since he was told that his child was autistic. For him acceptance is a process that lasts a very long time. He has accepted the diagnosis in many ways, but there are still some issues that he feels that he needs to resolve. In his own way, he is still battling with it... However, acceptance is a concept that is elusive. He frequently finds himself asking what acceptance really is. From the stories that he has read it seems to him that acceptance is a phase in people's lives where they actually enjoy their child, or when autism is not seen as a barrier anymore. This could appear to be somewhat of a blissful state. If that is what acceptance is, he argues, then "I guess I have not really found that"... Notwithstanding its elusive nature Frank understands why it is important for people to "find" acceptance" [Frank] (p. 175).

4.10.1. The question of "why me?" (Element)

One of the most emotional questions that some of the fathers raised was the "why me?" question. This question was anxiety provoking for the fathers, particularly because it generally remained unanswered:

"[Fred]...finds himself asking... 'why me?' However, this is yet another question that he does not have an answer to. He then finds himself thinking about things which are related to the "why me" question: "Why was I born in the first place? To have a child with autism?" He also asks why his daughter is autistic? Did nature or god pick him to be the parent of this child? This is when he stops posing himself questions and asserts: so be it!... Fred however is a staunch believer that everything happens for a reason. He always had this point of view, even before his daughter was born. He believes that god has a plan for everyone and that he just has to go through it. He is sure that his plan was written for him the day he was born. Part of the plan specified that he had to have a child with autism" [Fred] (p. 208).

Fred's story sheds light on how the "why me?" question was particularly stressing for him, and also illustrates how this question also led Fred to ask existential questions such as: "Why was I born in the first place? To have a child with autism?" The story however illustrates how Fred used 'religious coping' to make sense of his child's condition and his fathering experience. This coping strategy is also illustrated in other stories:

“What puts his mind at rest is the thought that god has a plan for [his son] him” [Ian] (p. 193).

Interestingly, Luke’s story also illustrates how he tried to positively reframe his experience by reminding himself that autism is a product of chance and that things could actually be worse:

“Ever since finding out about his son’s diagnosis there have been moments where Luke was angry about the situation. Sometimes he even asked himself why things had to be this way. However he also makes a conscious effort to look at the positive side... Luke quickly says to himself: it is tough, but “it could have been much worse”. Luke also reasons that this is question of ‘chance’ and that this is how it turned out to be” [Luke] (p. 221).

4.10.2. The question of “what caused autism?” (Element)

Another question that the fathers seem to have asked is the question of ‘what caused autism?’ The stories collected seem to illustrate that this question, in most cases, was accompanied with self-blame and doubt, which consequently impinged on the fathers’ process of ‘coming to terms’ with their children’s diagnosis.

“Frank occasionally does ask himself difficult questions like: ‘was it my fault? Did I do something wrong? Did I leave it too late? Is it related to age?’ He argues that parents like himself do look to blame themselves in one way or another, and believes that, although natural, this type of thinking will not get you anywhere and is more hindering than productive” [Frank] (p. 175).

“Every day that passes William asks himself the question: “what caused the autism?”... On some occasions, William finds himself looking at his son’s difficulties and blaming himself for them. He finds himself blaming his son’s autism on the vitamins and supplements he used to take when he was younger whilst doing resistance training at the gym. William and his wife sometimes blame themselves. They ask if things might have been different if they hadn’t given James the MMR injection. Could the MMR be the reason for all of this, they ask?” [William] (p. 228).

Some of the fathers’ stories also illustrate how the fathers tried to cope with the “what caused autism?” question and with the anxiety that came with it. The coping strategy

that both Frank and Oliver used was to be pragmatic and consciously chose to not ponder on this question. Rather, they chose to utilise their time and energy for more productive activities like helping their children with their development:

“At the beginning, when his children were first diagnosed with autism he found himself asking the question of ‘why my children?’ Oliver states that it is normal to ask such a question. Oliver also went further and was eager to know what might have caused autism? However he did not spend a lot of time asking such questions. He admits that he did ask questions for a short period of time. He however has today moved forward and acted. He finds it useless to torment himself. Rather he tried to change his attitude” [Oliver] (p. 189).

4.11. Effects of autism on fatherhood (Event)

The stories illustrate how ASD impacted the fathers’ quality of life. Luke and Isaac’s stories in particular shed light on this aspect of fathering a child with ASD. Luke and Isaac both seem to have had to reorganise their priorities in life, and in so doing they had to give up on many things they would not have had to give up on if their children had not presented with such difficulties:

“The diagnosis of ASD made Luke reorganise his priorities in life: both as an individual and as a father” [Luke] (p. 217).

“The work that Isaac did with his son yielded benefits. The work he did required time and energy. The progress made by John thus also came at a price for Isaac. In the past and at present he had to take important decisions that involved his work, and his personal life, to make sure that he was able to see to his son’s needs. Some of these decisions involved letting go of some of the important things he was doing in his life” [Isaac] (p. 183).

Other stories shed light on how ASD impinged on their experience of their children and consequently on their fathering experience:

“For William, autism is an obstacle for his son’s development. Autism is robbing him of his life. His son reminds him of a star or a comet; its there, its beautiful, it exists. However, he cannot live it” [William] (p. 228).

“John never told his father or his mother that he loved them and never said, “love you”. That was really painful. Sometimes the lack of such interaction used to be very frustrating. Both Isaac and his wife used to be affected to the point that they occasionally had bursts of anger” [Isaac] (p. 182).

“Frank is sometimes not sure if the physical aspect of their relationship is an expression of his son’s emotions or if it is his son’s way to obtain the sensory stimulation that he requires. This question has been lurking in his head for some time now, and is yet another source of frustration. Frank believes that in the case of a neurotypical child he could easily assume that it is not a sensory issue. In the case of his son, he is unable to make such an assumption. The uncertainty surrounding this issue makes him feel as if he was in limbo” [Frank] (p. 174).

“Ian feels that the difficulties related to autism have impinged on the father-son relationship and on his fathering experience to some degree. Particularly for his son Franco, who seems to be living in another world. For Ian, it is as if his son doesn’t care whether his father exists, and the only things that matter are his PC and going to swim. Ian occasionally feels that it is as if all he is doing for Franco is keeping him alive. There is no qualitative relationship between him and his son. Rather, it is more of a one-sided relationship” [Ian] (p. 191).

4.11.1. Positive effects of the diagnosis (Element)

Kayfitz et al. (2010) postulate that parenting a child with ASD could also have a positive effect on parents. Some of the benefits identified could be: learning through experience of special problems; source of strength and family closeness; personal growth and maturity; source of pride and cooperation; and expanded social network. The stories gathered in this study substantiate some aspects of Kayfitz et al.’s (2010) study. The stories in fact illustrate how fathering a child with ASD, on some occasions, made the fathers’ more resilient (e.g. William’s story), encouraged the fathers’ personal growth and maturity (e.g. Isaac’s story), and also was a source of family closeness:

“The circumstance and challenges that he has been through ever since being faced with the challenges brought about by a diagnosis of autism made William more resilient; more stubborn; and more determined than ever” [William] (p. 225).

“Isaac feels that this experience, of fathering a child with autism, has not only been stressful. Rather, this experience has helped him grow as an individual. His child, as well as his condition has taught Isaac to empathise even more with people who he comes across in his line of work. The experience of fathering a child with ASD has taught him to sympathise more and understand more the experiences that people go through. Today when people present him with their problem, he is more patient and tries harder to comprehend and empathise with them even more” [Isaac] (p. 182).

4.11.2. Thoughts on having other children (Element)

One of the issues that the stories shed light on is the fathers’ concern about having other children. After learning about the diagnosis of ASD, some of the fathers that participated in this study had second thoughts about having other children, as they were worried that they would also have difficulties related to autism. Thus, their children’s diagnosis effected their decision to not have other children:

“Luke would have liked to have another child after [his son] Alex was born... However, both Luke and his wife were afraid of the possibility of having another child with autism” [Luke] (p. 216).

“The decision Frank and his wife made to have one child and not two is partly financially motivated. This decision also has to do with his understanding that if he had to have another child there is a 70% chance that that child would also be autistic” [Frank] (p. 177).

Frank’s story also sheds light on an interesting issue - that of the down side of not having other children:

“Frank believes that this decision could also have its down side, particularly for his son who would not have a sibling. He is also afraid that there is a chance that he and his wife would one day come to regret this decision” [Frank] (p. 177).

Oliver and William’s stories also shed light on the way fathers look back at their decisions of having other children:

“As [his son] Larry was actually diagnosed with autism, Oliver wife was expecting the twins. It was official that Larry was autistic only after the twins were conceived. In hindsight, if he knew about Larry’s autism

beforehand he would have not opted to have more children” [Oliver] (p. 186).

“William also believes that if his first child had been diagnosed with autism, he would not have tried to have a second child” [William] (p. 229).

4.12. Relationship with spouse (Event)

The fathers’ stories, to some degree, all shed light on the added stress that the children’s difficulties placed on the mother-father relationship. However, many of the stories illustrate the different ways that this stress impacted the fathers’ relationship with their spouses:

“As a result of all the stress and pressure they experience, William quarrels frequently with his wife. They find it very difficult to spend some quality time alone with each other and at times do not find the time to go out as a couple. One of the reasons for this is that everyone around them seems to be ok with keeping an eye on their eldest daughter but refuse to be held responsible for their son” [William] (p. 229).

Other stories, such as that of Jesmond, seem to indicate that parenting a child with autism did not impinge on the husband-wife relationship:

“Jesmond does not feel that the diagnosis of autism has affected the relationship that he has with his wife” [Jesmond] (p. 214).

On the other hand, the stories of Isaac, Alan and Ian illustrate how the added stress and pressure of parenting a child with autism contributed to make their relationship stronger:

“Another positive aspect of his experience is its impact on his relationship with his wife. Through the experience he has realised even more that his wife and himself are both on the same wavelength... Today he feels that this experience has helped them become even stronger as a married couple” [Isaac] (p. 183).

“The diagnosis has impacted the couple’s relationship by making them stronger. The diagnosis and the difficulties related to [his daughter] Mary’s condition contributed to more responsibilities. This added ‘load’

however made them even more committed and co-dependent on each other” [Alan] (p. 199).

“With regards to his relationship with his wife, he feels that all the circumstances they have been through together have made them even stronger” [Ian] (p. 194).

Rupert’s story goes further to illustrate how the help they have received from the people around them has enabled them to cope better with the stress and pressure, by enabling them to find time to nurture their relationship:

“For Rupert, quality time with his wife is as important as quality time with his kids. On Fridays, his wife and himself have a ‘no children day’. Both Rupert’s and his wife’s parents help them out with this by supervising their children” [Rupert] (p. 61).

4.13. Society and autism (Event)

The stories collected shed light on the fathers’ experiences and views of society’s perception of autism:

“What hurts Isaac is to see the stares that people sometime give his son. For him people’s stares at times are worse than their tongues. He doesn’t actually care about people’s opinion but such actions towards his son do hurt him. That is why he wants to protect his son” [Isaac] (p. 183).

“Luke is of the opinion that most of the general public is not informed well about the subject of autism. Some people are actually very insensitive towards autism and the difficulties brought by the condition” [Luke] (p. 221).

Some of the fathers felt that people were not informed about autism and about how this condition affected children. This could be seen in Oliver’s story:

“Oliver feels that many people are clueless when it comes to autism. When for the first time he told some acquaintances and friends about their children’s diagnosis their reaction was bland. This was because they were unaware of the implications and consequences of the diagnosis, and for this reason it did not make a difference to them” [Oliver] (p. 189).

The stories also illustrate how some of the fathers came across a lack of awareness and sensitivity also from people who were very close to them:

“The notion of there being a lack of awareness stems from William’s family’s difficulties with themselves not understanding autism” [William] (p. 229).

Interestingly, Luke’s story illustrates how he tried to make sense of this apparent lack of awareness:

“...he sympathises with these individuals, as he feels that if his son had not been diagnosed with the condition he would have not been aware of the condition. Luke is of the opinion that when something does not affect individuals personally, like the way autism has affected him and his son, they do not take an interest in learning about that condition” [Luke] (p. 222).

On the other hand, Ian’s story illustrates how he perceives that the awareness regarding autism is gradually changing:

“Nowadays he even feels that people don’t stare at his son when he makes eccentric noises with his mouth. Ian has never come across members of the general public who, when they perceive his son being different, have accused him of being a bad parent. Furthermore, he also states that many people immediately realise that his son has autism, and for this reason he was never labelled as a bad parent. However he has met other parents, whose child was diagnosed with autism, who went through similar experiences and were labelled as bad parents” [Ian] (p. 194)

4.13.1. Negative social experiences (Element)

The fathers’ stories include various examples of instances or events when they experienced society’s lack of sensitivity towards the condition of autism. These could be seen in Luke’s, Oliver’s (who recounts his wife’s experience) and Jesmond’s stories:

“...on one occasion Luke and his family attended church to hear mass. Alex is not a child who just stays in one place and stays still. Rather he tends to move around all the time. There are times when he is active in moments when he should be quiet. Because of this, Luke and his family

had decided to stay in the “crying room”... That day Alex was very active and energetic and was making a lot of noise. So Luke’s wife, in order to keep him quiet and amused, opened a packet of crisps. When an individual, also seated in the “crying room”, saw this she arrogantly told Luke and his wife: “do you think that you are at a restaurant?”... Luke then tried to explain that Alex is autistic...[however]...this person in particular did not seem to understand and just continued complaining [Luke] (p. 221).

“...at Sunday’s mass when he would kneel down, gaze backwards and shush off the general public who were participating in mass. Jesmond used to hear people commenting on [his son] Aaron’s behaviour. He occasionally heard people say things like: “what a shame, he is a careless parent, he is not vigilant and tolerates that his son misbehaves during mass [Jesmond] (p. 214).

Jesmond’s experience of being labelled as a bad parent is similar to that of other fathers. The stories in fact illustrate how individuals who accuse them of being incompetent parents, and also attribute their children’s difficulties to them, hurt the fathers:

“His children’s behaviour is often linked with parents who are unable to control or manage their own children... Sometimes people conclude that Oliver and his wife are incompetent parents and they are failing in their parenting. Such an attitude makes matters worse for Oliver and his family. However, these days he ignores other’s opinion regarding his children. He tries his best to see that his children do not annoy other people, particularly in view of the fact that he does not tolerate people who annoy his children” [Oliver] (p. 189).

Some of the stories also illustrate how fathers try to tackle the issue of society’s lack of sensitivity by educating the people around them about the condition of autism:

“Frank reasoned that if he did not do anything to educate the people around his son, then he would just be seen as different and would be considered an outcast. If he did educate the parents, the parents would hopefully educate their children, and the children would then be in a position to understand his son better. In this way Frank was hoping to prevent his son from becoming socially isolated” [Frank] (p. 175).

4.14. The future (Event)

One of the most common elements of the fathers' stories is that of the future. The stories illustrate how most of the fathers perceive the future - with hope but also with a lot of concern. The stories illustrate how many of the fathers deliberate and reflect about what the future may hold for their children. However their forethought appears to have contributed to a lot of uncertainty and ambiguity:

"Frank has always been preoccupied with his son's future... The most unsettling aspects of the future is the "not knowing", and the fact that he can't take anything for granted" [Frank] (p. 177).

"William realises that notwithstanding his best efforts, he cannot plan ahead for his son. He states that he cannot do what he had always planned or dreamt for his son" [William] (p. 230).

"When Ian learnt about his children's condition he suddenly found himself pondering a lot about the future. He suddenly started looking towards the future with a lot of doubt and uncertainty... Furthermore, Ian is anxious about Franco's future, as he is concerned that he could not be able to live an independent life" [Ian] (p. 193).

An issue that seems to concern the fathers that participated in this study is the question of what will happen once they are not able anymore see to their children's needs. This question seems to provoke the fathers a great deal of anxiety:

"The thought of his children's future makes Oliver anxious. Oliver is worried about when he will one day pass away and leave his children alone. He is aware that this will happen sooner or later. However he tries his hardest to repress this agonising thought"[Oliver] (p. 188).

"...Alan also has some concerns about his daughter's future... His sense of urgency is also motivated by the uncertainty and anxiety that arises when he thinks of the day that he and his wife will not be able to take care of Mary anymore" [Alan] (p. 201).

"Jesmond is conscious of the fact that eventually he will one day kick the bucket. This thought, and that of leaving [his son] Aaron on his own, makes him apprehensive. He occasionally finds himself pondering on Aaron's future and asks himself whether he would be able to lead an independent life. Jesmond is hopeful that he would see Aaron develop his

capabilities later on and also lead an independent life. However he is aware that one cannot predict the future” [Jesmond] (p. 214).

An issue regarding the future that is particularly unsettling for the fathers is that of the ‘inclusion’ of their children in society and the fear of their children’s institutionalization. Some of the fathers’ stories illustrate the dread and dismay that comes with the notion of institutionalizing their children:

“An aspect about the future that he is concerned about is the issue of inclusion. He states that many parents who have children with a disability are concerned about their children’s inclusion in today’s society. He feels that life is scary for people with no difficulties, let alone for children with this condition” [Fred] (p. 209).

“The thing that hurts Luke the most is when he hears someone saying that he can place his son in a home or an institution. This thought upsets him a lot” [Luke] (p. 222).

“One of his greatest fears is that if she [his daughter] is not able to take care of herself, she would have to be taken in care and would have to stay there. If she is locked in an institution she will never reach her potential. Rather, she would definitely regress. That would be Alan’s worst nightmare. He refuses to see her get locked up in an institution: “over my dead body! Never! No way!” [Alan] (p. 201).

Some of the stories illustrate how the fathers’ concerns about their children’s future, and their wish to see their children overcome their difficulties and lead an independent and autonomous life, led them to search for ways to help their children once they were gone:

“Luke also tried to look towards the future and start saving some money for [his son] Alex and have also put a savings plan in place. In the future the bank will take over the management aspect of the funds saved when they both are no longer alive... This is somewhat reassuring for Luke” [Luke] (p. 222).

“He hopes that by the time his children grow up they will be independent and self-sufficient. However, as always, he is also thinking about what could go wrong. Thus, he is making sure to save enough money for them to receive the care that they would need, should they still need someone to care for them when they grow up” [Rupert] (p. 62).

4.14.1. Hopes and dreams (Element)

Apart from worry and anxiety, the fathers' stories illustrate the fathers' dreams and wishes for their children's future. The fathers seem to look towards the future with the hope that their children will one day overcome their difficulties and lead an independent life. Some of the fathers' wish is to see their children cured from autism. Other fathers' wish was to see their children become autonomous and self-sufficient:

"...his hope is to see his children all progress rapidly, and ultimately become capable of living an independent life... However, if he had to make a wish, he would ask for his children to not be affected anymore by autism. The ideal situation would be that with the click of a button, he would cure them. Oliver is aware that this is only wishful thinking and not really possible. For this reason, he would be equally content if his children were able to lead an autonomous life" [Oliver] [p. 188].

"He hopes that in the future his son will be autonomous and independent. He has an image of his son working in computing. He describes it as a "geek type of route" [Frank] (p. 177).

"Alan's wish is to see [his daughter] Mary overcome certain barriers. He feels that she is able to do so and feels that there are good chances of seeing her progress, and this gives him hope" [Alan] (p. 200).

In the next section, this commentary and also the individual stories will be discussed in terms of the research questions of this study.

CHAPTER 5 – DISCUSSION

5.1. Introduction

In this chapter I will present a more in depth commentary and analysis of the outcomes of both phases of study: the ‘storying phase’ and the ‘commentary phase’. I will start by discussing how the findings of this study link with previous research. This will be done in relation to the study’s research: to gain a better understanding of the life and experiences of a father of a child diagnosed with autism. I will then present reflections on the findings, and will also discuss how the study impacted my own perceptions regarding the phenomenon of fathering a child with ASD. This will be followed by a critique of the study’s research design, reflections regarding the rigor and trustworthiness of the study, and reflections on the researcher’s contribution to the study. Finally, the study’s contribution to the current knowledge base will be presented as well as the study’s implications for future research and for EP practice.

5.2. Processing the findings

The ‘commentary phase’ in Chapter 4 provided an overview of the stories gathered and helped identify common events that were present across the fathers’ stories. The common events identified (Table 4.1. p. 64) could shed light on a common ‘storyline’ or ‘plot’ that consists of some or all of the events identified. These events illustrate temporal aspects of the experience of fathering a child with ASD, as described by the participants. They describe the participants’ past and contemporary experiences, as well as their thoughts about the future. In the next section, these events will be discussed in light of the study’s research questions:

Minor research questions:

i. How do fathers of children diagnosed with ASD live and experience their children, and their diagnosis?

ii. What challenges do fathers of children diagnosed with ASD encounter

and how do such challenges affect their notions of fatherhood?

iii. What aspirations, hopes, dreams, concerns and reservations do fathers of children diagnosed with ASD have with regards to the future of their children?

Main research question:

“What stories do fathers of children with ASD tell about fatherhood and about their fathering experiences?”

The next sections will present the reflective process that followed the ‘storying’ and ‘commentary’ phases of the study. This reflective process consisted of going back and forth, from the original stories, to the common ‘storyline’, and to the literature identified in chapter 2, to understand the fathers’ experience. The following sections will present the resulting outcome of this process and will be presented in the form of a discussion.

5.2.1. How do fathers of children diagnosed with ASD live and experience their children, and their diagnosis?

The narratives illustrate how the roles espoused by men, vis-à-vis their children, influenced their behaviour and also their relationship with their ‘autistic’ children. Analysis of the storied data illustrates how even before becoming fathers, men had preconceived ideas of what their fathering experience would consist of. Miller (2010) postulates that even before the birth of their first child, men have predetermined intentions with regards to their role as fathers, and preconceived ideas on how such intentions would actually be practiced. Such notions generally consisted of what Finn and Henwood (2009) defined as a ‘hybridized’ definition of fatherhood that included both caring and guiding responsibilities.

The roles espoused by the fathers who participated in this study also included roles described by Pleck (2007), and roles identified in other studies (such as Summer et al., 2006):

- Teaching the child the skills necessary to be independent;
- Providing physical interaction in the form of play and care giving; and
- Providing emotional, physical and financial support.

The stories indicate that such roles were unaltered by the knowledge of the children's diagnosis. Rather, the diagnosis seems to have 're-dimensioned' certain aspects of their roles and further strengthened their commitment towards the roles they had expected to fulfill before their children were born. However, the implications of the diagnosis did affect the way that the fathers lived and experienced their child. Initially, the diagnosis was met with feelings of disappointment, pain and frustration by the fathers who could not have predicted such news. To a certain degree, the news of the diagnosis cast doubts on all of the fathers' expectations of what fatherhood would and should consist of. Furthermore, the diagnosis brought about a lot of uncertainty and many question, which the fathers found to be very stressful and anxiety provoking. Some of the stories also illustrate how the lack of sensitivity on the part of those who broke the news to parents, and the lack of information presented by certain professionals made their first encounter with the word autism even more shocking.

The fathers' stories illustrate, how in their eyes, a diagnosis that impinged on their child's development and behavior, and which put their child's future in doubt, needed to be fought or controlled to a certain degree. Thus, the fathers dedicated a lot of time to providing their children with adequate support and also trying to help their children "overcome" the condition. They dedicated a large amount of time to such roles. This monopolized to a certain degree the fathers' relationship with their children and also their experience of their child. The fathers' need to support their children's development and their need to find a solution to the problem of autism overwhelmed their life and became their main priority.

The search for solutions to the problem of autism meant that fathers needed to dedicate time to look for ways and means that could help their children. Furthermore, the fathers needed to make sure that they could in fact see to the costs incurred by the therapies and interventions sought. This increased the responsibility and burden of

providing for their families and children. In addition, fathers also had to spend less time with their children and also with their families. Fathers took pride in fulfilling the role of providers. Their ability to provide for their family could have contributed to their perception of competence as a parent, which could have in turn lowered their levels of stress (Hartley et al., 2012).

The search for solutions also led the fathers to espouse the role of teacher or mentor. The storied data indicates that fathers dedicated time working on teaching their children academic and self-help skills. The amount of time that fathers spent with their children on such activities varied. Yet, the majority of the stories seem to indicate that many fathers took up this ‘mentoring’ aspect of their fathering role. The teaching or mentoring styles the fathers adopted with their children also varied from one story to the next. The styles varied from a calm and indulgent style to a more strict and authoritarian style of mentoring. The difficulties related to the children’s impaired central coherence, difficulties with theory of mind, difficulties with communication and also difficulties related to the fathers’ lack of training in teaching led to added frustration on the fathers’ part, which could have also frustrated their children to some degree. Thus, this aspect of the men’s fathering responsibilities was challenging.

The fathers’ increased workloads and the fathers’ ‘mentoring role’ also meant that they spent less quality time with their children. This however did not prevent them from displaying the more caring and nurturing side of their roles as fathers whenever they found the opportunity to do so. The stories indicate that the fathers enjoyed spending time with their children. The fathers seemed to enjoy the playful aspect of their relationship with their children, and enjoyed engaging in rough play. This style of play seems to be common with fathers, whose play generally tends to focus on rough-and-tumble play (Labrell, 1996).

The stories also illustrate the ambiguous relationship that the fathers had with their children’s diagnosis. The news of the diagnosis was very upsetting for many of the fathers. It also brought about a lot of difficult questions such as: “why me?” “why my child?” and “what caused autism?” The stories illustrate how these questions remained mostly unanswered and how these were the cause of a lot of distress;

particularly the latter question, which brought about uncertainty, anxiety and guilt. When confronted with such question, some fathers found refuge in religion, others in statistics. Nevertheless, at various instances in the stories, fathers seemed to see the diagnosis to be separate and somewhat disconnected from the child. Fathers spoke about the anguish that autism brought about. Yet, they also talked about the joy that their children brought. They spoke about the love that they had for their children and how they wouldn't change anything about their children. Some of the fathers did express their wish to 'rid' themselves of the condition of autism. However, some of them even asked; if their children were not to be 'autistic', would they actually be the same children that they had seen grow?

5.2.2. What challenges do fathers of children diagnosed with ASD encounter and how do such challenges affect their notions of fatherhood?

The studies included in the literature search in Chapter 2 identify various difficulties that fathers of children with autism go through, which consequently impinge on their fathering experiences and possibly also on their overall wellbeing. The stories gathered in this study corroborate some of the findings of previous research and also build on some other studies' findings. The research question being discussed in this section aims to shed light on two aspects of the study: the challenges and difficulties that fathers of children with ASD go through and how such difficulties become stressors; and on how such difficulties possibly impinge on the men's fathering experiences and on their notions of fatherhood. These two aspects of the fathers' experience will be discussed separately in the next two sections.

5.2.2.1. What challenges do fathers of children diagnosed with ASD encounter?

Some of the challenges and difficulties experienced by the fathers that participated in this study, which were also identified in previous studies regarding parents of children with ASD, were: the children's behavioral problems (Lecavalier et al., 2006; Baker-Ericzen et al., 2005); the children's difficulties with communication (Donaldson et al., 2011); the children's difficulties with social relatedness (Ornstein Davis & Carter, 2008); the increased financial burden and disruption in family planning (Rodrigue et al., 1992); restrictions in their social lives; and thoughts and concerns regarding the

future, educational concerns regarding their child, and personal constraints (Tehee et al., 2009).

The fathers' stories illustrate how the diagnosis of ASD and the difficulties manifested by their children tended to dominate and overwhelm many of the aspects of the father's lives as well as the lives of all of their family. Cullen and Barlow (2002) argue that because of the high level of needs of the children, who sometimes present with 24-hour demands, most parents tend to feel isolated, frustrated and bewildered. This was the case of many of the fathers who participated in the study, who felt alone in their struggles. The aloneness was not related to their relationship with their spouses. Rather, the feeling of isolation was mostly a result of the lack of information that they were given by the professionals who provided the diagnosis. Many of the fathers felt that they had to go on a 'crusade' to find the right help and support for their children and also for themselves and their family.

The lack of support and information received was not the only difficulty experienced by the fathers. The stories shed light on the other difficulties that fathers experienced. Their children's conditions markedly affected their personal lives. As a result of their children's condition, fathers needed more money to be able to see to their children's needs. Furthermore, as mentioned in the previous section, many of the fathers dedicated more time to their children's education. For these reasons, fathers needed to re-organize their lives and cut back on certain activities that they previously enjoyed. Many fathers had to renounce their dreams to advance in their jobs, or to advance academically by pursuing their studies.

The fathers' and the whole family's 'revolutionalized' lives also had an impact on the husband-wife relationship. In this regard, McCabe (2008) proposes that a child's diagnosis of ASD could have an impact on the marital relationship. McCabe (2008) postulates that spouses tend to argue more as a result of having their lives revolve around their child. These findings seem to be corroborated to a certain degree in this study, as most of the fathers' stories are suggestive of an increase in marital conflicts. They also spoke about increased restrictions in the couple's social lives. Notwithstanding these difficulties, the stories illustrate how some marital relationships were strengthened by the difficulties that husband and wife have gone

through. However, the stories seem to indicate that the couples who found support from meaningful others were able to cope better with the stressors they encountered.

One of the fathers' sources of stress, which is illustrated in the stories, is that of their children's behavior. The fathers' stories illustrate how the children's peculiar behaviors were what initially spurred the fathers or their spouses to look for professional help. Yet, these behaviors, that included flapping, side glancing, tiptoeing as well as rigidity, tantrums and oppositionality, were also sources of frustration and stress. This seems to concur with Tehee et al.'s (2009) study that indicates that a child's inappropriate and unpredictable behaviour is one of the major sources of stress for fathers. Yet, the stories seem to indicate that the child's inappropriate and unpredictable behaviors were not always the major cause of stress. Rather, it was society's reaction to such behaviors that brought about a great deal of frustration. The fathers' stories in fact illustrate various moments in the fathers' lives where people interpreted their children's behaviors as being the result of bad fathering. The stories seem to indicate that on many occasions society displayed a lack of awareness of autism and as a consequence displayed a lack of empathy towards children with such difficulties and their families. This lack of sensitivity and the lack of awareness of the 'general public' was a cause of stress for many of the fathers.

This lack of sensitivity did not only come from the 'general public'. Some of the stories illustrated that certain members of staff in schools also demonstrated a lack of sensitivity with regards to their children's condition and needs. Occasionally, the fathers also experienced reluctance, on the school's part, to do what was necessary to integrate their children in 'mainstream' activities. However, on many occasions, this was not a result of a conscious effort to sabotage the child's inclusion. Rather, it was more an issue of the members of staff's lack of knowledge about the condition. Nevertheless, this again contributed to the fathers' feelings of isolation, as this made them see themselves, together with their spouses, as the only people who were trying to help their children.

One of the most stressful challenges the fathers seem to have encountered is that of their children's communication difficulties. Communication is seen as a very

important attribute that contributes to the fathers' relationship with their children (Donaldson et al., 2011). The stories illustrate how the fathers' relationships with their children, or lack of, was influenced considerably by the children's difficulties with communication. Interestingly, the stories also illustrated how the lack of communication impinged on the fathers' fathering experiences by considerably impinging on the fathers' prospect of living up to their 'pre-birth' expectations of what their fatherhood role could look like. Fathers seemed to have had expectations that did not materialize completely. Furthermore, even though not explicitly, in various instances of the study, the father's could be noticed trying to express their disappointment, and to ask the question "what would it have looked like if my child did not have autism?"

One could speculate that the men in the study who father more than one child, at least one of whom is not affected by the condition, could see things differently and not ask themselves such a question. Yet, the stories illustrate that this is not the case. No matter how many children a father has fathered, fathers tended to be affected considerably by their children's condition and experience their children's condition with the same intensity as that of a father of an only child with ASD. In fact, many of the fathers that participated in this study were affected so much by their children's condition that, after learning about the diagnosis and after experiencing their children's difficulties, they had second thoughts about having other children. The stories illustrate how this decision was taken after a great deal of thought and reflection. This decision was taken whilst keeping in mind the condition of ASD, and also the possibility of having other children affected by this condition. Some of the fathers' stories also illustrate how the decision to not have any other children was accompanied with guilt and regret.

5.2.2.2. How do the challenges that fathers of children diagnosed with ASD affect their notions of fatherhood?

The aim of the study was not to compare the father's notions of fatherhood before they were informed of their children's diagnosis with the aftermath of the diagnosis. However, the stories shed light on how the participants experienced their children's diagnosis and the difficulties that they encountered and how these in turn impacted

the father's notions of fatherhood. The degree to which the difficulties and challenges, mentioned in the previous section, impinged on the fathers' notions of fatherhood was influenced by how well, or not, the fathers coped with such difficulties.

The data gathered in this study indicates that fathers tended to make use of an array of coping strategies that included: positive reframing strategies; emotion-focused strategies; solution-focused strategies; and religion/spiritual means of coping. The fathers also seem to have used what Hastings et al. (2005b) describe as 'problem-focused' coping strategies which consist of trying to find help, and searching for support. However, the stories illustrate how this coping mechanism was not as effective as they hoped, as many fathers found support and information to be lacking. Consequently, the stories corroborate previous studies (e.g. Gray, 2006) and illustrate how the fathers' coping strategies changed over time. As time progressed, the children's needs and their difficulties changed, together with the strategies the fathers used to cope with the stressors they experienced.

Notwithstanding the various coping strategies that the fathers seem to have used, the difficulties and stressors experienced appear to have impacted the fathers in various ways. However, the extent to which the participants' notions of fatherhood changed after their children's diagnosis is somewhat vague and difficult to gauge. This is in part due to the study's design, which did not include a control group or any baseline measure that would have yielded data that would have enabled such conclusion to be made. Nevertheless, the storied data gathered in this study sheds light on the fathers' notions of fatherhood, which in turn could be compared to the outcomes of previous studies concerning fatherhood that were identified in the 'literature review' chapter.

For most of the fathers who participated in the study, fatherhood was seen as a big responsibility that comprised numerous challenges and sacrifices. The stories illustrate various elements and characteristics of fatherhood, which were consequently translated into fathering behaviors. One facet of fatherhood illustrated in the stories is that of the loving, caring and ever-present father who is involved in all aspects of child rearing. This notion seems to be shared by most of the men that participated in the study. Another element of fatherhood was that of men serving as mentors to their children. In this case, because of the children's learning and developmental

difficulties, fathers took up a role that consisted of teaching and coaching their children with the hope of producing more positive developmental outcomes. In this case, the fathers generally put aside their more nurturing characteristics and used strict and disciplined approaches in their ‘teaching sessions’ with their children. Such aspects of fatherhood seem to be similar to those reported in previous studies. In fact, in Finn and Henwood’s (2009) study, men interviewed seemed to espouse a more ‘hybridized’ fathering role.

Duckworth and Buzzanell (2009) postulate that fathers of children of typically developing children tend to prioritize family and believed that work was necessary for them to care for their family. Furthermore, Duckworth and Buzzanell (2009) postulate that problem solving constituted one of the fathers’ main activities. Similarly, the fathers of children with ASD who participated in this study indicated that work was necessary, not only to take care of the family, but also to see to their children’s needs. The stories illustrate how many of the men who participated in this study espoused the breadwinner’s role and took it upon themselves to provide financially for their family and for their children’s needs and ensure their family’s economic stability. This aspect of fathering was part of the problem-solving coping strategy that many fathers took up. In many cases, fathers were also very proactive in trying to find a solution to their children’s condition; a condition that they considered to be somewhat of a ‘puzzle’ which was meant to be solved.

Twoy, Connolly and Novak’s (2007) study suggests that parents of children with ASD are resilient in adapting to the challenges of caring and raising their children. This seems to also be corroborated by the fathers’ stories. In fact, an aspect of fatherhood that the data of this study illustrates is the resilience and perseverance that the fathers seem to have developed as a result of having a child diagnosed with ASD. Some of the stories show how some of the participants’ notions of fatherhood evolved to incorporate a more assertive and insistent characteristic. This was mostly a result of the many difficulties and stressors, such as those related to their child’s schooling, that the fathers encountered. Some of the stories illustrate how fathers needed to ‘be like a lion’ or have to ‘fight’ for their children in order for them to make sure that their children’s needs and rights were not ignored. This element of ‘fight’ seems to

form part of the participant's notion of fatherhood and is an aspect of fatherhood that seems not to have been mentioned in previous studies.

Miller (2010) suggests that there could be a tendency for fathering identities to gradually shift away from hegemonic masculinities, and move towards fathering practices that are hands-on and caring. This seems to be the case with the fathers who participated in this study, as the fathers' stories seem to illustrate fathering notions that revolve around the concepts of providing. The father's activity sought to provide their children with: financial stability; with emotional support; with guidance and learning opportunities; and with love, care, and attention.

5.2.3. What aspirations, hopes, dreams, concerns and reservations do fathers of children diagnosed with ASD have with regards to the future of their children?

Questions concerning the future seem to be fundamental to the fathers' stories. The stories illustrate how the future could be a source of uncertainty and stress for the fathers who participated in the study. Other studies, such as Tehee et al. (2009), indicate that thoughts regarding the future are indeed major sources of parental stress. This seems to be the case for many of the participants of this study. Yet, the stories also suggest that in some instances, the future presents the fathers with hope and promise and gives the fathers energy and motivation to continue working hard to see their children improve and progress.

Many of the stories illustrate how the hope to see their children one day overcome their difficulties gave the fathers a goal to work for. This goal in turn also seems to have given meaning and purpose to many of the fathers' lives. Some of the stories illustrate the fathers' wish to see their child cured of autism. Some of the fathers even went to great lengths, by attempting various therapies and spending a great deal of money, to see this happening. However, notwithstanding their best efforts, most of the stories indicate that the results were not as positive as they had initially hoped. Nevertheless, the fathers seemed not to give up and continue to strive to increase their children's chances of being independent, autonomous and self-sufficient.

The reason behind such staunch commitment to the goal of independence is the insecurity and anxiety brought about by the question of what will happen to their children once they die and leave their children to cope with the world on their own. In fact, the stories shed light on the fear and pain brought about by the thought of their children's future. This aspect of the fathering experiences is an aspect that does not seem to have figured in studies concerning fathers of neurotypical children. The reason being that fathers of children with ASD seem to be burdened by the thought that autism is a life-long disorder. Many of the stories illustrate how the fathers came across this piece of information and also how it was met with a lot of apprehension. Thus, the fathers learnt, through reading articles and also by consulting with various professionals, that autism was not something that their children were going to grow out of. This considerably changed their outlook regarding the future. The fathers at times found themselves seeing their children make steps forward. However, they seemed to always interpret improvements in term of the big picture, which is the future.

The aspect regarding their children's future could have also impinged on what Shirani and Henwood (2011) described as the father's desire for idleness or redundancy in terms of fathering responsibilities and duties. In their study, Shirani and Henwood (2011) claim that some fathers express a desire for their children to reach a stage or level of autonomy where they (the fathers) were not needed any more. In the case of the fathers that participated in this study, their children's diagnosis meant that the prospect for the fathers' idleness or redundancy was considerably reduced. This impact of the diagnosis on the father's prospective idleness was different for many fathers and varied according to the severity of their children's difficulties and according to the fathers' perception of their children's 'prognosis'.

Another aspect of the future that seems to be stressful for the fathers is that of their child's care when they themselves eventually pass away. Many of the stories illustrate how the fathers are distressed by the prospect of there not being adequate support for adults with autism. The fathers seem to be distraught by the image of their children being institutionalized in homes that are not able to see to the needs of adults with autism. For this reason, some of the fathers have worked and continue to work hard to see their children progress and thus decrease the likelihood that their children would

need such a provision. Furthermore, the fathers also work hard to save enough money for their children, so that when they will not be able to provide for them anymore they would still be in a position to fund the right type of care.

5.3. What stories do fathers of children with ASD tell about fatherhood and about their fathering experiences?

The narratives gathered in this study tell the stories of fathers of children who were diagnosed with autism. The narratives consist of connected events that illustrate the fathers' accounts of their experience of becoming fathers, of learning about their children's condition, and of living with their children and their condition. The narratives tell stories that are specific and idiosyncratic in nature. Yet, as the findings illustrate, the stories have a lot of events that are common, even though such events seem to be lived and experienced differently by each participant. The previous research questions analyzed the findings of the study in light of the three research sub-questions. Consequently, these sub-questions helped to inform the major research question: what stories do fathers of children with ASD tell about fatherhood and about their fathering experiences?

The theoretical assumptions that guided this study were: Pleck's (2007) integrated ecological-parental capital theory of paternal influence; Lamb et al.'s (1985) tripartite conceptual model of paternal involvement; and Identity Theory (Litton Fox, 2001; Stets & Burke, 2000). These theories were very useful when trying to conceptualize paternal involvement as well as 'father identity'. For this reason, the main research question will be answered also with reference to these theories as well as to the research identified in previous chapters.

Similarly to Cullen and Barlow's (2002) findings, the stories illustrate the father's immense love towards their children whilst also illustrating their distress and unhappiness from the impact that autism has had on their life and on their family's life. In fact, the fathers' narratives tell the stories of how the fathers pictured and planned their fatherhood; the joy fatherhood and their children brought; the pain that they went through when they learnt about autism; the manner with which they

experienced their children and their difficulties; and also the manner in which their children's condition influenced their notions of fatherhood.

The stories illustrate how the participant's identity hierarchies seem to prioritize the 'father identity'. The participant's commitment towards their 'father identity' seems to be high. This could be seen in the decisions that the fathers seem to have taken during the course of their narratives. According to Litton Fox and Bruce (2001), a particular identity is reflected in the behaviors, associated with that identity, which an individual decides to engage in. Such behaviors could be better understood by using Lamb et al.'s (1985) tripartite conceptual model of paternal involvement.

Lamb et al. (1985) argue that paternal involvement could be conceptualized using three constructs: accessibility; responsibility; and interaction. The stories illustrate how the fathers' behaviors primarily consisted of behaviors aimed towards seeing to the children's welfare and care (i.e. responsibility). However, this is not because they did not have any intention to focus on other aspects, such as 'accessibility' and 'interaction'. Rather, their stories reveal the father's efforts to make themselves accessible to their children. However, their financial commitments and responsibilities made it difficult for them to be available for their children as much as they would have liked. Nevertheless, the fathers strived to engage with their children in both a direct and indirect manner. They tried to engage directly by working with the child to teach him/her new skills. They tried to engage indirectly by attending to parent-teacher conferences, by taking their child to the doctor etc. The children's difficulties however impinged on a particular aspect of paternal involvement that concerns direct interaction. As evidenced in the storied data, the difficulties in communication and in social reciprocity manifested by their children impinged on the father-child relationship, to various degrees.

The diagnosis of autism and its related difficulties seem to have made it hard for fathers to prioritize other aspects of their identities, such as the 'husband identity' or the 'professional identity'. In fact many of the stories illustrate how fathers found it difficult to find a balance between the various identities related to their 'self'. The stories thus suggest that fathers of children with autism struggle to reach a harmonious balance between the various domains and identities that form the 'self'.

Furthermore, their preoccupation and concern about their children's future seems to force them to behave in ways that prioritize their responsibilities to ensure that their children's welfare, needs and rights are not being overlooked. Furthermore, the responsibilities also include providing the child with social capital (guidance, teaching and mentoring) and material capital (financial capital for the child's present and future), at various "ecological" levels (Pleck, 2007).

Behaviors that contribute towards the 'father identity' described above could fit into what Eerola and Huttunen (2011) describe as a 'modern narrative'. This consist of differentiated parental roles in which the father is primarily the family's breadwinner but still readily contributes towards his children's upbringing by taking up the role of the mother's assistant (Eerola & Huttunen, 2011). At first glance, this could be a fitting description for many of the fathers' narratives. However, this study also indicates that there is more to the fathers' stories than that. In their study, Eerola and Huttunen (2011) also describe a 'transition narrative' (characterized by the father's search for his role and involving a father's endeavor to engage with a family-centered life-style) and a 'postmodern narrative' (characterized by the father's full participation in family planning and intention to further engage fully in a nurturing and care-giving role).

Eerole and Huttenen (2011) used these three categories to describe the contemporary narratives and storylines of fatherhood. Whilst being relevant and useful for this study, it is nevertheless very difficult to categorize the stories collected in this study in any one of these categories. The reason for this difficulty could be because of the sample used in Eerole and Huttenen's (2011) study, which consisted of fathers of typically developing children. Notwithstanding this, rather than the issue being the descriptions of the categories, the difficulty is with the notion of categorizing the narratives in the first place. Thus, the better way to understand the narratives presented in this study is in terms of a continuum. The stories in fact seem to indicate that the fathers' narratives changed over time. This did not necessarily mean that stories transitioned steadily from a 'modern' style narrative to a 'postmodern' style. Rather, stories moved back and forth and changed in ways that placed the father in a position to best influence their child at that given time and context.

5.4. Reflections about the research process

This study consisted of two ‘emotional’ experiences that occurred in parallel. The first was that of the participants, who were asked to talk in detail and in length about their experiences. The other was that of the researcher, myself, who entered the lives of the participants and learnt about their experiences through the stories that they told. A number of studies, such as Alexander et al. (1989) and Milling-Kinard (1996), argue that researchers who are involved in gathering and reviewing case records of stressful, emotional or traumatizing experiences tend to be influenced considerably by the data gathered. This was also the case in this study, as the whole research process did have a bearing on me. The interviews that I had with the fathers were particularly emotional and moving. Furthermore, throughout the interviews I came into contact with some of the stress and the pain that the fathers went through as they recounted their experience of the diagnosis of autism. At the same time I also experienced the love and passion that they had towards their children.

Most of the fathers initially appeared hesitant and slightly uncomfortable to talk about their stories. However, this discomfort was short-lived. In fact, as the interview unfolded it became more evident that the fathers seemed to have welcomed the opportunity for them to be ‘heard’ and to have their stories acknowledged. Consequently, what I also perceived during the meetings with the fathers was their eagerness to have their stories told, their appreciation for being listened to, and their keenness to have their views and experiences validated.

During the ‘check-backs’, the fathers met the narratives with mixed feelings. They all commented on the realism and authenticity of the stories. Some of the fathers commented about the awkwardness they felt when reading their story. However, the awkwardness was not a result of an inaccurate story, but of the experience of having their thoughts and their words being presented back to them. Some of the fathers felt revitalized by their experience, whilst some were emotional when they read the story. However, in general, the outcomes of the ‘check-backs’ were positive, as most of the fathers felt that the validation of their thoughts and feelings and experiences impacted them positively. Furthermore, some of the fathers commented on the ‘therapeutic’ benefits they got from their participation in this study.

5.5. Reflections and critical evaluation of the study

The reason for using the qualitative design implemented in this study was to be able to process fathers' experiences and the meanings of their experiences. Furthermore, the narrative paradigm utilized enabled me to "interpret what they experienced...allow for discovery, and do justice to their perceptions and the complexity of their interpretations" (Atieno, 2009, p. 16). Thus, the research design was used to exploit the advantages that such a research paradigm presented: i.e. "to understand phenomena deeply and in detail" (Atieno, 2009, p. 17).

The current study was a co-constructed accomplishment (Denzin, 1994; Gubrium & Holstein, 2002) that consisted of myself, the researcher, gathering stories of men through the use of open-ended interviews. The fact that I was recording the interviews was one of the factors that influenced the participant's stories. The act of observing a phenomenon (i.e. the telling of a story) influenced the phenomenon being observed, i.e. the story itself (Robins, Mendelsohn and Spranca, 1996). On the other hand, my contribution played an important role in the construction of the stories. Thus, the interviews gathered as well as the narratives storied were influenced by my own views and experiences. For this reason, the stories gathered in this study are not objective accounts. Rather, they are co-constructed interpretations of experiences that were elicited and shared using the medium of interviewing and are products of the interactions between the interviewer (myself) and the interviewees (the fathers). Thus, one of the limitations of this study is that the 'commentary phase' is based on my 'interpretation' of the fathers' 'voice', and could thus be seen as a 'third-hand' analysis of data. Nevertheless, this 'commentary' was based on real narratives that were 'authenticated' by the fathers themselves.

The 'commentary phase' mostly consisted of a 'bottom-up' approach. However, in my commentary, theoretical aspects from previous studies were not completely barred. The 'commentary phase' of the study appears unstructured and unorthodox, and this could be seen as a limitation of this study. I am aware of the sense of ambiguity that such non-conventional form of 'analysis' could convey. With this regard Law (2004) argues that a degree of vagueness in scientific research "is not a

sign of a methodological failure” (p. 14). Rather, he argues that ‘assembled methods’ such as that used in the “commentary phase”, which is perceived as vague and indefinite is sometimes needed to investigate a world that is in itself “enacted in that way” (Law, 2004, p. 14). Furthermore, Popay, Rogers & Williams (1998) argue that, “the hallmark of a good qualitative methodology is its variability, rather than its standardization” (p. 346).

Another ‘limitation’ regarding this study is that of the lack of ‘generalizability’ of the findings. With this regard, Atieno (2009) argues that this is one of the disadvantages of using a qualitative research design; that the study’s findings cannot be extended to wider populations. The issue of the lack of ‘generalizability’ of the findings was a result of the research design, which was chosen in the first place for its potential to produce intense descriptions. The lack of ‘generalizability’ of the findings was also a result of the ‘sample’ used for this study, and particularly the number of participants recruited for this study.

The number of participants that were going to partake in this study was initially an issue, as I was unsure about the number of stories that would have been necessary for me to answer the research questions adequately. Eventually, ten fathers that participated in the study. These fathers were the first to have sent back the “participation letter”. The response that I received from the “participation letters” sent was relatively low. In total, from the 80 “participation letters” sent, I received 13 replies from fathers who met the criteria and who were willing to participate in this study. The reasons for the lack of participation could be many. One could assume that:

- fathers were too busy and did not have the time to participate in the study;
- fathers were too tired or stressed and did not find the energy to participate in the study that required a lot of emotional strength and effort;
- fathers were not comfortable to share the intimate details of their experiences of fathering a child with ASD;
- fathers felt nervous at the thought of having to articulate their thoughts or feelings and preferred not to do so;
- fathers were not interested in this study.

The above-mentioned reasons could shed light on the characteristics of the fathers that did actually participate in this study. The fathers that participated were comfortable to talk about their stories; were confident that they could articulate their thoughts effectively; were interested in this study; and were in a position, emotionally and logistically, to participate in the study. Thus the findings and the analysis and discussion of the findings were conditioned by the participant's characteristic (Parker, 1992), as they were based on stories belonging to fathers with such characteristics. For this reason, the findings of the study cannot, and should not, be generalized to the general population of fathers of children with autism particularly because of the reasons mentioned above.

An issue regarding this study that should be noted is that of "demand characteristics" (Parker, 1992). Parker (1992) argues that a possible danger of any study is that of participants attempting to make sense of the research and consequently seeking to "formulate their own version of what the hypotheses or aims of the study are" (Parker, 1992, p. 6). Consequently, this could lead to participants attempting to confirm what they believe to be the desired outcomes of the study. This could have been the case for the participants in this study. However, the open-ended nature of the interviews and the study's design, that focused on describing experience, rather than proving or disproving hypothesis, decreased to a certain degree the possibility of this happening.

Another issue that was pertinent to the data collecting technique utilized in this research is the issue of fathers, purposefully or unconsciously, refraining from disclosing certain aspects of their experience. Examples of such aspects could hypothetically be related to: their children's, their spouses' or their own behaviors; the effects of their children's diagnosis on their intimate relationship with their spouses; and the effects of their children's diagnosis on their partner's, or on their own, mental or emotional wellbeing. Yet, these are just suppositions, as it is difficult to identify with certainty which aspects could have been omitted by the fathers during the interviews. If the fathers supposedly did omit certain aspects of their experience, it would also be difficult to ascertain the reasons for them doing so. Yet, some examples of such reasons could be: to protect their children, their families and themselves; to avoid talking about aspects of their experience that are perceived as threatening for their emotional wellbeing; or to avoid disclosing aspects of their experience that they

have not yet dealt with effectively. This issue does not put into question the trustworthiness of this study, as the study's purpose was to learn about the experiences of fathers, as told by the fathers themselves. Thus, the study focuses on the aspects of the fathers' experience that were relevant to them, and also on those aspects that they were comfortable to disclose and discuss. Any further efforts, from my part, to try to encourage them to discuss anything that they were not comfortable with disclosing would have posed a threat to the fathers' safety, to their psychological wellbeing, as well as to the ethics of this study."

The following sections will focus on discussing issues regarding the rigor and trustworthiness of this study.

5.6. Rigor and credibility of the study

'Rigorousness' is that which makes a successful and useful research (Morse, Barrett, Mayan, Olson, and Spiers, 2002). 'Rigorousness', according to Morse et al., (2002) is also what prevents research from becoming fiction. Traditionally, reliability and validity are the criteria with which rigor and credibility are measured. However, reliability and validity are quality-measuring criteria usually associated with quantitative methods (Horsburgh, 2003). Creswell (2008) argues that reliability in qualitative research is concerned with uniformity of method across different studies. However, in the case of narrative inquiry, this criterion seems to be an unsuitable measure of quality. This is because of the pluralistic nature of the 'narrative' methodology. Mishler (2006) argues that the hallmark of the narrative epistemology is its 'multiplicity' in terms of method. Thus, whilst diversity is not necessarily a bad thing, it poses challenges to conventional notions of 'reliability'.

Notwithstanding this issue, Kirk and Miller (1986) postulate that qualitative researchers should never shun matters relating to 'reliability'. Thus, Kirk and Miller (1986), as well as Altheide and Johnson (1994), encourage researchers to transparently record the procedure utilized in all stages of the study. In this study I have endeavored to clearly document the procedure used to recruit participants, to collect raw data through interviews, to story the raw data, and to explore the storied data. This does not necessarily mean that another researcher would come up with the

same conclusion if he/she followed the same procedure, as the findings of the study are contingent on the participants and also on the time when the interview was carried out. In fact, the temporal dimension is very important to the narratives, as it influenced greatly the father's interpretation of his experience. However, the findings of the study are clearly outlined and explained in this write-up: both in terms of process and outcome.

With regards to the notion of 'validity', Guba and Lincoln (1981) argue that in qualitative research, the criterion of 'trustworthiness' is a better measure of a study's credibility. Guba and Lincoln (1981) argue that paradigm-specific criteria are necessary for addressing the issue of what they term as 'trustworthiness' of a study. Lincoln and Guba (1985) propose 'dependability', 'conformability', 'credibility', and 'transferability' as measures of 'trustworthiness'.

'Confirmability' and 'dependability', are concerned with making sure that the study is clear about how the conclusions are made, so that 'others' (readers and other researchers) could see how the researcher has reached that particular conclusion (Merriam, 1998). To ensure 'confirmability' an audit trail was included (see Appendix 15, p. 237). This provided a transparent picture of the steps taken all throughout the study (Creswell and Miller, 2000). Creswell and Miller (2000) propose an "external audit", which is the process of having a researcher who is not involved in the research process explore the process and outcomes of the study, as a means to review the study's 'confirmability' and 'dependability'. In this study, two independent observers examined my findings: my research supervisor and a sociology graduate who was recruited specifically for this task. During the "external audits" anonymity of the fathers was always maintained.

'Credibility' refers to one's confidence in the 'truth' of the findings. Thus this entails establishing that results are plausible from a participant's perspective. To ensure 'credibility', check backs were carried out with the participants, who had the opportunity to read and feedback on the stories produced from the raw data. Transferability is about showing that the findings have applicability or can be transferred to other contexts (Trochim, 2006). To ensure 'transferability', Holloway (1997) suggests that researchers provide 'thick descriptions' of their field experiences

to see to the issue of ‘transferability’. This was done all throughout the study where detailed accounts of field experiences were provided.

Apart from the procedures referred to above, I, as a researcher, asked questions related to the coherence of the stories reproduced: are the episodes of the narrative in sync? Are there major gaps and inconsistencies? Herman and Vervaeck, (2001) argue that the coherence of the participant’s narratives and the researcher’s analytic endeavours are significant aspects of credibility. Secondly, I also asked whether my restorying account was persuasive or not? A good narrative research persuades readers (Emerson & Frosh, 2004). The check backs with the fathers also served to ensure authenticity and persuasiveness, as it was they who actually approved of the story’s validity and trustworthiness. With regards to the issues of accuracy and transparency, I kept electronic records of the conversations gathered through the interviews. I also included in the appendices section the samples of the ‘interim narratives’ of the stories (pp. 168-170), and the ‘temporal relation framework’ used in the second phase of the analysis phase (pp. 234-235). This practice also encouraged methodological awareness and ongoing reflexivity (Emerson & Frosh, 2004). In this way, as mentioned earlier, I also included an ‘audit-trail’ (see Appendix 14, p. 237), which, in turn, also provided truthfulness, persuasiveness and coherence.

In the next section I shall discuss further the element of reflexivity and include reflections about the research process and the role of the researcher in this study. The aspect of reflexivity is important to the study’s credibility and confirmability (Creswell and Miller, 2000).

5.7. Reflexivity

Hardy, Gregory and Ramjeet (2009) describe reflexivity in research as “a process through which a person attempts to identify and recognize external and internal influences that can affect his or her understanding of a phenomenon under investigation” (p. 11). Sullivan (2002) argues that reflexivity is an important and essential element of qualitative research. In this regard, Shaw (2010) states:

...when the researcher and researched are of the same order, that is, both living, experiencing human beings, it is necessary for us as researchers to reflect on how that might impact the research scenario when gathering and analyzing data. (p. 233)

In all stages of this study, I was personally involved and served as the main “research instrument”. For this reason, reflexivity became even more essential. Throughout this study I have endeavored to maintain a reflexive attitude (Watt, 2007). I was open and honest about my values, my experiences, my cultural and professional background, as well as my values and assumptions. Furthermore, I was also clear and honest about my ontological and epistemological position. I was also honest about my reflections and about how the research process influenced my knowledge and my perception on the subject matter.

All throughout this study my reflexive attitude was maintained by:

- (i) Keeping a reflective diary. The reflective diary was an important aspect of my research. Various excerpts of the reflective diary were included and ‘woven’ together with this write-up. The diary was extremely useful when it came to the ‘commentary’ phase of the research;
- (ii) Having on-going reviews and discussions with my professional and academic tutor at University of East London, and with my supervisor at the School Psychology Service (SPS. Malta);
- (iii) Having on-going discussion with a number of my ‘critical’ colleagues and members of staff and at SPS;
- (iv) Having numerous conversations with professionals within the Psychology and Education department at the University of East London.

5.8. Reflections on the ethics of the study

Throughout the process of this study, a number of ethical issues relating to the participants’ safety and to ‘scholarly research’ arose. Some of the ethical issues were:

- How can I ensure anonymity of the participants?
- Could the study cause the participants harm?
- How could I ensure that I did not hurt the participants' feelings, whilst also remaining true to the research objectives?

The issue of anonymity was crucial at all instances in the study, particularly in light of the small size of the Maltese community. Thus, the steps taken to ensure anonymity were:

- Pseudonyms were used in all of the stories.
- Details of the story that could lead to the participants being identified were removed.
- Certain details that could not be omitted, as this would have impinged on the integrity of the story, were altered in such a way as to reduce the possibility of the participants being identified.

The possibility of causing potential harm to participants was encountered at various stages of the study. Potential harm could have been caused as a result of the interviews carried out; as a result of the storied narratives; and as a result of the commentary produced on the stories. The possibility of having distressing interviews was highlighted in the "Participation Letters" sent. This 'step' was taken not to reduce the possibility of this from occurring, but to make sure that the fathers made an informed decision when weighing whether they should participate or not in this study. Furthermore, the training that I received as part of the Doctorate in Educational and Child Psychology put me in a position to cope with the possibly emotionally charged interviews. Furthermore, I was prepared to continue to 'monitor' the interviewees after the interviews and also was prepared to refer the fathers to apposite organizations where they would have received professional support. However, whilst the interviews were at times emotional, there was no need for such referral.

The storied narratives as well as the commentary on the narratives could also have caused harm to the participants. Josselson (2007) argues; “the written word, at least in Western society, has a power far beyond that of words that are spoken” (p. 548). With this regards, she suggests:

Certainly, we must take care in our written reports to maintain our respect for the dignity of our participants as individuals, recognizing that what we are treating as an exemplar that illustrates a conceptual or theoretical point is a very personal narrative to the person whose story it is. (Josselson, 2007, p. 550).

I was aware of this issue during both storying and commentary phases of the study. With this regards, Josselson (2007) also postulates:

As an ethical position at this point, we must be prepared to stay in relationship with the participant, to explain our purposes as fully as we can, to make transparent our choices in as kind a way as possible. (p. 551).

In line with Josselson’s (2007) claim regarding ethical positioning, the ‘checkbacks’ that were carried out with the participants served for me to ‘stay in relationship’ with the participants. During these ‘checkbacks’, I made an effort to explain to the participants the decisions that I took with regards to this phase of research with as much transparency as possible. I explained how this ‘storying phase’ of the study consisted of rearranging the raw data collected through the interviews in more meaningful and coherent wholes. I explained that in this stage of the study, the element of interpretation, whilst definitely being present, was at a minimum. However, I was the one who rearranged and storied the data in a manner that was meaningful for me. At this stage, a meaningful narrative was a functional one, in terms of its usefulness for the study. However, I also explained that I had made an effort to compose authentic narratives by remaining faithful to the raw data obtained from the interviews.

This issue of harm was even more present in the ‘commentary phase’ of the study. The objective of this phase of the study was to ‘analyze’ and comment on the stories in terms of the research questions. However, the “commentary phase” was not in any

way a reflection of one particular narrative or of one particular participant's lived experienced. Rather, the engagement with the research questions was characterized by an understanding of the interconnections between the 10 narratives that were storied in the previous phase. The 'checkbacks' also served to elucidate this part of the research. In this way, if the participants were to read the study's write-up, potential harm towards them would be minimized.

The next section will focus on discussing the distinctive contributions that have been made by this study and the implications of the study for future research and to EP practice.

5.9. Contributions and insights of the research study

The current study was completed on the island of Malta, and for this reason it helped to provide information and insights about a unique group of 10 fathers who are residents of Malta. I myself, the researcher, am also a resident and native of the island. Thus it is important to recognize that the study was also influenced by the cultural values and norms that are prevalent in the country. Consequently, these values influenced the outcomes and insights the study produced. Notwithstanding this, the 10 narratives produced, and the 'commentary' on the narratives, shed light on various events that the fathers experienced and how the fathers made sense of those experiences. These descriptions, whilst not being undisputed truths, contribute towards uncovering pluralistic aspects of the experience and to knowledge regarding fathers of children with autism.

5.9.1. Implications for further research and for EP practice

The study seems to indicate that a child's diagnosis, and the consequent difficulties related to the condition, could have an impact on a father's life and also on the father's notion of fatherhood. However it is difficult to conclude from this study how the experience of fathering a child with autism impacted the father's notions of fatherhood. As a number of fathers articulated during the interviews, it is difficult for them to 'quantify' how their lives would have been different if their children were not diagnosed with the condition. An element of the research design that could help future

researchers understand this better is the inclusion of a ‘control group’ and other groups of fathers whose children are diagnosed with other conditions. The control group would consist of a number of fathers whose children are not diagnosed with ASD. The other groups could consist of fathers of children with Fragile X, Down Syndrome, Cerebral Palsy etc. Having information from various groups of participants would enable a researcher to compare data obtained from the various groups and be in a better position to understand how the diagnosis impacted the fathers.

Another aspect of this study that in the future could be altered would be its size. As mentioned earlier, the study was a relatively small study consisting of a small sample. A larger sample would probably yield further insights and further descriptions of fathers’ experiences. However, after conducting this study, the feasibility of using this research design with a larger sample could be questioned. The interviews, the transcription process and the ‘storying’ of the interviews were very time-consuming as well as being very demanding. Thus, for larger samples, a different methodology that is less ‘time-consuming’ could be taken into consideration. Furthermore, mixed methods, using both qualitative and quantitative methods, could also help researchers to obtain both breadth and depth of the father’s experiences. In so doing, the researchers could use the strengths of both research paradigms to identify, describe and quantify the fathers’ experiences.

Apart from providing insights and descriptions, the findings of the study also bring about further questions concerning the experience of fathering a child with autism:

- How are professionals informing fathers and mothers about their child’s diagnosis?
- Are professionals being sensitive enough to the parent’s emotional wellbeing when it comes to breaking the news of the diagnosis?
- Are professionals supporting the fathers by helping them cope with the aftermath of the diagnosis?

- Are professionals informing fathers sufficiently well about the prognosis of their children's diagnosis?
- How are professionals helping fathers cope with their children's difficulties?
- How can fathers cope better with the stress associated with fathering a child with autism?
- Is society in general informed enough about the condition of autism?
- How can society become more informed about autism?

This study also has implications for the practice of Educational Psychology. The study highlights the need of Educational Psychologists who work with children with ASD to also include in their practice the people who are closest to the children. Working with the fathers, by training them to engage better with their children, could help fathers feel more competent at interacting with their children. Consequently, this could reduce the symptoms of stress and have a lifting effect on the whole of the family system. The study also has further implications for EP practice, and particularly for EPs that work within the local Maltese context:

- EPs, and professionals working with children with autism, could be even more transparent in their work, particularly when assessing or identifying autism. This would further reduce ambiguous scenarios where fathers are left in the dark on how professionals have come to conclude that their child has autism.
- EPs could further support fathers of children with autism by helping them cope with the emotional impact of their child's diagnosis. This could be achieved by providing frequent consultations or therapeutic interventions.
- EPs could further endeavor to sensitize society about the condition of autism. In this way the public could be more aware of the strengths and difficulties related to the condition. Furthermore, people could also be in a better position to empathize with fathers and with the difficulties that fathers (and parents) go through.

- EPs could also further endeavor to influence policy makers to provide services and create policies that are “father-friendly”. Furthermore, policy makers could also work to provide residential home-services that cater for the specific needs of children with autism. This would be important to help the fathers cope with the difficult question of “what is going to happen to my child when I am no longer able to look after him/her?”

5.10. Concluding remarks

This study has contributed to the body of knowledge regarding fathers of children with autism. This study did not provide definite answers to the research questions. Rather, it provided insights, in-depth descriptions and interpretations that enabled a better understanding of autism from a father’s perspective.

An interesting issue that was highlighted in this study is that of the fathers’ ability and aptitude to learn about autism and learn how to help their children cope with their condition. This was a particular characteristic of the sample of fathers that participated in the study. This characteristic seems to have played an important part in the father’s lives, as their ability to search, discover and learn about their children’s condition helped the fathers to cope with the stressors and challenges they faced. This became even more important for them especially in light of the lack of support that they were provided with, as in many occasions the fathers seem to have had to face the challenges related to their children’s condition alone. Thus, the question that I ask is: is it actually unavoidable for fathers, together with their spouses, to face this experience of fathering a child with autism on their own. Is this just how things are? Is it inevitable? The answer that I hope to give to fathers of children with autism is ‘no’. This study serves to emphasize that fathers should not be left alone to cope but need to be supported. Furthermore, my hope is that this study also shows fathers who father a child with autism, that they are not the only ones who are living such experiences and that they are not alone in this.

This study illustrates how fathers of children with autism go to great lengths to try to “find a solution” to the problem of autism. The fathers’ commitment to the search for

a solution appears to be relentless. Whatever the fathers' motive, the stories seem to have illustrated how the fathers' sense of urgency, as well their urge to support their children, drives them to search and attempt various interventions that claim to "cure" or help children. Some of these interventions do help the children. However, some people offering these interventions could exploit fathers who seem to be willing to attempt anything to help their children. Thus, this highlights the need for professionals to contribute further towards teaching fathers about autism, and exposing them to the evidence base available relating to treatment and interventions. Furthermore, the study should also encourage professionals to be even more transparent with regards to the identification of the condition, whilst also being very sensitive to how they inform fathers about the diagnosis. Professionals could also contribute more to increasing awareness regarding autism amongst the general public. Such contributions could play an important part in decreasing the fathers' feelings of aloneness and also contribute towards decreasing their feelings of stress.

In conclusion, this study should serve to validate the fathers' experiences and points of view. It also should help EPs, and other professionals, working with children diagnosed with autism understand better the fathers' complex needs. This study highlights the need for EPs to not only work with the children and target the children's difficulties, but also to work with the family and especially with fathers. Finally, this study should also help to give a voice to the fathers' concerns regarding their children, regarding the difficulties they are encountering, and also with regards to their children's future. My hope is that this study serves to give courage to the fathers and to give them strength in their 'struggle' with their children's condition, whilst also finding joy in their everyday interactions with them. My wish is also that they find further help and support from professionals and experts in the area of ASD, as well as from the general public. My plea to the general public is that they become even more aware of the condition that is ASD, and appreciate the fathers' effort, work and commitment to their children; whilst always remembering, in their everyday interactions with them to "be kind: [for] everyone you meet is fighting a hard battle" (Watson, 1995, as cited in Moon, 2001, p. 55).

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Appendix 1 - Summary of literature focusing on fatherhood

<i>Reference</i>	<i>Purpose of study</i>	<i>Sample</i>	<i>Study Design</i>	<i>Findings Reported</i>
Goodsell, Barrus, Meldrum and Vargo (2010)	<p>To understand what fatherhood means for first time expectant fathers;</p> <p>To understand what it means to be a good father for first time expectant fathers;</p> <p>To develop a metaphor for how multiple contexts of fatherhood are understood.</p>	<p>Fathers (N=42, USA). Participants ranged in age from 18 to 36;</p> <p>All of them agreed to enter the study while they were still expecting the birth of their first child.</p>	<p>Qualitative – ethnographic inquiry of narrative that used a “modified grounded theory analysis”;</p> <p>Interviews - Fathers were invited to recount stories that illustrated what fatherhood meant for them.</p>	<p>The metaphor developed for understanding fatherhood was that of “Harmony”;</p> <p>Harmony is composed of three elements: polyphony, movement, and subjectivity.</p>
Duchworth and Buzzanell (2009)	<p>To understand how fathers construct work-family balance in their life contexts;</p> <p>To understand how fathers perceive their fatherhood roles.</p>	<p>Fathers (N-18, USA); Participants ranged in age from 26 to 55;</p> <p>Participants were had biological, adopted, or step- children living with them.</p>	<p>Qualitative – explorative; Semi-structured interviews;</p> <p>Constant comparative technique was used for the analysis of data.</p>	<p>Work-family balance was framed as a negotiation between work and life;</p> <p>Family is seen as a very important aspect in the fathers’ lives;</p> <p>Family is linked to the fathers’ meaning of work;</p> <p>Fatherhood was defined as a “web of responsibility”;</p> <p>Problem solving was one of the fathers’ main activities.</p>

<i>Reference</i>	<i>Purpose of study</i>	<i>Sample</i>	<i>Study Design</i>	<i>Findings Reported</i>
Miller (2010)	<p>To explore how men's intentions around their fathering involvement are imagined and shaped in prenatal interviews;</p> <p>To explore how men's prenatal intentions are actually practiced.</p>	Fathers (N=17, UK); Participants ranged in age from 24 years to 39 years.	<p>Qualitative – explorative and longitudinal;</p> <p>Interviews: prenatal and postnatal (carried out at 9-10 months following the birth and at approximately two years);</p> <p>Analysis of interviews was done thematically and comparatively.</p>	<p>Men 'prenatally' imagined fatherhood roles consisting of paid work, hours spent in the work place & ideals of hegemonic masculinities;</p> <p>Fathers also spoke about "being there" and caring for their child;</p> <p>Fathers tried to find a balance between hands-on caring and providing financial support for their children.</p>
Shirani and Henwood (2011)	To investigate fathers' relationships and their involvement with their family.	Fathers (N=2, UK, selected from a sample of 46 men) – Rick (aged 35 at first interview) and Keith (aged 31 at first interview).	<p>Qualitative longitudinal research;</p> <p>Case study;</p> <p>Interview: pre-birth interviews, post-birth interviews, and 8 years later.</p>	<p>Father involvement with his children is seen as an important aspect of good fatherhood;</p> <p>Pre and post-birth interviews indicates that fathers' involvement with their children is conditioned by gender distinctions and expectations;</p> <p>Interviews carried out 8 years after suggest that gender barriers are no longer relevant.</p>

<i>Reference</i>	<i>Purpose of study</i>	<i>Sample</i>	<i>Study Design</i>	<i>Findings Reported</i>
Finn and Henwood (2009)	To explore the identificatory positionings that are apparent in men's talk of becoming first-time fathers.	Fathers (N=30, UK); Participants ranged in age from 18 and 40 years;	Qualitative; Semi-structured interviews; just before and after the birth of their child; Focus groups with 13 of the fathers.	Men talked about “hybridized” responsibility that included a more nurturing role & guidance.
Eerola and Huttunen (2011)	To outline the contemporary narratives and storylines of fatherhood as told by young Finnish first-time fathers.	Fathers (N=16, Finland); Participants ranged in age from 23 and 29 years;	Qualitative - Narrative inquiry; Interviews using narrative and thematic questions.	Three different narratives were identified/constructed: the modern, the transition and the postmodern narratives of fathering

Appendix 2 - Summary of studies that focus on fathers of children diagnosed with autism

<i>Reference</i>	<i>Purpose of study</i>	<i>Sample</i>	<i>Study Design</i>	<i>Findings Reported</i>
Rogrigue, Morgan, and Geffken (1992)	To explore the psychosocial adaptation of fathers of children with ASD, Down Syndrome and developmentally normal children.	Fathers (N=60, US: ASD, n=20; Down Syndrome, n=20; developmentally normal children, n=20).	<p>Quantitative study:</p> <p><i>Data gathering:</i> Administration of standardized questionnaires that measure the fathers': perceived efficacy and competency as a parent; feelings of frustration, anxiety and motivation with regards to parenting; coping strategies; perceived levels of stress; perceived levels of family cohesion; perception of impact of raising a child on family finances; perceived level of social support.</p> <p><i>Data Analysis:</i> Multivariate analysis of covariance.</p>	<p>Fathers of children with ASD experience more disruption in family planning than other groups;</p> <p>Fathers of children with ASD experience increased financial burden that other groups;</p> <p>Fathers of children with ASD reported levels of perceived parenting competence and marital satisfaction that were similar to other groups.</p>

<i>Reference</i>	<i>Purpose of study</i>	<i>Sample</i>	<i>Study Design</i>	<i>Findings Reported</i>
Hartley, Seltzer, head and Abbeduto (2012)	To examine psychological wellbeing (measured by three indicators of wellbeing: depressive symptoms, pessimism, and coping) in fathers of adolescents and young adults with Down syndrome, ASD, and Fragile X syndrome.	Fathers (N=240, US: Down syndrome, n=59; ASD, n=135; Fragile X, n=46); Sample overlapped with that of Abbeduto et al. (2004) who studied maternal psychological well-being.	Quantitative study: <i>Data gathering:</i> Administration of standardized questionnaires <i>Data Analysis:</i> 1. One-way analyses of covariance was used to examine differences in three indicators of psychological wellbeing. 2. Group comparison of 4 factors of paternal age, child behavior problems, the presence of additional children with disability, and maternal depressive symptoms. 3. Hierarchical linear regressions were used to explore if the factors mentioned above could account for variation in paternal psychological wellbeing.	Fathers of adolescents and young adults with ASD reported more depressive symptoms than fathers from other groups; Fathers from the Down syndrome group experienced less pessimism about their children's future than did fathers of adolescents and young adults with ASD and Fragile X; Fathers used similar coping strategies that included emotion-focused and problem-focused strategies; Challenges related to ASD are more stressful than the other conditions; Fathers from the ASD group may experience poorer wellbeing as a result of the high levels of stress they experience.

Appendix 3 - Summary of Studies evaluating outcomes of in-house training of fathers of children with autism.

<i>Reference</i>	<i>Purpose of study</i>	<i>Sample</i>	<i>Study Design</i>	<i>Findings Reported</i>
<p>Donaldson, Elder, Self, & Christie (2011).</p> <p>Reference: Donaldson, S. O., Elder, J. H., Self, E. H., & Christie, M. B. (2011). Fathers' perceptions of their roles during in-home training for children with autism. <i>Journal of Child and Adolescent Psychiatric Nursing</i>, 24, 200-207.</p>	<p>To explore the fathers' perception of their roles during in-home training for children with autism.</p>	<p>Fathers (N=10, USA): Age ranged btw 31-51 years; 9 Caucasian, 1 African-American; All with college education; All fathers of children diagnosed with ASD (according to DSM-IV criteria) aged between 3-8 years.</p>	<p>Descriptive – qualitative – design focusing on fathers' experience and perceptions of in-home father training; In-depth semi-structured interviews.</p>	<p>A child's communicative skills is highly valued by fathers; The quality of attention men receive from their children contributes to make them feel like fathers; Fathers benefited from in-home training by learning how to help their children and how to help improve their children's communication skills.</p>
<p>Elder, Valcante, Won, & Zylis (2003).</p> <p>Reference: Elder, J. H., Valcante, G., Won, D., & Zylis, R. (2003). Effects of in-home training for culturally diverse fathers of children with autism. <i>Issues in Mental Health Nursing</i>, 24, 273-295.</p>	<p>To define the concept of fatherhood in different cultural context; To evaluate the effects of in-home father-training intervention for autistic children.</p>	<p>Children (N=4, 3 boys and 1 girl, USA) diagnosed with ASD (according to DSM-IV criteria) and their parents representing four ethnic groups.</p>	<p>Quantitative; Multiple baseline single subject experimental design; Ten-minute parent-child sessions were videotaped and coded for child/parent initiating and responding behaviors; Intervention 1 (focused on imitating with animation) & 2 (focused on expectant waiting) spanned over 12 weeks with two home visits per week.</p>	<p>Fathers developed more awareness of their children's interests and preferences; A fathers' observational skills and their ability to follow their child's lead during play contributes towards improving father-child interactions & reduce the father's tendency to direct their children's behaviors;</p>

<i>Reference</i>	<i>Purpose of study</i>	<i>Sample</i>	<i>Study Design</i>	<i>Findings Reported</i>
<p>Elder, Valcante, Yarandi, White, & Elder, (2005).</p> <p>Reference: Elder, J. H., Valcante, G., Yarandi, H., White, D., & Elder, T. H. (2005). Evaluating in-home training for fathers of children with autism using single-subject experimentation and group analysis methods. <i>Nursing Research</i>, 54, 22-32.</p>	To evaluate a father-child in-home training program for its possible effect on the acquisition of precommunication skills by children diagnosed with ASD.	Fathers (N=18, USA) and 18 children (N=18, 14 boys and 4 girls).	<p>Single-subject experimental design: Frequency counts of skills taught to fathers and of the children's behaviors were obtained through videotaped father-child play sessions. Data was analyzed for each session by using graphs and visual analyses. Father-researcher feedback sessions.</p>	<p>Increased use of imitating with animation strategies by fathers. Initiation of interaction and vocalization by the child increased.</p>
<p>Elder, Donaldson, Kairalla, Valcante, Bendixen, Ferdig, Self, Walker, Palau, & Serrano (2011).</p> <p>Reference: Elder, J. H., Donaldson, S. O., Kairalla, J., Valcante, G., Bendixen, R., Ferdig, Self, R., Walker, E., Palau, J., & Serrano. C. (2011). In-Home Training for Fathers of Children with Autism: A Follow up Study and Evaluation of Four Individual Training Components. <i>J Child Fam Stud</i>, 20(3), 263-271.</p>	To evaluate: (i) the effects of in-home training of fathers; (ii) the fathers' ability to consequently train mothers in the same manner.	Couples with children diagnosed with ASD (N=18, 17 boys and 1 girl, USA).	<p>Single-subject experimental design: Fathers were taught 2 interventions (which included imitating/animating, following child's lead, expectant waiting and commenting). Fathers were videotaped for 10 minutes for 3 times every week for 12 weeks whilst interacting with their children. Fathers were taught how to teach these skills to mothers. Mothers were consequently videotaped.</p>	<p>An increased frequency in imitation with animation behavior, expectant waiting, and commenting on the child in fathers; An increased frequency in imitation with animation behavior, expectant waiting, and following the child's lead in mothers; Initiating rates and non-speech vocalizations increased in children.</p>

<i>Reference</i>	<i>Purpose of study</i>	<i>Sample</i>	<i>Study Design</i>	<i>Findings Reported</i>
<p>Ferdig, Amberg, Elder, Donaldson, Valcante, & Bendixen, (2009).</p> <p><u>Reference:</u> Ferdig, R. E., Amberg, H. G., Elder, J. H., Donaldson, S. A., Valcante, G., & Bendixen, R. (2009). Autism and family interventions: The use of the Internet to train fathers of autistic children. <i>International Journal of Web-based Learning and Teaching Technologies</i>, 4(3), 55–69.</p>	<p>To evaluate if: (i) a web-based intervention be used for father training; (ii) if a web-based training system could be used to scaffold training of other members of the family; (iii) impact of web-based system when compared to the impact of in-house training.</p>	<p>Fathers of children with ASD (N=24, USA) and their families.</p>	<p>Single-subject experimental design: Stage 1: Fathers received in-home training as well as web-based training and are encouraged to train mothers. Stage 2: Repeat process but only using web-based training.</p>	<p>Research still in process.</p>
<p>Seung, Ashwell, Elder, & Valcante (2006).</p> <p><u>Reference:</u> Seung, H. K., Ashwell, S., Elder, J. H., & Valcante, G. (2006). Verbal communication outcomes in children with autism after in-home father training. <i>Journal of Intellectual Disability Research</i>, 50, 139-150.</p>	<p>To study the efficacy of in-home father training on the communicative outcomes & social reciprocity of children with autism.</p>	<p>Parents (N=11, USA) who participated in Elder <i>et.al's</i> (2005) study.</p>	<p>Retrospective study using analysis of data collected by the third author - Elder <i>et al.</i> (2005); Transcriptions of parent–child videotapes used in previous studies; Verbal utterances were coded into verbal and non-verbal utterances.</p>	<p>Children with ASD showed an increase in one-word utterances produced and increased the number of different words produced.</p>

Appendix 4 – Information Letters

Dear Sir or Madam,

I, the undersigned, am a 2nd year student at the University of East London – School of Psychology. I am currently reading for a Professional Doctorate in Educational and Child Psychology. In partial fulfilment of the requirement of the Professional Doctorate in Educational and Child Psychology I am in the process of conducting a research study that aims to look into the lives and experiences of fathers whose children have been diagnosed with Autistic Spectrum Disorder (ASD).

Although there is some research on the kind of impact that parenting children with intellectual and developmental difficulties has on a family, there is very little on the impact of a diagnosis of ASD on fathers. Thus, the study's aim is to gain insight into how fathers experience their children who have been diagnosed with ASD.

Through the analysis of the participant's stories and narratives, I seek to gain a better understanding of how ASD - the diagnosis, the symptoms and characteristics associated with the condition - could impact a father's selfhood and how this could in turn influence father-child interactions as well as influence other important family dynamics. The study also aims to gain insights on a father's hopes, aspirations, fears and concerns about the present and future of his child.

The study's title is: **"A father's tale: stories and experiences of fathers whose children have been diagnosed with Autistic Spectrum Disorder"**.

The study will be relevant to professionals working with children with ASD, as well as to the families and fathers of children with a diagnosis of ASD. My hope is, that through the project, professionals, particularly Educational and Child Psychologists, could become more conscious of the impact of father-child interactions on children with a diagnosis of ASD.

For this reason, I would like to ask you for your help with finding the adequate participants for this study. If you agree to support me in recruiting the participants, you will be asked to send **"Participation Letters"** to the fathers that are involved with your organisation who have children diagnosed with ASD whom you believe would be willing to participate in this study. This participation letter is a letter that will explain the aims and purposes of the study and will explain how to get in

contact with me. This letter will be sent to you in due time; when all ethical consents from University of East London Ethical Committee (London) and UREC (University Research Ethics Committee, Malta) have been obtained. Until then, I would like to ask you to refrain from contacting and/or refrain from talking about the research study with any potential participants, as this would be in breach of ethical policies and regulations.

It is important that you are aware that participants who would consequently agree to participate in this study will be doing so on a voluntary basis and will have the right to refuse to take part in the study, or to continue doing so, at any time during the research process. Furthermore, any personal information about the participants will not be shared with any third parties. In the study's write up, no real names will be used. Rather, identities will be anonymized and pseudonyms will be used instead. Finally, when the research will be concluded, the participants will have the right to the results if they ask for them.

If you and your organization agree to support me with recruiting the participants, please sign the form attached overleaf, and return it to:

**Louis John Camilleri
Doris House,
Luqa Road,
Qormi. QRM 9071.**

For more information on this study, please contact me by phone: **(00356) 99450534**, or by Email: **louisjohncamilleri@yahoo.com**

If you have any questions or concerns about the study or on how it is being conducted, you may also contact the study's supervisor:

Dr. Mary Robinson,
School of Psychology,
University of East London,
Water Lane, London E15 4LZ.
Email: mary8@UEL-Exchange.uel.ac.uk
or

Chair of the School of Psychology Research Ethics Sub-committee:

Dr. Mark Finn,
School of Psychology,
University of East London,
Water Lane, London E15 4LZ.
(Tel: (0044) 20 8223 4493. Email: m.finn@uel.ac.uk)

I thank you in advance for your help,

Regards,

Louis John Camilleri

UNIVERSITY OF EAST LONDON

School of Psychology
Stratford Campus
Water Lane
London E15 4LZ
England

On signing this document, I agree, in the name of my organization, to participate in the study called:
“A father’s tale: stories and experiences of fathers whose children have been diagnosed with Autistic Spectrum Disorder.”

I am aware that the organization will thus be using its available database to aid the researcher with the recruitment of participants for the study.

I have been made aware that the study is concerned with issues, problems, challenges, joys, elation and contentment that revolve around the fathering of a child with Autism Spectrum Disorder.

I understand that my organization has been asked to participate in this study because the members pertaining to the organization possess the right criteria set by the researcher for the study. I am also aware that the potential participation of the organization’s members would be on a voluntary basis and I understand that they can refuse to take part in the study, or to continue doing so, at any time during the research process. I have been informed that the entire study is confidential and any personal information about the participants will remain strictly confidential. Only the researcher involved in the study will have access to identifying data.

I have been informed that no real names will be used in the research text. Rather, identities will be anonymized and pseudonyms will be used instead. I also understand that once the research is over, I have the right to the results if I ask for them.

I am of the knowledge that the study will help in developing a better understanding of how fathers experience their children; their diagnosis; their strengths; their difficulties; their joys; and their lives.

I am also aware that the organization will receive no direct benefit in participating in this study.

I have read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which my organization will be involved in have been explained to me.

I hereby freely and fully agree, in the name of my organization, to participate in the study by helping the researcher recruit the participants. I have been given the researcher's contact details in the event of further questions related to the study.

Name of organization (BLOCK CAPITALS):

.....

Name of organization's official representative (BLOCK CAPITALS):

.....

Signature of organization's official representative:

.....

Name of witness (BLOCK CAPITALS):

.....

Signature of witness:

.....

Researcher's Name (BLOCK CAPITALS):

.....

Researcher's Signature:

.....

Date:

Appendix 5 – Participation Form

UNIVERSITY OF EAST LONDON

School of Psychology
Stratford Campus
Water Lane
London E15 4LZ
England

Dear Sir,

I, the undersigned, am a 2nd year student at the University of East London. I am currently reading for a Professional Doctorate in Educational and Child Psychology. In partial fulfilment of the requirement of the Professional Doctorate I am in the process of conducting a study that focuses on the experiences of fathers whose children have been diagnosed with Autism Spectrum Disorder (ASD).

This is a rather under-studied area of research. Although there is some research on the kind of impact that parenting a child with intellectual and developmental difficulties has on a family, there is very little known on the impact of a diagnosis of ASD on fathers. Thus, the study's aim is to gain insight into how fathers experience their children who have been diagnosed with ASD.

The purpose of this letter is to ask you for your help by participating in this study and also to provide you with the information that you need to consider in deciding whether to participate in the research study.

In this study, through the analysis of your stories and narratives, I will be seeking to gain a better understanding of how ASD - the diagnosis, the symptoms and characteristics associated with the condition - could impact you as a father and how it touched or effected your experience of fatherhood. The study will also aim to gain insight on your joys, hopes, aspirations, fears and concerns regarding the present and future of your child.

The study's title is:

“A father's tale: stories and experiences of fathers whose children have been diagnosed with Autistic Spectrum Disorder”.

The study will be relevant to professionals working with children with ASD, as well as to the families and fathers, such as yourself, of children with a diagnosis of ASD.

Participation in this study will require interviews spread over not more than 2 sessions (1 hour 30 minutes per session) where I will be asking you to recall memories of your fathering experiences. I will also be asking you to talk about your thoughts and feelings on fatherhood, on your relationship with your child, and on the joys and sorrows of your fathering experience. The interviews will be recorded using an electronic device, so that they may be later transcribed and analysed.

At times during the interviews, we may also be using photographs and use them to get a better understanding of your personal experience. The use of photographs alongside conversation could be used at the discretion of the interviewee (yourself) and used to aid with the interviewing process. Such photographs would ideally be representative of your fathering experience and will be selected by yourself and discussed during the interviews. The photos will not be included in the research; rather they will be solely used to aid in the conversation.

Consequently, after the interviews are concluded, I will be reconstructing the data that I would have collected during the interview into a narrative. After this I will be checking back with you to corroborate the content of this narrative. This “checking back” will be done not more than twice; depending on necessity. These “checking back” meetings will consist of not more than 45 minutes.

The interviews will be preferably held at the interviewee’s (father) residence. However, this is negotiable and alternate venues could be considered, given that the venue does not disrupt the interviewing and recording process.

Due to the nature of the topic discussed, the interviews could be potentially distressing to the interviewees as well as to the interviewer. Thus, I must make you aware that participants that partake in this study will be doing so on a voluntary basis and have a right to refuse to take part in the study, or to continue doing so, at any time during the research process. Should you choose to withdraw from the study you may do so without disadvantage to yourself and without any obligation to give a reason.

The entire study is confidential and any personal information about the participant will not be shared with any third parties, and will only be used for the benefit of the research. In the study’s write up, no real names will be used. Rather, identities will be anonymized and

pseudonyms will be used. The data will be collected and the research will be conducted according to Data Protection Act, which was enacted in Malta on the 14th December 2001, and according to the University of East London's Research Ethics Committee policies.

Finally, when the research will be concluded, you will have the right to the results if you ask for them.

If you would like to participate in this study, please fill in the end section of this letter and return it, using the addressed and stamped envelope attached with this letter to:

Louis John Camilleri
Doris House.
Luqa Road.
Qormi. QRM 9071
Malta

Otherwise, call me on: **(00356) 99450534**, OR email me at: **louisjohncamilleri@yahoo.com** to ask for further information on the study.

If you are happy to partake in this study you will be asked to sign a consent form prior to your participation. Please retain this invitation letter for reference.

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor:

Dr. Mary Robinson,
School of Psychology,
University of East London,
Water Lane, London E15 4LZ.
Email: mary8@UEL-Exchange.uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee:

Dr. Mark Finn,
School of Psychology,
University of East London,
Water Lane, London E15 4LZ.
(Tel: (0044) 20 8223 4493. Email: m.finn@uel.ac.uk)

I thank you in advance for your help,
Sincerely yours,

Louis John Camilleri

I am interested in participating in this study and thus give permission to the researcher to contact me with the intention of setting up a meeting:

Name: _____

Surname: _____

I prefer that you contact me by (tick your preference):

Email

Post

Phone

In person

Other

Contact details: _____

Signature: _____

Date: _____

Appendix 6 – Consent Form

UNIVERSITY OF EAST LONDON

School of Psychology
Stratford Campus
Water Lane
London E15 4LZ
England

CONSENT FORM

On signing this document, I am giving my consent to participate in the study called:

“A father’s tale: stories and experiences of fathers whose children have been diagnosed with Autistic Spectrum Disorder.”

The study is concerned with issues, problems, challenges, joys, elation and contentment that revolve around the fathering of a child with Autism Spectrum Disorder.

I, as a participant, am aware that by participating in this study I will be asked to take part in conversations, in an interview style, with the researcher and give personal accounts and renditions of personal experiences, as well as answer delicate questions. I have given my contact details to the researcher and understand that I can be called on again if any queries need to be resolved.

I understand that I have been selected for the study because I possess the criteria set by the researcher for the study. My participation is on a voluntary basis and I understand that I can refuse to take part in the study, or to continue doing so, at any time during the research process. I have been informed that the entire study is confidential and any personal information about me will remain strictly confidential. Only the researcher involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I have been informed that no real names will be used in the research text. Rather, identities will be anonymized and pseudonyms will be used instead. I also understand that once the research is over, I have the right to the results if I ask for them.

I am also aware that my conversations will be recorded using electronic equipment and consent for my conversations and interview with the researcher to be documented by means of transcription.

I am of the knowledge that the study will help in developing a better understanding of how fathers experience their children; their diagnosis; their strengths; their difficulties; their joys; and their lives.

I will receive no direct benefit in participating in this study.

I have read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I hereby freely and fully consent to participate in the study. I have been given the researcher's contact details in the event of further questions related to the study.

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....

Researcher's Name (BLOCK CAPITALS)

.....

Researcher's Signature

.....

Date:

Appendix 7 – Original Interview Questions

- Can you tell me about your family? What is your perception of your family?
- What do you think is your role within your family?
- Can you tell me about your fathering experience?
- Can you describe how a typical day looks like for you?
- Can you tell me about your life ever since being a father?
- What were your expectations of fatherhood before you became a father? Do you think that these expectations were met? Have you ideas/notions regarding fatherhood changed by means of your very own fathering experience?
- Can you tell me how you think fatherhood has impacted your life?
- How would you describe your child? Can you describe him/her for me?
- Which stories and experiences could describe best your son/daughter; his/her character and temperament?
- Can you tell me about your relationship with your son/daughter?
- Tell me some stories that you think represents best the relationship that you share with your son/daughter.
- Can you tell me about your experience of ASD? What is ASD for you?
- How did you get to know about ASD? What do you know about ASD?
- Can you talk to me about when you found out that your child would be diagnosed with ASD?
- Can you tell me on when and how did you notice that your child was experiencing certain difficulties?
- How do you think you, as a father, can help your child cope better with his/her difficulties?
- What do you believe are your child's strengths?
- Can you talk to me about how and when did you notice your child's strengths? What stories would best represent your child's strengths?
- Can you talk to me about the joyful and rewarding experiences of being a father of a child with ASD?
- Can you talk to me about the difficulties you have encountered, if any, with raising a child with ASD?
- Can you tell me stories that you think represents best your difficulties?
- How do you cope with such difficulties? Can you recall and describe specific memories and experiences.
- What are your hopes for the future for your son/daughter?
- What are your aspirations for your son/daughter?
- What sort of story would you fashion for your child's future?
- What concerns you mostly about the present and future of your child?
- Can you talk to me about your notions of fathering/fatherhood?
- What does it mean for you to be a father?
- What contributions do you feel you have made and can make, in the future, towards your child's overall development?
- As a father of a child with ASD, do you feel supported enough by private/public agencies – emotionally, physically (even through funding), educationally (through courses, workshops)?

Appendix 8 – Study timeline

<u>Time Period</u>	<u>Activity</u>
<i>November 2011</i>	Submitted research proposal at University of East London (UEL)
	Submitted 'Ethics Approval Form' at UEL
<i>February 2012</i>	Obtained ethical approval from UEL School of Psychology Ethics Sub-Committee
<i>March 2012</i>	Registered research with School Research Degrees Sub-Committee (SRDSC) at UEL.
	Obtained clearance to complete my research in Malta from Directorate for Quality and Standards in Education, Malta. <i>This was however subject to approval from the University of Malta Research Ethics Committee (UREC).</i>
<i>April 2012</i>	Obtained Ethics Approval from UREC, Malta.
<i>May 2012</i>	Start of literature search related to fathers of children with ASD.
	Contacted organizations by phone and organized meetings to explain my research. Organizations were given 'Research Information Sheet' and 'Organization Consent Form', which they signed.
<i>June 2012</i>	Organizations distributed 'Participation Letters' and 'Data Protection Form'.
	Received reply by post or by email from fathers. Received 13 replies.
<i>July 2012</i>	Contacted parents by phone to schedule interviews. The study was explained to the fathers, as well as the steps that I would be taking to ensure anonymity. Their right to withdraw from the research was also explained.
<i>July 2012 – October 2012</i>	Consent forms were signed by the fathers. Interviews were carried out and recorded.
<i>August 2012 – December 2012</i>	Transcription of the interviews.
<i>November 2012 – January 2013</i>	Storying of the narratives
<i>January 2013 – February 2013</i>	Check-backs with the fathers.
<i>February 2013 – March 2013</i>	Completed the commentary phase of the study
	'External audit' of 'commentary chapter' by external auditors: the study's supervisor and by a sociology graduate
<i>May 2013</i>	Literature search completed
	Research write-up completed

Appendix 9

Examples of how 3D framework was used in practice

RUPERT'S 3D STORY SKELETON

INTERACTION		CONTINUITY			SITUATION
Personal	Social	Past	Present	Future	Place/context
<ul style="list-style-type: none"> His wife's pregnancy was totally unexpected because of the complications his wife had with her cycle. 	<ul style="list-style-type: none"> Rupert and his wife wanted to start a family. 	<ul style="list-style-type: none"> Rupert and his wife had been trying to have children but were encountering difficulties conceiving a child. Rupert received a text message from his wife after she had visited her gynecologist. This was a surprise, as she had not visited the doctor to consult regarding pregnancy. 	<ul style="list-style-type: none"> Rupert and his wife have two children: a boy and a girl 	<ul style="list-style-type: none"> Rupert would like for his children to be happy, healthy and autonomous. 	<ul style="list-style-type: none"> Home/Family
<ul style="list-style-type: none"> Rupert's wish was that his children were normal. He associated Autism with disability. He was afraid of the label of autism, which would have denoted disability or difference. In actual fact he did not know what autism was. The first things that came to mind when he heard autism were wheel chairs and Rain Man. 	<ul style="list-style-type: none"> Rupert consulted with various professionals: his daughter's Kindergarten assistant; Head of school; teacher. Rupert has also consulted with Psychologists and other professionals whose area of specialty is ASD. 	<ul style="list-style-type: none"> Rupert was in denial when his wife told him that she suspected that their daughter had autism. Rupert was also in denial even when he was approached by various professionals, such as teachers and Kindergarten assistants. He interpreted this 'special interest' in his daughter as a sign of fixation or obsession from the professional's part. 	<ul style="list-style-type: none"> Both Rupert's children have been diagnosed with Autism. Rupert has today accepted the diagnosis. 	<ul style="list-style-type: none"> Rupert would like his children to be self-sufficient. He would like to keep on working to help them achieve this goal. 	<ul style="list-style-type: none"> School/Special setting.
<ul style="list-style-type: none"> Rupert is a problem solver. He is very proactive and tried to find solution to problems rather than ruminate on them. 	<ul style="list-style-type: none"> Rupert is looking for ways to 'solve' the puzzle of autism. He looks for solutions that could be considered my mainstream medicine as being unconventional e.g. BioMeds and Hyperbolic Oxygen Therapy. 	<ul style="list-style-type: none"> Rupert has spent a lot of time researching thoroughly various therapeutic interventions for autism. 	<ul style="list-style-type: none"> Today Rupert wakes up every morning and prepares the BioMeds for his children. He visits a DAN doctor on a quarterly basis to consult on the medications he administering to his children. Rupert also makes sure that his children receive more conventional and 'widely 	<ul style="list-style-type: none"> Rupert hopes that research advances in this area. He will keep looking into different ways to help his children improve and become more independent. 	<ul style="list-style-type: none"> Private / personal context

INTERACTION		CONTINUITY			SITUATION
Personal	Social	Past	Present	Future	Place/context
			accepted' therapeutic input such as speech therapy, and behaviourist interventions.		
<ul style="list-style-type: none"> Rupert feels fathers should be present and involved in their children and in their family lives. He also feels that he should provide financially for the family. 	<ul style="list-style-type: none"> Rupert recalls his own upbringing and his relationship with his own father. He believes that the concept of fatherhood today has changed. Previously father were mostly breadwinners and did were not expected to spend a lot of time with their family. 	<ul style="list-style-type: none"> Rupert and his wife went out more, and were free to do so. Rupert and his wife had fewer responsibilities. Rupert and his wife both worked. 	<ul style="list-style-type: none"> Today, having two children has changed their style of living. It is important for Rupert to spend good quality time with his family. Rupert focuses on spending quality time with his children and his wife. He enjoys playing with his children on a daily basis. Rupert and his wife try to have one evening a week away from their children to nurture their relationship. 	<ul style="list-style-type: none"> Rupert always tries to imagine ways in which he can relate further and better with his family. 	<ul style="list-style-type: none"> Family/home setting.
<ul style="list-style-type: none"> Some of the symptoms of autism frustrate him and occasionally anger him. 	<ul style="list-style-type: none"> People sometimes do not seem to be sensitive and aware of autism. People get angry at the children when they have or when they do not understand what is expected of them: Incident at playroom with daughter; incident at shopping centre with son on Rupert's birthday. 	<ul style="list-style-type: none"> Incidents were his son or daughter had tantrums in public places. 	<ul style="list-style-type: none"> Today Rupert and his wife prepare their children by explaining to them thoroughly what is expected of them. 	<ul style="list-style-type: none"> Rupert envisions the future and tries to predict what could go wrong. Like this he prepares himself and his children 	<ul style="list-style-type: none"> Playrooms/ playgrounds/social settings.

FRANK'S 3D STORY SKELETON

INTERACTION		CONTINUITY			SITUATION
Personal	Social	Past	Present	Future	Place/context
<ul style="list-style-type: none"> Unsettling thoughts brought about by the fear of the unknown. Not being able to take anything for granted is stressing. Having a child is new to him. Having a child with autism is also new. 	<ul style="list-style-type: none"> Comparison of his childhood with his son's childhood. Reflected on his very own childhood and about the things he wished he had done with his father. Asks: how is my child going to relate to me? How is going to function in social situations that I have been through? 	<ul style="list-style-type: none"> Prepared himself for what he thought would mean to be a father. Started forming ideas of the future, and on what his child was going to do. 	<ul style="list-style-type: none"> The diagnosis of autism has unseated him. It was unexpected. Currently working to develop his son's abilities as best as he can. Concerned about going out to public places with his son. His son finds new experiences and public places stressing and hard to cope with. 	<ul style="list-style-type: none"> What will happen to his son when his wife and he are not there anymore? Future is his main concern. Future is however blurry and unclear. 	<ul style="list-style-type: none"> During the 9 months of pregnancy and 1 year after his son was born.
<ul style="list-style-type: none"> Asks himself: "why me, and why my son?!". 	<ul style="list-style-type: none"> Different people see autism in a different way. People who have not experienced it, as in do not have a child with autism, could see it in different light. A friend of Frank thought that it was a "cool" condition. 	<ul style="list-style-type: none"> Knew very little about autism. Was not aware of the difficulties associated with autism. Was not aware of the affect that autism has on families, and the therapy that is involved and also the help that is needed. 	<ul style="list-style-type: none"> Feels as if he has known about Autism all his life now. Autism has affected his life in a variety of ways. Today sees autism as being a result of probability: "There are stats and probability and that is all that there is to it. There is no divine plan deciding that you are having autism and that you are not." 	<ul style="list-style-type: none"> The diagnosis brought about thoughts about the future and about his ability to provide for the needs of the family. 	<ul style="list-style-type: none"> Personal: the relationship with the concept of autism.
<ul style="list-style-type: none"> Regrets for not having another child. He and his wife are scared of having another child now. 	<ul style="list-style-type: none"> Feels he and his wife could be too old to have other children. Frank and his wife discuss the issue of having children. However they are aware of the fact that they have a 70% chance that their child would also be on the spectrum. Frank feels that there is a lack of support from his family since they are living in another country. 	<ul style="list-style-type: none"> Would have liked more children. 	<ul style="list-style-type: none"> Frank is scared to have more children, as he is concerned that they might also be on the spectrum. 	<ul style="list-style-type: none"> Financial issues/burdens/ constraints, responsibilities is also what comes to mind when talking about having another child. 	<ul style="list-style-type: none"> Personal: concerns he and his wife share regarding other children and autism.

INTERACTION		CONTINUITY			SITUATION
Personal	Social	Past	Present	Future	Place/context
<ul style="list-style-type: none"> Feels that his wife and himself have to fight various battles for their son. 	<ul style="list-style-type: none"> The State would aid if his son were to attend a government school. He feels he has to fight against bureaucracy. At school, there are things that they did right, that they did wrong, and other things they did not manage very well. 	<ul style="list-style-type: none"> Never had he thought of such difficulties. 	<ul style="list-style-type: none"> Sometimes school poorly manages certain issues. Has to visit school and set the record straight and say: “look, this is not acceptable and you guys need to get your act together. I am paying you a lot of money”. He feels lacking control over his schooling experience, as he is not always aware of what is happening at school. 	<ul style="list-style-type: none"> Worried about which school shall fit his son best. Worried about the finances involved with paying for an LSA in a private school. Concerned about how his son is going to cope in a secondary school. 	<ul style="list-style-type: none"> School
<ul style="list-style-type: none"> The issue of a lack of communication is frustrating. 		<ul style="list-style-type: none"> The strain of never having spoken to him or him never spoken to Frank and his wife: that has probably the biggest thing for. 	<ul style="list-style-type: none"> The hardest thing to deal with was when he is interacting with his son when he is being difficult: “that is when you get tired and get frustrated and you can’t talk to him.” Every time Frank sees a child his son’s age on a video who can talk, he gets angry. Recently he has been able to understand “turn the TV on”. 	<ul style="list-style-type: none"> Wishes to hear him say “I love you daddy”. Would like him to articulate what he wants. Hope he can understand better what his son wants. 	<ul style="list-style-type: none"> Everyday situations
<ul style="list-style-type: none"> Feels that he is not doing enough for his son. Feels that he should be spending more time with him. There is conflict between his need to rest after a hard day at work, and spend more quality time with his family. 	<ul style="list-style-type: none"> Society expects that women remain working. The situation necessitated that his wife stops working. 	<ul style="list-style-type: none"> Before having children, both his wife and himself worked. They had more financial stability and fewer responsibilities. Frank and his wife together decided that his wife was to quit her job. This was when they realized that their son, and his difficulties, was going to occupy most of his wife’s time. 	<ul style="list-style-type: none"> Frank is the breadwinner in his family. Spends a lot of time working and feels guilty about not spending more time with his son and his family. Needs some time alone to recover from demands of work and also from family demands. He feels that he did not have to give up his career, whilst his wife has had to do just that. He feels this was very disruptive and difficult for his wife. 	<ul style="list-style-type: none"> When he is working, he feels that he should be spending more time with his son. When he is with his son, he becomes aware of the need for financial stability. He hopes he can balance both the financial and personal domains of his life. 	<ul style="list-style-type: none"> Work and home

INTERACTION		CONTINUITY			SITUATION
Personal	Social	Past	Present	Future	Place/context
<ul style="list-style-type: none"> • He wants and needs to feel close to his son. • He needs to feel that he is part of his son's life. • Role of a father is to provide emotional support, happiness, future planning. 	<ul style="list-style-type: none"> • Experience has given him mixed feelings on what it is to be a father. 	<ul style="list-style-type: none"> • He had a loving relationship with his own father but did not always feel as close as he wanted to. • Once he spent a couple of days with his son alone whilst his wife had to go abroad. 	<ul style="list-style-type: none"> • "Being a father is about feeling close to your child". • Today his son looks for him a lot and tends to "hang on" to him a lot. • Being a father today also means to support your child and your wife emotionally. • Frank depends on his today as he gives him purpose. 	<ul style="list-style-type: none"> • He looks forward to being even closer to his son. But is aware that this could be difficult because of the autism. 	<ul style="list-style-type: none"> • Home
<ul style="list-style-type: none"> • The experience of raising a child with autism is a hard one. He can see how it could split people up. 	<ul style="list-style-type: none"> • Frank is very close to his wife. • However, the experience of raising a child with autism "puts a huge strain on you and it does things like make you feel that you want to run away. It feels like your partner wants to run away." 	<ul style="list-style-type: none"> • Frank and his wife were free spirited before they had a child. • His wife went through a depression prior to having a child. 	<ul style="list-style-type: none"> • The difficulties they have faced have brought them even closer together. • Occasionally the lack of sleep, lack of communication and lack of understanding is very stressing and tiring for Frank. • Frank is sometimes envious of other parents who can take "normal" development for granted. 	<ul style="list-style-type: none"> • You cannot assume that development will unfold naturally with autism: "with autism, you feel that you actually have to instil these things. Like ok, we need to do this artificially. You have to build these things up that would have grown naturally." 	<ul style="list-style-type: none"> • Home
<ul style="list-style-type: none"> • Frank yearns for answers and for solutions. 	<ul style="list-style-type: none"> • There are expectations that people place on you as a parent and also regarding your child's development. 	<ul style="list-style-type: none"> • Frank had suspected something was wrong. However nothing was ever confirmed. • He visited a public place where he saw a child who mirrored his son's difficulties. • He looked for professional help from then onwards. 	<ul style="list-style-type: none"> • Received the confirmation regarding autism from CDAU. • Today uncertainty and lack of information regarding autism is frustrating. • Is on a journey through learning: learning about the condition, about his son and about himself. • He experiences strain with living day to day, when he wakes up and doesn't know what to expect. 	<ul style="list-style-type: none"> • Wished his son will grow out of autism, but is aware that is it very improbable. 	<ul style="list-style-type: none"> • Clinic & home
<ul style="list-style-type: none"> • He is aware of both good & bad. The good is sometimes overlooked because of the very intense bad. • Everything is seen in context. • The future is very much affecting the current context. 	<ul style="list-style-type: none"> • People see the improvements that his son makes. They see the positive. However they are not aware of the bigger picture. 		<ul style="list-style-type: none"> • Progress or achievements are sometimes overshadowed by negative concerns. • Some achievements have an emotional impact of Frank. 	<ul style="list-style-type: none"> • Everything is interpreted in light of the future. • What needs to be done to allow him to function well in society in the future? 	<ul style="list-style-type: none"> • Personal & interaction with others.

Appendix 10

Examples of Transcripts

Excerpt from 1st Interview with Rupert

Louis	5	Did you know anything about autism before you had your children diagnosed?
Rupert	6	No nothing at all. It was something unexpected, and unanticipated. In fact the first indication came from my wife. This was when my daughter could not even walk. This is when my wife mentioned something. My first reaction was denial. As usual.
Louis	7	Was this denial from your part?
Rupert	8	Yes, I actually went as far as to print out indicators describing the symptoms of autism and the triad of impairment. At the time she couldn't even walk or talk. I checked...she is still doing this and not doing that. At the time I thought that I was doing a lot of fussing over nothing.
	9	Then, she started attending play-school. Looking back, I realise that back then there already were some indication of autism. Back then, the professionals at the play-school tried to tell us about autism but they didn't want to be the ones who actually broke the news to us. However they did try to give us some hints.
	10	They told us: listen she is not talking. Take her to a Speech Language Pathologist (SLP).
Louis	11	Who exactly were these professionals that didn't want to tell you?
Rupert	12	Its not that they didn't want to tell us. These were the people from the play school. They were the carers and staff. However they did try to give us some indications. In fact she was the first one who sent us to the SLP.
	13	This is when we started speech therapy. The carer at the play-school told us that her peers were talking but she wasn't. We didn't know about this. There were also other signs. She used to get a book instead of playing with other children. I used to enjoy this as I also enjoy reading. So I used to say to myself that she is like me, she is going to like reading. There are other indicators: she used to like stacking things on top of each other. Now, in hindsight, it is easy to identify autism.
Louis	14	So when you used to see her stacking things up, what did you use to think?
Rupert	15	I didn't think that it was abnormal. I thought that everything seemed to be moving forward normally. Even the paediatrician used to tell us that everything was proceeding as normal. Again, in hindsight things look different.
	16	After play-school, she started kindergarten. Ever since the beginning, in September, they immediately told us that she was not playing like others. I think, what was happening was that at school she used to have a lot of tantrums, and whilst at home she didn't. This could be because we were anticipating the tantrums, and avoiding them from occurring.

Excerpt from 1st Interview with Frank

Louis:	1	It seems that you managed to come up with a couple of pictures.
Frank:	2	Yes. I took them from a point of view of everything that I feel about fatherhood, and my son and also autism. I am not sure how you want to use these. I guess they are here and we could use them as we talk. If you would like to start with them we can do that.
Louis	3	Sure, It seems to be a good starting point.
Frank	4	Exactly. It should serve as a good icebreaker. So these are not in any particular order. They are just various pictures. [Pointing at one of the pictures] Most of this is about the future. As I thought about these pictures and as I thought about this I seemed to have learnt more about myself and it seems that I am preoccupied about the future.
	5	The future is the one thing that you are unsure of. You are suddenly unseated; you start of on the journey of having a child and you start learning and reading. Then you do what every parent does; you get an overload and realize that there is conflicting guidance; there is this and there is that.
	6	You fall in a certain sort of step, if you like; you get an idea of what is coming; you start forming ideas of the future, and on what your child is going to do. Then, once you learn about the fact that your son has autism, then all of that thinking and hoping is gone: at least to a degree. All of that is gone.
Louis	7	So what were your ideas and dreams of what your son was going to turn out to be?
Frank	8	I guess it consisted of 9 months awareness during pregnancy and 1 year after that. So it took around 2 years of building up an idea – a naïve idea, because obviously, you know, it didn't turn out like I had imagined it.
	9	It all consists of the usual things. These two years of building ideas is the time to reflect on your very own childhood and about the things you wished you had done with your father and on what you actually did do with your own parents. I then ended up projecting forward and thinking of my own son. So I was thinking of the kind of discussions that I had with my parents and imagining that sort of thing: imagining your own childhood through your child. Also, you think about the things that you didn't do with you parents as a child. You see, my father was never really that social: we never really went out together, so that is something that I always imagined that I would do with my child. Suddenly, with autism, that is something that comes into question.
	10	So there is a pessimistic side that says that he is autistic and he is never going to have independence. Then there is the optimistic side that says that that is not at all true. But obviously, you are thrown a little and so you cannot take anything for granted. So being in a pub and being in a social setting may not be a comfortable activity or situation for a person with autism.
	11	The fact is that you don't know, and that is the thing: it is the not knowing. You can't take anything for granted, and this is unsettling. [Pointing towards another picture]

Excerpt from Interview with Ian

Louis	76	What was your reaction when you discovered that news?
Ian	77	First and foremost we tried to find out about the possibilities that could help him; both locally and internationally. At first you feel hopeful and energetic, and afterwards all the hopes tend to fade. As far as I know they are not aware what causes autism, and most of the solutions are experimental.
	78	When it comes to a cure, and academically speaking, everything is on trial. There are few options available, and Malta is limited. I was even considered emigrating in Massachusetts USA, for the reason that there are several institutions available that offered solutions. However my wife objected.
	79	Are you aware of these institutions abroad?
Louis	80	Yes I am aware of such institution. So, did the knowledge that your children had autism affect your role as a father? Where there any changes if any?
Ian	81	When my son decides that he wants to drink a cola there's no way that you can change his mind. If he wants something he will get it, otherwise he starts yelling. It is hard to accept, and sometimes I feel that I don't feel that I have a say on things that matter for Franco. It seems that he is living in another world. In my opinion he doesn't care if I exist, the most important things for him is his PC, going to swim, and that's it.
Louis	82	Do you believe that autism diminished the possibilities of your input as a father?
Ian	83	I definitely agree. It is as if all I am doing is keeping him alive. There is no relationship whatsoever. With my youngest child it is a total different story we are able to communicate he asks for our permission before doing something.
	84	For instance if we go at the cinema he can choose his own drink. However, there's no feedback from Franco.
Louis	85	Therefore you feel that having qualitative feedback is important.
Ian	86	I wish that he had been like his brothers.
Louis	87	Did your son ever call you daddy?
Ian	88	No [upset voice]. If I ask him "who am I" he is able to reply " <i>papa</i> or dad" but it is not spontaneous.

Appendix 11 - Examples of Interim Narratives

Sample from Alan's Interim Narrative

Fatherhood

Yes. It is very meaningful to me to call me daddy (2, 115).

Temple Grandin's mother was her daughter's mentor. That is what I would like to be for my daughter. I hope that she is lucky to have me as her scientist (1, 136).

Lately I built a robot for my daughter to get her attention. I would like to come up with some computer programmes that could help her. I think I could also introduce her to some programming that she could do herself. I think that she would enjoy it. I think that she would also be a good programmer (1, 138).

I would like to give her this direction. This is something that all fathers do: they give their children direction (1, 139).

Today I don't feel any lesser than other fathers. However I feel that I have a larger vision than other fathers (1,143).

I would say fatherhood is a challenging but important role (2, 124).

At this stage, my first priority in my life is my daughter (2, 125).

I try to find a balance between being a father and being a husband. However I am more of a father than a husband. I cannot see it any other way (2, 128).

The effects of autism on fatherhood

It is difficult to say. However, when one imagines how he is going to be as a father, you imagine that your daughter is going to be approaching you to tell you how her day at school was. You imagine that you will be giving her advice on her personal life and helping her out with her homework (1, 131).

Some of these things sometimes happen. There are times when she does come up to me and tell me what she did at school. I am still proud to see her overcome a hurdle (1, 132).

E.g. when she did her holy communion. At first I wanted her to sit down and do what she had to do. In the end she actually did these things. I was really proud of her (1, 133).

Another father whose child would do such things without any challenges would see things differently. However I was really proud. It was as if she had won all the prizes available at school (1, 134).

I still have goals and objectives and feelings, just like fathers of neurotypical children. I still have those feelings. However, my goals are different (1, 135).

Autism is what makes my daughter my daughter (1, 181).

Sample from Luke's Interim Narrative

Priorities

However the priorities are what they are today. The priorities today are different. In fact I had actually started my Masters degree. However, after three months I realised that my priority was my son, so I decided to stop (47).

An example of this is...I have a degree. I would have loved to do a masters. But I do not have time to do that. A Masters degree takes a lot of time to complete. There is a lot of studying involved. So, that is something that stresses me a lot (44).

Then when you see others who are doing something similar you tell yourself "I wish I could do something like that". However I know that is hard. I cannot even move right now with all the things I have to do (45).

Then, as if I was literally "stealing time", when they are all sleeping in the evening, I try to do some things that I enjoy. That is something that stresses me (46).

Difficulties brought about by the condition

But in general, I do not feel that there are so many difficulties (54).

Sometimes because of the stress, you feel more susceptible to stress (152).

I stopped doing some things that I used to do which I really used to enjoy. Time has become an issue. I spend more time with my son, and this has reduced the time I used to spend doing such things. That is how it changed mostly (156).

So we stopped the gluten. So we started a gluten free diet, which is really difficult to do. This is because there isn't a lot of gluten free food here in Malta. There is not a variety of products in Malta. Abroad we did find a lot though. The expenses were high (102). For example, a regular packet of spaghetti is 50c, a packet of gluten free spaghetti is two euro. These are things that you think about (103).

There are times when you find yourself thinking negative thoughts. I feel very sad and also very tired. There are times when I ask myself if I should end it all. But I know that that is stupid and silly. If I had to do that I would solve absolutely nothing. Rather, you would be leaving many problems behind and a lot of people who need you with a lot of added problems (196).

So now I reason, that my life is what it is. But I am still making the best out of it. There are limitations. There are the good moments and there are the bad moments (197).

Lack of verbal communication

The most obvious of answers is communication. However, to a certain point. The type of communication which is the most difficult is that using words with him. Alex communicates a lot using gestures (49).

In fact, when he wants something e.g. like a drink, he grabs my hand and takes me next to the fridge. He puts my hand on cold water to indicate what he wants (50).

With Alex you cannot do things that you could do with other children. However he does understand a lot of the instructions and commands I tell him (51).

Sample from Isaac's Interim Narrative

The ups and downs

We had bought them a bike for Christmas. I am a middle distance runner. It was a blessing for me but a curse for my children. A particular winter, my children wanted to learn the bike. We started going together. They on the bike whilst I am running. This is when there was a lot of crying (70).

This year however they both had a bike day at school. At school they had to take their bike with them. Only two children in my youngest son's class knew how to ride a bike. He enjoyed this. He enjoyed this so much that he started to show off (73).

When these things happen I am very happy. Particularly in this case, when we went abroad a couple of months ago, we had the opportunity to rent a bike and ride it together (75).

Let me show you this picture it was taken in a salt mine in Austria. This is a family picture of us, we are close together, he is smiling, interacting with us (8).

Let me tell you. Whilst telling you this I will be getting emotional for sure. It is a very emotional thing. Holy Communion was very important for me as a father. I told the Head of the Doctrine Classes to try to get children more involved during mass. When I said it I immediately knew it was going to be tough for him. However...his role was to read a small prayer in front of everyone. He did his bit, you would not have thought that he has autism. His behaviour was excellent; he stayed next to me, the proud father. That is why I showed you that picture. He was happy, he took pictures, he thanked his mum.....[long pause] [tears] (65).

Expression of affection

Another thing that is positive about him is the way that he shows love. Many children with autism find it difficult to express feelings (76).

Affection and expression of love were once absent. As a parent, both for my wife, and me this was very difficult. This lack of affectionate interaction used to be really distressing for us. There was an evident lack of eye contact before. He never even told us that he loved us. He had never said "love you" (78).

That is really painful. Very painful!! Sometimes the lack of such interaction used to be very frustrating. Both my wife and myself used to be affected to the point that we occasionally had some burst of anger. We used to seem to take these in turns. Sometimes it was me who had a rant, whilst some other times it was she. It all depended on our stress level (79).

One time whilst going around the block with my scooter, I fell and dropped my scooter on my foot. I came back home with a bruised leg (87). My son saw me and went on his mother and told her "Mama Isaac", cause that is how he calls me sometimes "is hurt". Then he brought me a bandage and also brought me some ice (88). Then he was constantly running after me and asking me "papa are you all right?" I must admit that that time I really enjoyed the attention (89).

It is extremely nice to see that type of affection. I love the fact that today we can communicate (90).

Appendix 12 – The Father’s Narratives

Frank’s Story:

A moment on the spectrum

Learning about autism

Prior to having children, the word autism did not mean much for Frank. However, nowadays it feels as if he has known about autism all his life. Frank learnt fairly dryly and academically about the condition that autism is. Initially Frank saw autism from a ‘savant’ point of view. The word brought about images of brilliant people. That is until he started to experience it.

On one occasion, he randomly bumped into a friend of his. He found himself telling his friend about his son. As he mentioned autism, to Frank’s surprise, his friend replied: “ah autism...it’s really cool isn’t it?” That struck Frank as really odd. He was not sure what to say, as this is definitely not how he would describe autism today. His friend probably was not completely aware of the difficulties brought about by the condition. He was probably unaware of the effect that Autism has on families and of the therapy that is required.

Finding out about his wife’s pregnancy

Frank recounts the day when his wife told him that she was pregnant. He is an individual who takes in information, and processes it gradually. That is why he was initially not jumping of joy when he heard the news. The elation only came later. The news led to thoughts about a typical ‘nest’ for his child, on what he was going to do when the child was born, and on the type of relationship the he was going to have with his child.

The news that his wife was having a boy brought about thoughts about his own childhood, about his relationship with his parents, and thoughts of how his childhood could compare to his child’s. Would he ride a bike? Will he go to college? Would he and his son be friends? From the day his wife told him that he was going to be a father, up until his son was 2 years of age, he found himself building ideas and also reflecting on his own childhood. Frank also reflected on the things he had wished he had done with his own father. In the mean time, lurking in background, he thought of what could go wrong during pregnancy. Back then autism had never crossed his mind.

Finding out about his son’s autism

The realisation that his son had autism is one of the clearest and most impacting moments of his life. The news of his son having autism reset all the ideas he had about the future. Once he learnt about the fact that his son had autism, all of the hoping was gone: at least to a certain degree.

The realization didn’t come all at once. However, early on he had realised that his son was different, as he used to express himself in a very particular way. He used to point in a peculiar way. He used to put his hands up and stand on things and also go through rather odd routines. Initially, his ‘odd ways’ were seen as funny and quirky; so Frank wasn’t too worried.

However, an incidental meeting with another child his son's age during a particular public event changed all that. This was when his son was a year and two months of age. Frank noticed this boy standing on a chair, and behaving just like his son. He had his son's same 'odd ways'. Frank did not know the boy and had never spoken to the parents. That just hit him like a log; that there was something that was unique. There was something that was causing this boy to do exactly the same thing. This prompted Frank and his wife to look for professional advice at Child Development Assessment Unit (CDAU).

By the time Frank and his wife received the psychology report, which confirmed that autism was his son's main difficulty, he had already started dealing with the diagnosis. It was just after his second birthday when the official diagnosis was made. By that time he already knew that his son was autistic. There wasn't any real doubt in his mind. But of course, when the psychologist said it out loud, that was difficult for him to hear. In fact, knowing beforehand did not lessen the impact on him or his wife. That day was indeed an emotional and tearful day. Nonetheless, the day after, Frank and his wife were getting on with their lives. They had no other choice.

Search for answers

The professionals who broke the news were understanding and sensitive to the situation. However, they were unable to answer Frank's main question: "what the hell do you do now?" For him, the concept of parenting changed there and then. Consequently he needed to know what to do with that information? He wanted to know more. He wanted, and needed, answers.

"He has autism. But for crying out loud, tell me how bad it is!? Is he going to speak? Is it severe? These were questions that remained unanswered. The lack of responses made him angry. There was a part of him that was saying that these people couldn't answer his questions. Then there was an emotional side of him that was yearning for answers: "give me something...anything". He was not asking anyone to lie to him, but he wanted someone to throw him a rope, and tell him at least if there even was a ten percent chance of one day hearing his son talk. Yet, this was not to be.

Lack of communication

The issue with communication is very stressing for Frank. The hardest thing to deal with, for him, is the fact that his son has never spoken to him. Frank gets emotional every time he sees a child his son's age talk. He yearns for his son to one day look at him and tell him what his needs, rather than having to figure out his son's need for himself. Even though he could see it in his son's eyes that he loves him, his biggest wish is to one day hear his son say to him "I love you daddy". Conversely, he would also be happy to hear his son ask for cornflakes.

Frustration with development

Frank is frustrated by the absence of normal and sustained progress seen in autism. Furthermore, with all the uncertainty surrounding autism and development, he often forgets to enjoy the little progress observed. He is sometimes envious of other parents who normally have the opportunity see their child develop naturally. He feels that whilst neurotypical children's mental faculties advance naturally, in autism this process is not as natural. He feels that with his son he has to instil these things. With children with autism, development occurs but in a rather artificial manner.

The bigger picture

As time goes by Frank does notice his son growing and improving to some degree. However, he constantly finds himself looking at the work and improvement that is still to be done. Furthermore, he doesn't always allow himself to recognize such improvement. Rather, his acknowledgment is more of an academic or clinical nature. According to him, with regards to his son, people will always 'grab at the positive'. However for him, as an involved parent, he is holding and balancing various perspectives and is seeing advances, difficulties, and other problems. For Frank it's about the big, or even, the very big picture. When somebody else comes and just notices the good, for him that is too much of a rudimentary depiction.

There were times when Frank has had a lot to deal with altogether. There is the bad behaviour that he has had to figure out and understand; which takes up a lot of his mental space at time. Then there is also the "good stuff"; which does give him an emotional high. An example of the latter is when he very recently cooked for his son, who in turn commented about the food by saying "nice". This brought tears of joy to his eyes. However, he does not always allow the "good stuff" to take up any mental space. For this reason, he frequently needs to remind himself to actually celebrate his son's advances.

Expectations

Frank feels that at times, autism 'forces' him to have low expectations. He constantly finds himself checking if his wife's and his own expectations are realistic or not, as unrealistic expectation leads to frustration, as well as to their son's and their own unhappiness. Thus, his philosophy is to let his son grow at his own pace and develop his potential.

An example of this is their son's development of speech. Frank, together with his wife, had set a mental goal or milestone. They said that they were not going to expect him to speak before the age of 4. This was a self-preservation strategy. When their son reached the age of four they started expecting him to speak. Day after day, and month after month, they eagerly waited for him to talk. However, speech remained as elusive as ever. For this reason, they decided to redress their expectations.

With regards to expectations, Frank feels that there should be balance, and that parents should refrain from not having any expectations at all. Having no expectation, he argues, is dangerous, as it could lead towards stagnation.

Difficulties related to autism

Notwithstanding the very good relationship Frank has with his wife, the difficulties that they faced, as parents of a child with autism, tested their relationship. It put a huge strain on them both. During one extremely stressful moment Frank wondered if it would be better if he got away from this all. In other moments, he was scared and asked himself if his wife ever wanted to run away? Wouldn't it be easier if they just didn't have this problem anymore, he asked? In such moments Frank felt caged, and felt claustrophobic.

In another stressful moment Frank thought about the people who were reported on the news to have abandoned their child at the airport. He argues: "as a parent, you

completely understand it. You lose it a little bit. You are sleep deprived. You are nervous and afraid. You can imagine coming out of that then you have a child who has very little communication. You got the tantrums. You got the not going to sleep and all of the things related with autism”. Whilst dismissing such thoughts as crazy and senseless, he talks about such feelings with a lot of guilt. He is adamant and utterly convinced that he would never ever dream of putting his child in harm’s way. Yet, he finds it very hard to accept that even in his darkest hour, such crazy thoughts lurk in his head.

Frank argues that experiences of the sort are either going to bring a couple together or are going to split them apart. Frank and his wife always worked well together, and this situation was nothing different, and also contributed to make their relationship a lot stronger.

Autism and Love

Frank loves his son to bits. He believes that love, and the reciprocation of love, is a fundamental emotion for humans. However, what if that reciprocation is put into question, as it is with children with autism? Frank is adamant that he will always love his son whether his son reciprocates it or not. Nothing is going to lessen his feelings for him. However, his concern is with how his son takes this forward with other people. The world is not just about father and son, but involves other relationships. Love and affection are essential aspects of relationships. Frank reasons that the difficulty individuals with autism evidence with understanding and expressing feelings of love and affection is probably the reason why they find it difficult to share an intimate relationship with another person.

Affection or sensory stimulation?

Frank describes his relationship with his son as a very affectionate and emotional one. His son enjoys hugging and kissing his father, who in turn reciprocates keenly. The relationship between father and son is very physical. For his son, relationships seem to be about physical proximity and about touch.

Frank is sometimes not sure if the physical aspect of their relationship is an expression of his son’s emotions or if it is his son’s way of obtaining the sensory stimulation that he requires. This question has been lurking in his head for some time now, and is yet another source of frustration. Frank believes that in the case of a neurotypical child, he could easily assume that it is not a sensory issue. In the case of his son, he is unable to make such an assumption. The uncertainty surrounding this issue makes him feel as if he was in limbo.

His son and society

His son’s atypical behaviour is occasionally a source of stress and uneasiness for Frank. His son is constantly running around; whether it is at their house or at a friend’s house. Because of this, Frank always has to keep an eye on him.

Both Frank and his wife have very supportive and caring friends. However, with their son’s difficulties, it has been difficult for them to socialize effectively with their friends without feeling worried or anxious. In one particular occasion, their son manifested some difficulties with socialising and relating with a daughter of a close friend of theirs. Difficulties of this kind occur from time to time, and are a cause of embarrassment. Because of such situations, Frank and his wife sometimes choose to

hold back from socialising with others. Nevertheless they are also keenly aware of the need for social exposure.

Educating the people around him about autism.

Notwithstanding the confirmed diagnosis of autism, the specialist that consequently worked with Frank's son, on an educational basis, was hesitant about such label. She argued that at that point it was a bit too early to be sure about the label. For that reason, for quite some time, Frank did not refer to it as autism. It was actually quite recently that he made a conscious decision to completely reverse that decision. This was because of school, his peers and their parents.

Frank reasoned that if he did not do anything to educate the people around his son, then he would just be seen as different and would be considered an outcast. If he did educate the parents, the parents would hopefully educate their children, and the children would then be in a position to understand his son better. In this way Frank was hoping to prevent his son from becoming socially isolated.

The question of why my son?

The question of "why my son" is a question which Frank tries to distance himself from. His is not an attempt to repress the matter. Rather, he consciously chooses not to dwell or obsess on the matter. He reasons that it is a matter of probability, and "probability is probability". If one in every 88 children is going to be on the spectrum, then it's just about probability, and nothing more. Just as people buy lottery tickets thinking someone has to win, children are born and some of them have autism. For Frank there are statistics and 'probability', and that is all that there is to it. There is no divine plan deciding who is to have autism or not.

Guilt and regrets

Frank occasionally does ask himself difficult questions like: "was it my fault?" "Did I do something wrong? Did I leave it too late? Is it related to age? He argues that parents like himself do look to blame themselves in one way or another, and believes that, although natural, this type of thinking will not get you anywhere and is more hindering than productive.

The Journey of acceptance

Frank has been on a journey for acceptance ever since he was told that his child was autistic. For him acceptance is a process that takes a very long time. He has accepted the diagnosis in many ways, but there are still some issues that he feels that he needs to resolve. In his own way, he is still battling with it.

However, acceptance is a concept that is elusive. He frequently finds himself asking what acceptance really is. From the stories that he has read, it seems to him that acceptance is a phase in people's lives where they actually enjoy their child, or when autism is not seen as a barrier anymore. This could appear to be somewhat of a blissful state. If that is what acceptance is, he argues, then "I guess I have not really found that".

Notwithstanding its elusive nature Frank understands why it is important for people to "find" acceptance. Frank is unsure if he could ever reach such a blissful state of being, and also questions if it is something distinct or particular to his character that stops him from reaching this state of acceptance.

Being a father

Frank's wife today is a full-time mother. Ever since there was the realisation that their son had autism, there was also the realisation that their son was going to take up all her world. In light of this, they jointly took the decision that Frank's role was to be a breadwinner, whilst his wife would take more of a "care giver's" role. This was a heartfelt decision for Frank, as he was aware of how tough it is for a person to relinquish their job or career to assume such a role. For this reason, fatherhood to Frank also consists of supporting his wife, as well as his son, and also helping her accomplish what she feels is fulfilling to her.

Thus, for Frank, being a father consists of providing and putting food on the table. His career is only a means to an end, which is to provide security and opportunities for his family. In this way he hopes to make his family happy, and feels that it is his job and responsibility as a father to do so. He strives to "keep everything out" and keep his son and his wife as happy as possible for as long as possible. With this in mind, Frank feels that for him to be in a position to make his family happy, he has to find a balance between his personal and his professional life. For this reason, he tries to spend time together with his family.

Frank argues that knowing that he is being useful to his family, and that his actions are contributing to his family's happiness, contributes towards his father identity. His identity as a father however took some time to ensue. At the birth of his son, there was a lot of numbness involved, particularly in the first few months. During this period of time, being called a father was almost alien to him. The "feeling comfortable" with the title of father came when his son was a year and a half. Frank's identity as a father became stronger when his son started hugging him and showing him that he wanted his father to lift him up. Very recently, his son also started improving on his eye contact. This contributed even further with making Frank feel even more connected to his son.

For Frank being a father also entails a certain amount of fight: fighting for his son. The fight is against bureaucracy at times, and is about trying to get the right support for him at school. From an emotional point of view, he sometimes feels like actually punching people. Even though this has never happened, being a father, for Frank, means that he has to be ready to get up and fight for his son.

Current Scenario

Currently, Frank's main concern is financial stability. Furthermore, he is also at a stage where he is still trying to find space for himself. He is constantly trying to find a balance between being a parent, being a husband, and being an individual. Thus, whilst making sure that he gives his "all" to his son, he also recognizes his human needs. For this reason he tries to find time for himself and time for his wife.

At the moment, Frank finds going out with his son or taking him out to social events or public places as being very hard and anxiety provoking. This is his challenge now as a parent. However, Frank believes that it is his role to provide his son with guidance. His son has a whole world in front of him and everything is new to him. However, in a way everything is also new for Frank. So for him, it feels as if he is an explorer guiding another explorer; as everything is new, both for Frank as well as his son.

Fear of having another child

The decision Frank and his wife made to have one child and not two is partly financially motivated. This decision also has to do with his understanding that if he had to have another child there is a 70% chance that that child could also be autistic. This is something that Frank takes into consideration, particularly in light of the additional educational and therapeutic input required, and also in light of the consequent financial requirements.

Frank believes that this decision could also have its down side, particularly for his son who would not have a sibling. He is also afraid that there is a chance that he and his wife would one day come to regret this decision.

The future

Frank has always been preoccupied about his son's future. He hopes that in the future his son will be autonomous and independent. He has an image of his son working in computing. He describes it as a "geek type of route". However, this route is dependent on what happens today and is determined by what Frank does now for his son. For this reason, Frank is paying for his son to attend educational based therapy. Nevertheless, Frank asks himself: is the therapy he is receiving now the right therapy? Is he in the right school? Is he going to go to a special school in the future, and in which case, is there one in Malta? Should he take his family to the UK? In which case, can he afford to do that? Is his job good enough to do this?

The most unsettling aspects of the future is the "not knowing", and the fact that he can't take anything for granted. Furthermore, the idea of his son not being independent, and being alone and scared is an image that is painful to think about. Another question that Frank asks is how would his son cope if he or his wife are not around anymore to take care of him?

From his point of view, it feels as if he is heading off and has something in sight; which is to build "independence" for his son. He knows that this is going to be hard. However he feels that everything is being thrown up at him and also feels alone in this journey. His journey also consists of many "good bits", but also of many "bad bits" that are incredibly intense. Furthermore, for him the "good bits" are very much in context, and are measured against the future and the things that he needs to do to allow his son to function independently in the future.

Picture perfect

Today Frank would not want to change anything about his relationship with his son: "between the three of us, the relationship is wonderful" he says. He wouldn't have his life any other way especially if that would change his son's character or if it would change the way that he relates with him. However if such elements remained the same, he would happily do without the autism and without the stress related to it. But if that requires that his son's character completely changed..."then I do not know".

Isaac's Story:

The boy who wouldn't speak

Family planning

Isaac and his wife always wanted to have more than one child. For them, the presence of their family in times of need made a real difference in their lives. In light of this, they did not want to leave their first child without a sibling. Isaac's wife got pregnant when their eldest was seven months of age. For them it was a no brainer: they did not want one child alone. Isaac and his wife now have two children; Joanne, the eldest; and John, the youngest.

The first concerns

Isaac was for the first time concerned about his youngest son's development when he noticed that he was already eighteen months old and he had not yet uttered his first word. However, the fact that he himself had started speaking at the age of three served to put his mind at rest; at least for a while. In fact he still was not convinced that his son's difficulties were solely related to a delay in speech. He soon started noticing certain particular behaviours that for him were rather peculiar. These behaviours prompted him to seek professional advice in the form of assessment and early intervention.

Isaac and his wife approached a psychologist for the first time when John was around the age of two and a half years old. They were conscious of the fact that it was early to have a diagnosis. However, they felt that advice from a professional was important, as they felt that there was something not quite right with John's development. In the mean time, Isaac also sought the advice of a Speech and Language Pathologist. Both Isaac and his wife tried their very best to provide John with the best help from as early as possible. Notwithstanding their best efforts, intervention was initially quite difficult, particularly because John was really reluctant to participate during his individual session. He did not want to comply, and it turned out to be a constant battle with him. With time, patience, and a lot of perseverance John started to respond to the intervention. In the end, the Speech Language Pathologist turned out to be one of the most important people in John's development. She was also the person who hinted out that there could be something more than a speech delay.

The diagnosis

The psychologist confirmed that it could be ASD after meeting with John a number of times. The moment when Isaac got the news, that his son could be on the autistic spectrum, is clearly imprinted in his mind. It was three o'clock in the afternoon, and it was a moment that he can never ever forget. His wife immediately started crying when the psychologist confirmed the news. Isaac put up a strong front to support his wife. However, emotions ran high that day, and he broke down in tears soon after leaving the psychologist's office. He was shattered. It was then where he felt that he had touched rock bottom.

Uncertainty

The first thing that came to Isaac's mind when he heard about the diagnosis was: "what am I going to do now?" The questions that came to mind were many. On the other hand the answers to those questions were lacking. Isaac asked himself what was going to happen to his child? He asked this question to his wife, who came from an educational background: "from your experience, when will he start talking?" Will the speech delay continue from now on?" Will he improve? Will he regress? What is going to happen now? In that instance, the uncertainty was great. Isaac did not know how John was going to develop and progress, and there were many "ifs" and "buts". John consequently received a 'statement' when he was in his second Kindergarten class, when he was around four years old.

Looking forwards

After the initial shock of the diagnosis Isaac got himself together and started looking for ways forward. He reasoned, that what had to be done just had to be done. He looked towards private tuition. He also decided that he was definitely not going to make use of the services offered by Child Development Assessment Unit.

Getting acquainted with the condition

ASD was a condition that Isaac was aware of to some degree. Yet, he was not aware of the difficulties that ASD would bring. This did not make it any easier for him to come to terms with his son's condition. Today he feels that he has found answers to some of the questions that plagued him when he first was told about his son's autism. However, he vividly recalls how uncertainty about the future used to be very stressing and anxiety provoking.

Today Isaac believes that autism is a condition that will never stop. It is a condition that, just like diabetes, an individual can control but not cure. He also defines autism as a condition that needs to be controlled.

Difficulties with accepting the diagnosis & Labelling

What was very difficult to accept was the fact that his son was suffering from a condition. It was and still is hard to digest for Isaac: "everyone wants his child to be perfect", he states.

An issue that Isaac was concerned about was the issue of labelling. He was not sure if his son needed a Learning Support Assistant in class. Furthermore, he was afraid that if he did his son would be stuck with a label whilst at school. The subject matter of the label of ASD is one that he is not very comfortable with. In fact, both in his family and his wife's family the word autism is not mentioned. This is because both Isaac and his wife do not want John to be labelled.

Schooling

The issue of the label of ASD and its implication caused Isaac some difficulties with the school administration. The issue led to Isaac clashing with John's assigned LSA who used to attribute his difficulties with learning to his condition. Isaac was anything but pleased with this as he was of the opinion that such an attitude was keeping John from learning as much as he could have been learning. The condition or the label should not be a way to excuse John, he believed. Furthermore, a diagnosis should not be there to limit a child, but should be a channel to get that child somewhere. In the

first place, that is why he and his wife decided on going for a diagnosis and a statement.

At one point Isaac received a note from school that read, “John is not doing well in school and he is not doing his school work”. This upset Isaac a lot, as he felt that it was up to the school to make him do his schoolwork and not allow him to slack on his work.

On one occasion Isaac had a near meltdown at school when John’s LSA blamed his lack of progress on his condition. Isaac was very angry and asked for a meeting with the school’s administration. The meeting served its purpose as after a while things changed to the better at John’s school.

Today Isaac is very pleased of his choice of schools. John goes to a public school near by their house. He insists that even if he were given money and gold, he would never change John’s school. He feels that his child is understood and supported at his school.

Fatherhood

The first time Isaac felt like a father was when he saw the first ultrasound of his first child. The moment when his first child just was delivered was the moment he really came to understand what fatherhood was all about. He was introduced to the chores of fatherhood when his first child was born. Soon after he was born his wife asked him to hold him. The proud moment when he held his son for the first time was also the moment when his son’s bowels opened up. This is when he ended up covered with faeces for the first time in his life.

Today Isaac feels that his role as a father requires him to be supportive. His desire is to provide his children with help and guidance. But most importantly Isaac feels that he is his children’s safety net: the person they fall back on when in need. With regards to John, Isaac feels that there are times when he needs help and support with everyday things. Particularly in view of his difficulties, Isaac strives to help him as much as he can and strives to provide John with the support and guidance he requires to overcome his obstacles.

Working hard to see progress

Ever since Isaac’s son has been diagnosed, Isaac has embarked on a voyage to help his son “control” the symptoms of autism. Isaac’s drive to help his son progress has led him to spend a lot of time working with his son. In fact, John has ‘worked’ a lot with his father as he was, and still is, strict, assertive and stubborn. Isaac also considers himself to be very persistent. According to him, these characteristics are very important when working with John.

In fact, Isaac recalls that it was a continuous battle to try to teach John to look at him and his wife when he needed something. Isaac’s strategy was to wait until John looked at him before giving him what he wanted. Slowly but surely John learned that for him to get what he wanted he had to look at his parents. After this, Isaac started to use a similar strategy to encourage him to speak. The theory was that if he wanted something, then he had to say what he wanted by using words.

Working with his son was difficult at first, especially due to John’s difficulties in communication. For Isaac it was as if his son spoke Russian. Thus, to be able to help

him Isaac needed to understand the way John communicated; he needed to learn his language. Sometimes working with John was very frustrating for Isaac. He used to ask himself: “Why doesn’t he get this right? Why doesn’t he understand this sum? Unfortunately for John, he also used to suffer as a result of Isaac’s frustration. Thus, Isaac’s persistence and assertiveness occasionally did backfire. However, Isaac quickly learnt to use different methods to try to teach John. For Isaac, it is very important to be flexible: “flexible, but persistent”.

Being cruel to be kind

Isaac believes that at times, as a father, he has to use the “be cruel to be kind” philosophy. This “disciplinarian” role was one that he willingly took on board because he felt it was his mission as a father. For Isaac that is what needed to be done, and that is what he did. This strategy was used when Isaac occasionally saw John flapping his hands inappropriately. When this happened Isaac used to get very cross at him and also gave him a time out. This is how John came to understand that flapping is an unacceptable behaviour.

A mean and determined look at times could also work wonders with John. When Isaac looks at John in this way, he tends to really be effected by this. However, when this occurs, and Isaac actually gives John that look, he really feels bad about this. However, according to Isaac, this is something that needs to be done.

The ups and downs

Fathering a child with ASD has been full of ups and downs for Isaac. An example of this is when Isaac and his wife bought a bike for Christmas for both their children. The children found riding a bike very difficult and needed ‘stabilisers’ to ride without falling off. John however was not happy about this and did not want to have stabilisers. In fact Isaac describes John as being a very adventurous child who knows no fear. However, this meant that he was going to fall off on many occasions. This consequently was the cause of a lot of crying and a lot of conflict between Isaac and his father.

However, when John that year had a bike day at school and was one of the few children who knew how to ride a bike, things quickly changed. Only two children in his class knew how to ride a bike. John enjoyed this. He enjoyed this so much that he started to show off. When these things happen Isaac is very happy. He remembers the struggle that he went through to get John to this point, and then enjoys the reward. Furthermore, when on one occasion they all went abroad together as a family they all had the opportunity to rent a bike and ride it together.

One of the most important milestones for Isaac is that of John’s first Holy Communion. Isaac keeps a picture of his son’s Holy Communion as a reminder of the strides forward that John has made so far. Holy Communion was a very important milestone for him as a father. Isaac recounts this experience with tears in his eyes. John’s role in this ceremony was to read a small prayer in front of everyone. He did his bit to perfection. At that moment, Isaac exclaims, no one would have thought that he has autism. His behaviour was excellent. He complied and followed instructions, making Isaac the proudest father at the church that day.

Whilst talking about this experience Isaac also brings out a photo of John that was taken a couple of years ago. “This is where it all started”, he exclaims. As he holds the

picture of his son's Holy Communion he says: "and this is where we are now", again with tears in his eyes.

Expression of affection

Another rollercoaster ride was John's difficulty with expressing affection towards his parents. Affection and expression of love were once absent. As a parent, this was very difficult for him. This lack of affectionate interaction used to be really distressing for him. There was an evident lack of eye contact before. John never told his father or his mother that he loved them and never said, "love you". That was really painful. Sometimes the lack of such interaction used to be very frustrating. Both Isaac and his wife used to be affected to the point that they occasionally had bursts of anger. However today that is a positive about John, as he could be noticed expressing his affection towards them. Isaac is conscious of the fact that many children with autism find it difficult to express feelings. For this reason, he is twice as happy to see John develop in this manner.

An occasion when John expressed his affection towards his father was when Isaac fell off his scooter, and ended up dropping his scooter on his foot. He then went back home with a bruised leg. When John noticed this he went running towards his mother and told her "Mama, Isaac is hurt". That is how John calls his father sometimes. He then brought his father a bandage and also brought him some ice. John then spent the rest of the evening running after his father asking him; "papa are you all right?" With regards to this, Isaac comments: "I must admit that that time I really enjoyed the attention". For Isaac it is extremely nice to see that type of affection. He loves the fact that today he can communicate in this manner with his son.

Benefits of early intervention

Isaac believes that now he can say that the actual hard and 'dirty' work has been done. However, if he and his wife had not worked with John early on, he is two hundred percent sure that John would not have reached this level. For Isaac early intervention was key to his son's development and to the progress that is evident today.

Nevertheless, he still thinks that there is a lot of work to be done. There are things that Isaac knows that he still finds hard to do. For this reason, both Isaac and his wife remain vigilant and always on the lookout. Yet, he is very happy with what John has achieved.

Communication

For Isaac, communication is a very important aspect in development and also to the father-son relationship. If John's communication did not develop as it did that would have been heart breaking for Isaac. He would have seen it as a failure from his part. That would have been an extremely frustrating situation. Isaac explains; "I do not wish my worst enemy to have a child who does not tell him that he loves him and does not communicate with him.

Positive affects of the diagnosis

Isaac feels that this experience, of fathering a child with autism, has not only been stressful. Rather, this experience has helped him grow as an individual. His child, as well as his condition has taught Isaac to empathise even more with people who he comes across in his line of work. The experience of fathering a child with ASD has

thought him to sympathise more and understand more the experiences that people go through. Today when people present him with their problem, he is more patient and tries harder to comprehend and empathise with them even more.

Another positive aspect of his experience is its impact on his relationship with his wife. Through the experience he has realised even more that his wife and himself are both on the same wavelength. He has come to appreciate her even more, particularly in light of all the difficulties that they have had to go through together. Today he feels that this experience has helped them become even stronger as a married couple.

Changes in his life because of autism

The work that Isaac did with his son yielded benefits. The work he did required time and energy. The progress made by John thus also came at a price for Isaac. In the past and at present he had to take important decisions that involved his work, and his personal life, to make sure that he was able to see to his son's needs. Some of these decisions involved letting go of some of the important things he was doing in his life.

Isaac needed to do some sacrifices for his son. However, he feels that that is what a father's role entails. He had to resign from a number of boards that he was a prominent member in. He also has to cut down from his middle-distance running training to spend more time with his son. However Isaac does not regret anything especially when he knows that he has contributed to his son's development.

Isaac feels that if his son were not diagnosed with autism he would have felt less obligated to do such changes. Having a child is one thing, he says. However, having a child with such a condition made him feel more obliged towards him.

Autism and society

What occasionally hurts Isaac is to see the stares that people sometimes give his son. For him people's stares at times are worse than their tongues. He doesn't actually care about people's opinion but such actions towards his son do hurt him. That is why he wants to protect John.

An experience that stressed Isaac a lot was when John was very young and used to attend a play school. The people at the play school didn't give much attention to John. They reasoned that he was autistic and that he wouldn't respond to anything they did. This was heart breaking for Isaac. Whilst attending playschool, Isaac and his wife were also working on toilet training John. Back then he wasn't able to communicate his needs. On one occasion John returned from school with a nappy. What Isaac discovered after this was that at the play school they used to make John wear a nappy to avoid the toilet training chores. Then they would change his nappy and put his underwear back on. This time however they forgot to take off the nappy before they sent him home. This was one of the most enraging events of Isaac's life.

The future

The issue that is currently on Isaac's mind is that of secondary school. He finds himself asking which secondary school should John attend? Till this day he has not found an answer to this question.

Other things that concern Isaac are John's future academic achievements, as well as his future relationships. "Is he going to be able to cope with the demands of school", he asks? "Is he going to do well in his studies?" "Is he going to be the last of his

class? Is he going to be a slow learner? How is he going to do in his O'levels?" What he will be doing with his life is not something that worries him too much. In fact he feels that if things continue to progress, John will be able to do something in the future. John is an adventurous boy who likes to do many things. For this reason, Isaac is hopeful that when the time comes John will be able to cope.

John's ability to make relationships also worries Isaac. "Would he have a girlfriend", he asks? However, for now it is not something that worries him that much. There is the issue with his exams right now that concerns Isaac. That is what is on his mind right now. However: "we shall see how this year goes, then we shall see".

Oliver's Story:

A nice but challenging experience

Finding out he was going to be a father

When his wife told him that they were expecting a child, Oliver was ecstatic. He had been expecting and hoping to get such news, and was delighted to hear that he was finally going to be a father. The period when his wife was expecting was a very special time for him. Everything was new to Oliver, so whilst he was content, he was continuously on the alert. During this time he was also extra thoughtful and caring towards his wife.

First time fatherhood

Seeing his wife in labour was a very emotional experience for him. For Oliver, his son's birth was a miracle and an amazing and unforgettable experience. He lucidly remembers holding his son for the first time. At that instance, he could not believe that the bundle of joy he was holding in his hands was previously in his wife's womb. His son, Larry, was the reason Oliver was crying tears of joy.

Life changed drastically upon the arrival of his first child. From the very first few hours, it was clear that his life was going to become very chaotic. He very quickly transitioned from hearing stories on parenthood to actually living it. All of a sudden he was obliged to be responsible and even more accountable.

Having a boy

The instance he realised that he was the father of a boy Oliver started imagining his son's future. He hoped, and also assumed, that he was going to follow in his footsteps. From the very early moments of his son's life, he tried his utmost to nurture him in the best possible manner. Moreover, he made sure to see to all of his son's needs.

Fathering another child

Soon after the birth of Larry, Oliver and his wife soon found themselves planning to have a second child: a brother or sister for Larry. Oliver still remembers the first time that he and his wife visited his wife's gynaecologist. That day they both got a surprise; they were informed that his wife was pregnant with twins.

Upon hearing the news, Oliver was shocked: at twenty-six he was going to be the father of three children. He found that new piece of information very hard to accept. Oliver's wife was so happy that she cried. Oliver also cried, however he cried for slightly different reasons. It's natural that a woman is enthusiastic about hearing such news, Oliver says. However, on the other hand, he was looking at the added responsibilities that such a large family would place on him. One of the first questions that he found asking himself was whether he would be capable of supporting his wife and their three children. Would he be able to provide for them financially?

Financial responsibilities

The financial responsibility brought about by fathering three young children frightened Oliver a great deal. What about when all the family were to go out together to the cinema or to the Luna Park? Oliver figured, that he now had to find the money for all of his three children and his wife.

Children are often associated with happiness, however it was not the case at that point in time for Oliver. He was always, by nature, a responsible and conscientious person. He thus found himself suddenly wondering whether he would be able to cope with this new situation and provide for his family.

Before Larry was born, Oliver's wife worked and had a stable income. However, after Larry was born, she left her job and focused on caring for Larry. At that time the couple only had Larry's expenses to see to. Eventually, when the twins were born, his wife was unemployed. Thus, Oliver found himself providing for a family of five: a task that was extremely difficult.

The first difficulties

The financial difficulties and worries associated with raising three young children were soon not the only thing that was on Oliver's mind. Oliver was worried about the instances when he would call Larry, and he would not answer.

In fact, Oliver started to suspect that something was wrong when Larry was recurrently noticed disregarding Oliver and his wife, even when he was sitting right beside them. At this point Oliver assumed that Larry was hearing impaired. However, to Oliver's surprise, when Larry overheard the jingle of a commercial he liked, from the other end of the house, he would immediately run towards the television.

The notion of Larry being deaf was ruled out when Oliver took him to visit an ENT specialist. The specialist stated that Larry was able to hear and that most probably his difficulty was due to some sort of psychological condition. Up until then Oliver had never heard about the word "autism".

The diagnosis

Soon after this, Larry was referred to an expert in child development. During the first appointment the expert examined Larry, and immediately remarked that Larry had autism. Oliver was shocked and even scandalized by the way that the professional, quite coldly, informed them that their son was on the autistic spectrum. Oliver remembers how it felt when he heard the news: like this was the end for his son and like there was no way out.

As he heard the news Oliver felt distraught and discouraged. He did not even have a clue on where to start, or where to search for help. What should he do now? How

could he help his son? The lack of information regarding autism made him feel helpless. The way autism was depicted and described by this particular professional left Oliver in a state of shock. He was traumatised and was very emotional. He had hoped that he would have encountered an individual who empathised with him and who would have encouraged him. Nevertheless, this was not to be, and Oliver was left feeling emotionally unwell whilst trying to make sense of the new piece of information that had shocked his life.

Coping with the news that his son was autistic

Oliver found it difficult to come to terms with the news. He felt puzzled and confused. Furthermore, instead of getting the answers that he hoped he would get from the expert, he was provided with even more uncertainties. The only support that Oliver had was the support of his wife.

His wife in fact was the one who started researching and reading books and articles on the subject of autism. She did her best to gather as much information as possible as she could about the condition. Oliver was unable to be at ease with the condition as much as his wife. His wife was exclusively focused on the every day matters related to their son and his condition, whilst Oliver took on the role and responsibility to support his family financially.

Difficulties with his youngest children.

Later on, after his son was diagnosed with severe autism, his youngest children Lawrence and Laura, were also diagnosed with autism. However, their diagnosis was that of 'mild' autism. According to Oliver, an individual's relationship with someone who is affected mildly by autism is better, particularly when compared to someone who is severe. For Oliver it is easier to express himself and communicate with Lawrence and Laura, who are affected mildly by ASD.

Hindsight

As Larry was actually diagnosed with autism, Oliver's wife was expecting the twins. It was official that Larry was autistic only after the twins were conceived. In hindsight, if he knew about Larry's autism beforehand he would have not opted to have more children. He would have rather focused exclusively on his condition and tried his utmost to get the most out of his abilities. Furthermore, when hearing about autism, Oliver and his wife were not aware of what it really was. They both had hoped that Larry's difficulties were a transient thing; something that Larry would grow out of.

Difficulties brought about by autism

The increased financial demands and consequent increased workload made it difficult for Oliver to find time to spend with his family. The amount of time he spent away from home, because of his work commitments, afflicted Oliver. This also meant that he was unable to inform himself adequately about autism.

In fact Oliver was initially unaware of the actual difficulties and complications that autism would bring. Today Oliver describes autism as a very challenging condition. Even though he feels that he is strongly attached to all of his children, he feels that autism is a barrier and is impinging on their relationship. He tries very hard to demonstrate his affection to all of his children, especially to his son. However Oliver

is not sure if Larry is aware of his love towards him. He would like to show Larry how much he loves him, but is afraid that Larry is oblivious to this.

Oliver also believes that autism makes the simple things a bit more difficult. He states that whilst all children are time consuming, autistic children are more. Oliver mentions that whilst neurotypical children could take around thirty minutes to finish their homework, Lawrence and Laura may take up to an hour and a half. He feels that when dealing with autistic children one should allocate more time.

Communication

For Oliver communication is very important. Communication is a fundamental factor in Oliver's relationship with Lawrence and Laura. Presently, Lawrence and Laura can speak and communicate relatively well, and for this reason communicating with them is easy. Oliver cherishes the times when he hears them 'stringing' together a new sentence. On the other hand, communication with Larry is somewhat problematic.

Larry finds it very difficult to express himself. When he is in need of something Larry is incapable of communicating his needs. Therefore Oliver and his wife frequently find themselves trying to figure out what Larry wants. Sometimes the long time needed for Oliver to understand what his son is requesting causes a lot of frustration, both to Oliver and to Larry.

Autism and the relationship with his wife

With a family of three, and with three children with autism, the time that the couple get to spend together and work on their relationship tends to be very restricted. However the few moments that they get to spend is enough for them to continue to strengthen their relationship. Today, Oliver and his wife are very emotionally attached. At times Oliver feels that autism actually made their relationship stronger.

Coping with the responsibilities

Oliver believes strongly that a couple's stable relationship and their mutual love can surpass anything. If there is love anyone can beat the difficulties life brings. The relationship between couples plays a vital role in a household with children. The couple's stability is the foundation of a good family. For Oliver, it does not make sense to have one million euro, and not having the opportunity to meet with his children because of a couple's separation. Oliver feels that children can get the ultimate education from both parents, not a single parent on his own. However, Oliver feels that his family must be considerate while budgeting their resources, whether it's one or a hundred euro.

Fatherhood

Responsibility, love and economic stability: that is what fatherhood is about for Oliver. Oliver is not just a father. Rather, he is a father of three children with autism, which makes everything much more difficult. Today he regards himself as a father of children with autism.

When he initially thought about fatherhood, he pictured his children being healthy. He also thought and hoped that his children would not have had any difficulties. He pictured himself taking his son to soccer practice after school, to religious classes and other social activities. As things turned out, Oliver doesn't take his son to any of these activities.

Today, instead of soccer practice, Oliver must ensure that his children attend regular occupational therapy appointments, sessions at INSPIRE Foundation, and speech therapy sessions. Moreover his son is not interested in soccer. Having a child with autism has proved to be different from what he was initially expecting. Nevertheless Oliver feels that such disappointments are part and parcel of parenthood. In this way, Oliver states, all children can bring both joy and despair.

Family life

“We are the greatest family ever”. Oliver says this with a lot of pride and joy and believes this with all his heart. He is extremely happy when during a weekend or a public holiday or during a day off work he heads off outdoors with his family and spends a whole day together with them. He states; “an ideal day would be one entirely spent with my family. I couldn’t ask for more.” In summer his family and himself are likely to spend a day by the pool, whilst in winter they enjoy to spend a day in the countryside. On days like these, Oliver and his wife enjoy prepare food whilst their children run and play.

If his children are happy, Oliver is happy. This isn’t solely tied to the fact that they’re playing with him, as at times, his children are happy to play on their own. Their happiness, in whatever context this occurs, is what makes Oliver happy.

The future

The thought of his children’s future makes Oliver anxious. Oliver is worried about when he will one day pass away and leave his children alone. He is aware that this will happen sooner or later. However he tries his hardest to repress this agonising thought. Oliver feels that he, together with his wife, is the only person that can make his children happy. He is afraid that when he is not with them anymore, their needs will not be seen to anymore.

Wishes

For this reason, his hope is to see his children all progress rapidly, and ultimately become capable of living an independent life. This would mean a great deal for him and would be a great accomplishment. However, if he had to make a wish, he would ask for his children to not be affected anymore by autism. The ideal situation would be that with the click of a button, he would cure them. Oliver is aware that this is only wishful thinking and not really possible. For this reason, he would be equally content if his children were able to lead an autonomous life.

If they had a job and even rented a house, this would mean that they are self-sufficient especially when Oliver would not be able to provide for them anymore. Oliver keenly points out that he does not want his children out of his house as soon as they turn eighteen. However he would be proud of them if they eventually managed to do so.

Search for solutions

A strategy that Oliver and his wife tried, with the hope of reducing the effects of autism on their children, was that of a gluten free diet. They also consulted with a foreign doctor who prescribed various supplements, vitamins and other remedies that could help his children. They tried every possible thing. They also took up the suggestion of the foreign doctor who suggested exposure in the hyperbaric chamber. Thus, they travelled to the UK where they underwent hyperbaric oxygen therapy.

Autism and society

Oliver feels that many people are clueless when it comes to autism. When for the first time he told some acquaintances and friends about their children's diagnosis their reaction was bland. This was because they were unaware of the implications and consequences of the diagnosis, and for this reason it did not make a difference to them.

This lack of awareness makes things for Oliver very difficult. His children have a very ordinary appearance, and thus, many people don't suspect that there's anything wrong with them. The condition is actually a hidden condition. What they could observe is their behaviour, which is sometimes somewhat different from what people typically expect of children their age. However, they assume that it's something related to lack of self-control. His children's behaviour is often linked with parents who are unable to control or manage their own children. Sometimes people conclude that Oliver and his wife are incompetent parents and they are failing in their parenting. Such an attitude makes matters worse for Oliver and his family. However, these days he ignores other's opinion regarding his children. He tries his best to see that his children do not annoy other people, particularly in view of the fact that he does not tolerate people who annoy his children.

His wife experienced an instance where Larry had a tantrum in a shop. In this occasion he laid on the floor banging his feet. A man scolded her, and instructed her to correct him. He suggested a way to restrain him. He also insisted that she ought to teach him self-control. She almost left the shop crying. If Oliver were to be confronted by a similar situation he would have been very angry. Oliver tries his best to disregard other people's opinion about his children. However, the lack of information and ignorance frustrate him and tend to make things worse for him and his family. For this reason Oliver believes that it would be best to let people know about his children's difficulties and sensitise them on the condition that autism is.

The question of why my children

At the beginning, when his children were first diagnosed with autism he found himself asking the question of "why my children?" Oliver states that it is normal to ask such a question. Oliver also went further and was eager to know what might have caused autism? However he did not spend a lot of time asking such questions. He admits that he did ask questions for a short period of time. He however has today moved forward and acted. He finds it useless to torment himself. Rather he tried to change his attitude. If he hadn't, he states, his children would not have even gone out of the house. "You have to adjust yourself", he says. According to Oliver, moving forward is the best thing anyone could do.

Ian's Story

Finding out his wife was pregnant

Initially Ian and his wife were encountering some difficulties with conceiving a child. For this reason, the moment when his wife told him that she was pregnant and that he was going to be a father made him jump of joy. He was over the moon. Ian feels that

god has a plan for everyone and that this was all part of god's plan for him and his wife. He feels that his family, including his children are part of this plan, so Ian tries his best to collaborate with god's plan.

Becoming a father

Becoming a father for Ian meant a lot. However, the realisation that he actually had become a father actually took some time. There was not an instance when he felt that he had become a father. Rather, it was more like a slow, yet natural, process. Ian feels that becoming a father has improved him as a person. Fatherhood has brought about a lot of challenges that he has had to overcome. For this reason, and as a result of such challenges, becoming a father has made him less rigid, and to a certain point has made him more flexible; consequently, he feels that fatherhood has "improved him".

Providing for his family

Ian believes that his role as a father also means being a provider. Ian takes this aspect of fathering very seriously. He feels that the most important thing is that of providing a good quality of life for his family and his children. Ian feels that he would rather provide his children with their basic needs and more, rather than saving his money in a bank. This outlook is one that is not always shared by some members of his extended family. In fact, he often clashes with his own parents as they feel that he could at times be a bit of a spendthrift and doesn't save enough money. However, Ian feels that if any of his children need a new pair of shoes, then he is going to make sure that they have a pair of shoes.

Autism

The first time that Ian has actually heard about autism was before he and his wife were married. This was when he had attended a meeting, and in this meeting there incidentally was a boy running all over the hall, yelling and gesticulating. At the time, someone had suggested that that boy might have been autistic. That was the only time he had heard of autism. The next time he heard of the condition was when he learnt about his son's condition.

This happened when his wife asked a Speech Language Pathologist (SLP) who used to live nearby their residence to assess their eldest son, who was presenting some difficulties in communication. After an hour-long assessment, the SLP diagnosed him with autism. At the time, his son was four years old. That is basically how the "ASD story" started for Ian and his family. His eldest son, David, was diagnosed with Asperger's Syndrome. Later on, his second born child, Franco, was diagnosed with autism.

Search for solutions

The first thing that Ian did upon hearing the news was to try to find out about the options and possibilities that could help his son. He looked at both local and international possibilities. He was initially very hopeful and positive about treatment or therapy. However, after the first inquiries, all the hope started to gradually fade and turn into frustration. Ian quickly found out that no one knew about what actually caused autism. Furthermore, he was disappointed to find out that many of the interventions proposed were experimental and under-researched.

The interventions that he came across whilst researching were all trials. Furthermore, he noticed that there were very little options available here in Malta. For this reason, he initially had considered moving to Massachusetts, USA, as he felt that solutions in the United States were more readily available. He had actually found some institutions that offered what he deemed as potential solutions to his sons' difficulties. However, he, together with his family, reconsidered and decided to stay in Malta.

Ian tried various strategies and interventions that were offered in Malta, particularly with his 2nd eldest son, who displayed marked difficulties. He signed both children up to the Eden Foundation (now called INSPIRE FOUNDATION). They also opted to try the Sunrise programme. However, after a lot of patience, a lot of time and a lot of money, Ian felt that that he did not see much improvement. Ian initially had a lot of hope before the start of each of these interventions. However, hope gradually turned into disappointment, as his expectations were not met.

Ian also opted to try BioMeds and decided to purchase vials of vitamin B from the United States. However, after attempting this, he also felt that the treatment was not as successful as he had initially hoped. There was a point where he decided that it was not worth the hassle or the money, especially since nothing he was trying was actually proven. Ian states that he passed through a phase in life where he was panicked and sought out every possible solution that could have helped his children. However, this feeling gradually cooled off and turned into disappointment.

The effects of autism on fatherhood

Ian's relentless search for solutions was also a result of the affects of autism on the father-child relationship. Ian feels that the difficulties related to autism have impinged on the father-son relationship and on his fathering experience to some degree. Particularly for his son Franco, who seems to be living in another world. For Ian, it is as if his son doesn't care whether his father exists, and the only things that matter are his PC and going to swim.

Ian occasionally feels that it is as if all he is doing for Franco is keeping him alive. There is no qualitative relationship between him and his son. Rather, it is more of a one-sided relationship. Apart from the two eldest children who are diagnosed with ASD, Ian also has children who are not on the autistic spectrum. So he could actually see and comprehend the affects that autism has on his children and compare that to the children who are not diagnosed with ASD. Whilst some of his children are able to communicate and relate with him, his eldest children find it very difficult to interact qualitatively with him. This upsets Ian somewhat. What also upsets Ian is the fact that Franco does not call him "daddy" spontaneously. Even though he is able to say "daddy", however this is done only when he is prompted.

Communication

Communication is an issue that frustrates Ian somewhat, as it was always an issue for both David and Franco. However their communication difficulties varied. When David was young he used to talk using a rather different tone in his speech. Today, whilst noticing an improvement in the quantity of communication, David tends to take words literally. Another difficulty is when Ian asks David to bring him something; even if he has done this a number of times before, he still asks him what that something is. What is even more frustrating for Ian is that at times he is not sure if David is actually doing this on purpose.

With regards to Franco, what frustrates Ian is the fact that he cannot have a conversation with him. Ian states that Franco is able to understand some instructions, such as to get his pyjamas on. However, if Franco is not in the mood, then he won't do anything. With him it is a one-way relationship. Whilst Ian tries his best to engage him, and also see to all of his needs, he does not get any type of feedback in return. Ian would really like to get a reply from his son; a simple yes or no when he asks him if he wants a drink. Ian hopes to see the day when he hears his son communicate with him.

Difficulties related to autism

Communication is however not the only difficulty that is brought about by autism. The difficulties related to autism extend also to the family's social life. Social outings have to be chosen very wisely. For example, when it comes to choosing restaurants Ian is limited to opt for McDonald's or Pizza-Hut. This is because he has to make sure that he can have Franco sit in a position and place where he can prevent him from drinking from other people's glasses.

On one occasion, Ian and his family all went to Disneyland for a holiday. However this holiday was more stressing than it was relaxing for Ian. After the trip Ian suggested to his wife that they shouldn't do it again, especially with the children. This was because he had to be constantly on the lookout for Franco. He had to constantly look out for his safety. Ian vividly recollects a moment during that 'holiday' when Franco ran away and nearly got run over by a car. This happened because he had seen something that interested him and just decided to run and cross the street. On another occasion, whilst swimming at a public place in Malta, Franco got lost and Ian and his wife spent hours looking for him. At the time Ian panicked, and thought that the worst had happened. Franco was then found, safe and sound, staring at a computer on a DJ stand that was currently on the beach.

The relationship with his children

The relationship that Ian has with Franco is different from his relationship with David. It is different because David has Asperger's Syndrome and he is able to communicate. Ian enjoys playing rough and tumble play with David and also enjoys going to the movies with him and asking him questions about the movie after it is over. Franco on the other hand is not as responsive as David. For this reason the activities that Franco is interested in are limited. Nevertheless Ian tries to spend time with both his children and tries hard to interact with them both.

Fatherhood

Ian's notion of fatherhood today comprises a lot of self-sacrifice. However, he feels that fatherhood also provides him with a lot of fulfilment. An instance where he displays a lot of self-sacrifice is when during dinnertime, Franco would want to sit on his lap; David would refuse to sit down; and the youngest son would not be able to eat by himself. Whilst feeling very frustrated, and also irritated, Ian tries to meet all of his children's needs.

An important aspect of fatherhood for Ian is "authority". Ian believes that fatherhood also consists of being an authority. This authoritarian parenting approach is the approach that his parents used to use with him whilst he was growing up. Even though he did not approve of his parent's regimental methods, nowadays he tends to use similar methods. However, he is aware of this and always finds himself questioning

this strategy. Ian hopes to always be close to his children and to be by their side whenever they need him.

Authoritarian vs. Democratic parenting

For Ian it is important that his children consider him as an authority figure and also show him respect. Ian feels that it is impossible to compare his own upbringing to contemporary child rearing. He feels that today's laissez-faire attitude tends to result in a general lack of respect from children towards their parents. He feels that nowadays parents tend to give everything to their children, and this could be destructive for them.

Ian recalls that when he himself was young there were times when he was angry towards his parents. Notwithstanding this, he never lacked them in respect. Ian asserts that both his parents educated him to be financially independent. His father played a central role in his upbringing and was the one who guided and directed his spiritual development and also instilled in him the right values. He hopes that he could be the same for his children.

From this perspective, Ian feels that he is somewhat old fashioned. He occasionally finds himself assertively warning his children or very gently smacking them. This happens rarely, however he feels that this could be necessary at times. His parenting style is somewhat different from that of his wife's. He feels that he needs to be assertive whilst his wife is more democratic. However he feels that both methods could be successful. Thus, he tries to find a balance between the two techniques.

Concerns about the future

When Ian learnt about his children's condition he suddenly found himself pondering about the future. He suddenly started looking towards the future with a lot of doubt and uncertainty. Ian is optimistic about David's future, as he feels that with the right tools he could lead an independent life. Independence and autonomy are very important goals for Ian, and he tries to work towards helping his children achieve such goals. However it is different in Franco's case, particularly in light of his difficulties. Furthermore, Ian is anxious about Franco's future, as he is concerned that he could not be able to live an independent life.

Nevertheless, Ian is of the opinion that worry will not solve any of his problems and will not make his situation any better. He feels that, even though sometimes it is difficult to avoid, worry is in actual fact useless. What puts his mind at rest is the thought that god has a plan for him.

The road towards acceptance

The moment when Ian felt most distressed and even angry was the period when he and his wife could not conceive a child. That phase was indeed a very difficult phase of his life. He felt very upset at the time. Fatherhood however made up for this anger and stress. Having a child meant a lot for Ian: becoming a father made him a very happy man. Ian feels that he was angrier at that time, when he thought that he could not have children, than when he found out that his children were on the autistic spectrum. He was happy regardless of their condition. Then again, he feels that if god were here "right now", he would still ask him to make his son a normal boy.

Today Ian is not angry, but he feels upset and sad. Whilst he has high expectations for David, he has doubts about whether Franco will one day be able to succeed: and that is what makes him sad. At times he feels sorry for Franco. However Ian feels that in a way Franco is lucky that he was born in this family, particularly because of the fact that he has brothers and a sister who could support him in the future.

There were times when Ian used to cry when he thought about his situation, but nowadays it doesn't happen that often. He still feels upset when he talks about his current situation and about the problems he and his children are encountering. He occasionally finds himself imagining what his life would have been like if his children did not have this condition. If that were the case he feels that Franco, in particular, would be able to participate in more activities on his own and would also do without the help of a Learning Support Assistant at school.

Relationship with his wife

Ian feels that things would not be the same if he did not have his wife. He feels that, considering all that his wife does for him and for the children, she is a super mother. Notwithstanding all the chaos that there is in a household of four children, Ian feels that he still manages to get things done. Ian and his wife have always worked very well together and have supported each other very well. Today they share chores and responsibilities, and try to make sure that all of their children's needs are being met.

Ian acknowledges that at times, when things are stressful, he does tend to get angry and even becomes intolerable. However, his wife accepts him and supports him. Nevertheless, he feels that their lives would be easier if none of their children were on the autistic spectrum. Yet, he feels that they cope well with the difficulties presented. With regards to his relationship with his wife, he feels that all the circumstances they have been through together have made them even stronger.

Autism and society

Ian feels that nowadays-Maltese society is becoming more and more like foreign societies. He is of the opinion that Malta today is becoming more similar to northern countries, where everyone minds his own business.

Nowadays he even feels that people don't stare at his son Franco when he makes eccentric noises with his mouth. Ian has never come across members of the general public who have accused him of being a bad parent as soon as they perceive his son being different. Furthermore, he also states that many people immediately realise that his son has autism, and for this reason he was never labelled as a bad parent. However he has met other parents, whose child was diagnosed with autism, who went through similar experiences and were labelled as bad parents.

What Ian is not very happy about is the current provisions as well as the research regarding autism in Malta. He feels that the facilities that cater for children with such difficulties are not enough. Furthermore, Ian feels that 'carers' who are responsible in schools and other places of the children's education should have the right training. He also feels that there is a need for seminars for parents and carers, for them to always stay up to date with the research, with the available treatments and available therapies.

Alan's Story

Thinking of becoming a father

Alan never actually prepared or planned for fatherhood. Rather, fatherhood just happened. The fact that he got married and bought a house did mean that he was thinking about it on a very unconscious level. However, when he got married he was not imagining that he was going to father a child in two years time. His mind was more set on spending more time as a married couple before actually having children

The news of his wife's pregnancy caught him unprepared. He recalls that he was abroad on the day when his wife called him to tell him the news. Even though he was aware of the fact that his wife could have been pregnant, he was definitely not mentally prepared for it.

Initially he wasn't exactly very happy about the news. "Ok" is a more adequate term to describe what he was feeling at that moment. However, he reasoned that this was yet another chapter of his life. From that point on Alan had nine full months to accept the fact that he was not anymore responsible for himself and for his wife alone. Rather, he was from that point going to be responsible also for a child: his child.

The birth

The day his daughter, Mary, was born was the happiest day of his life. His daughter made him the happiest man on earth. Alan was not informed of the sex of the baby before the birth, so when he was told that he was to father a girl he was jumping of joy. He was ecstatic.

For Alan marriage was not the biggest change in his life. The biggest change occurred when he became a father. In fact, apart from joy, his daughter's birth also brought with it a lot of new challenges and change.

Changes brought about by fatherhood

A change that was brought about by fatherhood was employment. In fact, a short time after his daughter was born Alan changed jobs. The reason for him changing his job was to be sure that he could be flexible enough to meet his daughter's needs. A few months after his wife got out of hospital she opened a new business. Alan bought in to his wife's idea and made his wife's business his full time occupation.

The first concerns

The nature of Alan and his wife's new business venture meant that they were both going to meet with a lot of parents who had children. The various encounters that his wife had with many parents and their children made her ask some questions about her daughter's development, who appeared to be different from other children's development. She noticed that many children were different from her daughter. This is when she started suspecting that there was something wrong.

Rather than talking about their being something wrong in Mary's development, Alan opted to give it some more time. He figured that if she were given more time, she would actually grow and improve. Nevertheless, when Alan compared Mary to other children, he did actually start to realise that there could be a problem with

development. His daughter did not talk as much as other children. She used to say “mamma”. However she stopped there and didn’t improve anymore, whilst other children moved on. Even her eye contact was somewhat concerning. In fact, when he used to talk to her she never used to look at him. Finally, as the level of concern started rising, Alan asked his daughter’s paediatrician to refer Mary to hospital for a more thorough examination.

The diagnosis

At hospital another Paediatrician assessed Mary. Initially the diagnosis was that of Pervasive Development Disorder – NOS. The Paediatrician also referred Mary to an early intervention specialist. Later on, Child Development Assessment Unit confirmed the diagnosis and also added the label of ASD.

Therapy

The diagnosis led to input from CDAU who provided Mary with Occupational Therapy and Speech Therapy sessions. At one point she was discharged from the O.T. department, but continued receiving speech therapy and weekly early intervention sessions at home.

Alan and his wife have also tried to spend two hours a day working with their daughter individually. This generally happens every day, and is done more by his wife, after she comes back from school. Alan and his wife also decided to take her to school from a very young age.

Search for solutions

One of the things that worked best for Mary was early intervention. However, Alan went further and looked for other ways that could help with Mary’s difficulties. Whilst making it a point not to go to extremities, Alan has always been keen about trying different things. He however has always done his homework and has attempted things after thorough research and contemplation, and after discussing possible strategies with his wife.

Alan tried to introduce a gluten free and casein free diet to Mary’s alimentation. However, Mary experienced some problems, as she was observed regressing rather than improving. So Alan decided to stop this sort of diet plan. One thing Alan believes could work with children with autism is Ritalin. He is still researching this hypothesis. However he believes that this would help her by making concentration easier for her. By trying various strategies, Alan hopes to help his daughter improve; he is not looking to cure Mary’s autism.

Whenever he has tried something new, he was always very hopeful about this. There were times when he didn’t believe that what he was trying was going to have an effect. However, he still gave it a go and still hoped for a positive result.

More self-awareness

Ever since his daughter was diagnosed with autism, Alan became more aware of his behaviors and personality traits. He became more mindful of the fact that when there was something that he wanted to understand or do he repetitively circled a table. At one point he also started to ask himself if he had similar characteristics as those of his daughter.

This has made Alan deduce that everyone could actually have “a little bit of autism” and that everyone could be on the spectrum. He feels that there are people who have a lot of the symptoms or characteristics, whilst there are others who have very little.

The road to acceptance

This self-awareness and apparent ease with the condition of autism did not come about in an easy manner. For Alan, coming to terms with autism was a gradual shift. Initially the word autism represented people who wanted to stay on their own.

Way before the diagnosis was confirmed, when Alan had noticed the behaviors and first symptoms that his daughter was manifesting, he immediately thought about autism. When he tried “googling” Mary’s symptoms, the first condition that was identified was that of autism. Consequently, he researched and read extensively about the condition. This is when he came across a shocking piece of information that described autism as a lifelong condition. The notion of autism being a pervasive and enduring condition was something that really made him uncomfortable. Many articles also described autism as being a condition that had no cure. For this reason, he refused to believe that it was autism, and was hoping that it was something else. Thus, he tried to convince himself that it was not autism.

At one point Alan also noticed that Mary used to enjoy spending time on her own and was not very keen about being with people. However, he was not worried about this, as at times he also enjoyed spending time on his own. So he reasoned that she was just like him. Hence, he started to look for other explanations for his daughter’s difficulties. Nevertheless, all the symptoms and behaviors seemed to be pointing towards autism.

Alan went through a three month ‘denial phase’ where he tried all he could to find evidence that contradicted the hypothesis of autism. That went on until he realised that his daughter was behaving totally differently from other kids. Gradually, after a lot of research and even more contemplation, Alan came to realise that what he was reading was right. Acceptance of the condition provided him with the impetus he needed for him to start problem solving. This is when another phase commenced: the phase when he started believing that he was going to solve the problem completely.

Again, he gradually came to see that this was a rather unrealistic goal. Alan then saw to redress his goal, and decided that the best thing that he could do was to start working on lessening the symptoms and work to increase his daughter’s quality of life.

Fatherhood

For Alan fatherhood is a challenging but important role. Today his first priority in life is his daughter. Nevertheless, he tries to find a balance between being a father and being a husband. Yet, he sees himself more as a father than a husband.

Alan today considers himself lucky to be able to hear his daughter call him daddy. The title of “daddy” is very meaningful for him. As a father his main focus is on giving Mary direction. According to him this is something that all fathers do: “they give their children direction”.

Alan is inspired by the famous Temple Grandin and her mother. Just like Temple Grandin had her mother as her mentor, he would like to be a mentor for his daughter.

In this way, he hopes to give his daughter direction by being her scientist. Alan is already trying to be a scientist for Mary and has tried to introduce her to robotics. He is also trying to introduce her to some programming that she could do herself. Programming could provide Mary with a future, as well as being something that she could enjoy doing.

The effects of autism on fatherhood

Alan does not feel any less than fathers of 'neurotypical' children. Rather, he feels that he has developed a broader 'schema' of what fatherhood represents, particularly when compared to other fathers whose children do not have autism. As a father Alan always wanted to pass on his interests to Mary. But that has not always been possible. As mentioned earlier, he has always wanted to be her scientist. Yet, autism has sometimes stopped him from teaching Mary new things.

Nevertheless, he finds it difficult to say exactly what sort of impact autism has had on his actual notion of fatherhood. When he initially tried to imagine how he was going to be as a father, he imagined that his daughter was going to be approaching him to tell him how her day at school went. He imagined that he was going to be giving her advice on her personal life and helping her out with her homework.

Today there are times when Mary does approach Alan and tell him what she did at school. This makes Alan very happy, particularly in light of the difficulties presented by the condition. Alan is also very proud to see her overcome certain hurdles, such as Holy Communion. He was very proud to see her sitting down and waiting to receive communion. He feels that another father whose child did not present with challenges of the sort would see things differently, as he would take such accomplishments for granted. For Alan, seeing his daughter receive Holy Communion felt like she had won all the prizes available at school.

Challenges

Mary today needs a lot of time and attention, particularly in light of the difficulties that she is manifesting. Alan states that Mary is in need of time and help today, and not when she is a teenager, as it would be too late then. Alan and his wife today both spend a lot of time trying to help Mary overcome the hurdles that she finds hard to overcome.

Alan feels that once Mary overcomes a specific hurdle she continues to progress steadily. But before overcoming that hurdle there are a lot of ups and downs. There are times when Alan nearly gives up, and other times when he also gets angry. Moments like these are very challenging for Alan, as when he gets angry with her he tends to raise his voice. Today he has realised that raising his voice does not help, neither him nor her, to achieve her goals.

An example of an occasion where Alan was very frustrated was when he was trying to explain to Mary the concept of addition. Mary could not understand the concept no matter how Alan tried to explain it to her. However, at one point he showed her a method and it worked. Before he found that method he was very frustrated and was about to give up. At that moment he thought to himself that his daughter was not going to be able to learn the basics of mathematics, let alone more complex concepts. How was she to progress further, he asked? Yet, she was able to overcome this hurdle and even continued to progress further in the area of numeracy.

Another challenge Alan was faced with was that of going to church without Mary having a tantrum. At times, during church, people used to turn around to see who was screaming. Some of them even gave Alan and his wife really bad looks. Alan is not as strong as his wife. His wife used to keep Mary in church even when she screamed. Alan says that he would not be able to do something like that. His wife used to stay in church until Mary got used to being in church. Today it is not a problem anymore for Mary.

Communication

What Alan would like Mary to develop more is her ability to use language to communicate. Mary understands instructions such as “go to your room”, and “put your shoes on and switch on the light and come back”. However, at this stage Alan sees the development of speech as one of the most important things. He would like to hear her communicate with him and his wife and tell them what she needs and wants. If she would tell them what she needs and wants, Alan feels that things would consequently improve for her and also for the whole family.

Alan dreams that one day she would be able to talk to him and have a conversation with him. Mary does communicate but only when she decides to communicate. Sometimes she tells him that she is feeling sick, however she rarely does that spontaneously. The lack of communication upsets and saddens Alan. His wish is for her to talk to him spontaneously and without the need of him prompting her. This would not only put a stop to him trying to read her mind, which he feels is not very good at, but it will also help him interact better with Mary. In so doing, this will help their bond grow even further.

Alan also feels that “speech” would also allow him to teach her many more things. It would also enable her to tell Alan what she enjoys and what annoys her. An instance where “speech” would have been useful is when Alan used to take Mary to piano lessons. At one point she didn’t want to go anymore, however she did not tell him what she did not like about piano lessons. If she had told him what annoyed her he would have been able to help her. But she doesn’t and can’t tell Alan.

Autism and the relationship with his wife

As mentioned earlier, having children has brought about a lot of changes for Alan. One of these was his occupation. It was a decision that he took so that he may spend more time with his family. He also feels that the diagnosis also affected other aspects of his life, including the relationship he shares with his wife.

The diagnosis has impacted the couple’s relationship by making them stronger. The diagnosis and the difficulties related to Mary’s condition contributed to more responsibilities. This added ‘load’ however made them even more committed and co-dependent on each other. Now they find themselves sharing a common goal: to see Mary progress. For this reason, they work hard together to help their daughter progress.

Autism and society

When compared to other children, Mary does things in a slightly different way. However, Alan insists that she does not have anything worse than anyone else. Rather, overall, she is doing very well when considering the difficulties she has encountered. Alan however is not happy when society tries to depict her as being

different. On one occasion, Alan took his daughter to a public play area. At the play area there were another two children. One of them was displaying symptoms that could be described as symptoms of autism. Whilst entering the play area with his daughter Alan heard one parent talking to another parent and telling her to be careful as one of the children in the play area was autistic.

He was right there next to them when he heard them talk that way about another child with autism. Even though they were not referring to his daughter Alan was upset, as it was painful for him to hear such comments. However he chose not to say anything to them. Today, as he looks back on the incident he wishes that he had told them something. What he wanted to tell them was that his daughter also was autistic and that parents should not be afraid to let their children play with an autistic child. What he also would have liked to tell them was that even though his daughter was autistic, she never hurt anyone. On the other hand, other children have hurt her.

Alan feels that there could be autistic children who are not aggressive. On the other hand, there are also neurotypical children who are aggressive and do not think twice to be aggressive with other children. However it seems to him that many people are misinformed about autism, and tend to make rash judgements about children with such a condition.

Society's apparent need to label autistic children as different is something that upsets Alan. He feels that this also starts at a school level by the provision of an LSA. The fact that his daughter is assigned an LSA whilst the other children do not have an LSA makes her feel different. Furthermore, he feels that Mary is intelligent enough to notice such a discrepancy, which in turn could also make her feel "different".

Hopes and wishes

Alan's wish is to see Mary overcome certain barriers. He feels that she is able to do so and feels that there are good chances of seeing her progress, and this gives him hope.

For him, the famous Temple Grandin provides him with a role model that he hopes that his daughter will one day emulate. He insists that he would be extremely happy to see his daughter reach half the level Temple Grandin reached: there is no need that she obtains a PhD, he states. If Mary manages to do obtain her O' Levels, for him it would be as if she has been awarded five degrees.

For Alan, the Temple Grandin success story provides him not only with hope for his child's future, but also with motivation for himself as a father. He feels that with the right guidance, his daughter could be able to one day attend school without the support of an LSA. She could also be able to finish school and have a goal in life. His wish is that when she is older she would be able to communicate all her needs, and also find a job. Whilst acknowledging that this is not an easy task, he feels that such goals are far from being impossible for Mary to reach. Alan is doing his very best to make sure that Mary would have the possibility to reach these goals. He feels that if there wasn't anything he could do about this he would surrender. However there is something that he and his wife could do.

Even though Mary has never actually articulated this, Alan is of the opinion that Mary is happy with her life. He also hopes that he has something to do with that, and is sure that he has.

Concerns about the future

Besides hope, Alan also has some concerns about his daughter's future. He is afraid that his daughter will not be able to overcome the difficulties related to her condition. He is afraid that she will struggle all her life with autism. However, Alan feels that she is a very intelligent girl, and that she will use her intelligence to make up for these difficulties. If there is something that he can do to help her to achieve it – be it medicine, ABA or whatever – and will help her to accelerate her learning, then he will be doing it. He approaches the future with a sense of urgency. He will not wait; rather, he will work now.

His sense of urgency is also motivated by the uncertainty and anxiety that arises when he thinks of the day that he and his wife will not be able to take care of Mary anymore. The fact that his daughter does not have any brothers or sisters is also a contributing factor to this uncertainty. Alan states that most probably she is not going to have any siblings. This is a decision that he has taken after his wife fell ill with leukaemia. For this reason sometimes he takes into consideration adopting a child.

However, he is aware that adopting a child could have a selfish motive: that is to have someone who took care of his daughter when he and his wife pass away. Even though this would provide Alan with peace of mind, as he would know that if he passed away she would have someone who took care of her. Nevertheless, he refuses to adopt a child based on this motive.

One of his greatest fears is that if she is not able to take care of herself, she would have to be taken in care and would have to stay there. If she is locked in an institution she will never reach her potential. Rather, she would definitely regress. That would be Alan's worst nightmare. He refuses to see her get locked up in an institution: "over my dead body! Never! No way!" Thus, he hopes that she will be able to take care of herself and would not need anyone to take care of her.

The most important thing for Alan is not to see Mary achieve certificates and qualifications. Rather, the most important thing is that he sees her live an independent life, so that when he passes away, Mary would be able to take care of herself.

Coping and living with reality

Alan states that as a father he initially started to hope, at least at first and until he got grounded, that after a few years or months everything would be normal. He hoped that his daughter would be living a normal life, without problems associated with autism. Then, as time passed by, he started to realize that autism was here to stay. However, autism is what made his daughter who she is.

Autism is what makes his daughter his daughter. If he came across a clone of Mary, who talked to him, she would not be his daughter. Alan insists that he wants his daughter to be his daughter, with all her characteristics. For him, Mary is Mary also because she is autistic, and loves her just for what she is: his daughter.

Fred's Story

Thinking about having children

Fred always would have liked to have children. However he also felt that he had to do some careful planning before having children. So soon after they got married, Fred and his wife started planning on how they were going to pay their bills and pay their home loan. They wanted to responsibly plan how much they were going to pay in bills, in loans and also see how much money was going to be left in their pocket. Fred thus felt that he first wanted to settle those commitments before thinking about having children.

It was New Year's Eve when Fred and his wife toasted for the year that had passed and for the year that was to come. With the toast also came a thought; that during the coming year they were to start trying to have children. After doing all the necessary calculations, they then figured that they were in a position, both financially and mentally, to have children. Fred feels that the mental aspect was as important as the financial aspect.

Thinking about becoming a father

The thought of him becoming a father was initially intimidating for Fred. Even though he had his ideas of what fatherhood would look like, he still felt that until he became a father he would never know what it actually entailed. He was afraid of the unknown as he felt that fatherhood was something he had no experience of.

For Fred fatherhood brought about a lot of thoughts and feelings. He did see himself fathering a child and would have been equally happy if that child were a boy or a girl. Fatherhood brought about images of toddlers and of grown up children. Fred always hoped that, just like him, his child would be a dog lover. He hoped that he would have had a good and close relationship with his child and also saw himself spending a lot of time together with his son or daughter at the beach and also at playgrounds. Fred also pictured himself and his wife going abroad, hopefully to Euro Disney in Paris, together with their child. He always saw himself conversing with his child and talking about anything: from the everyday things to sexual education. Fred always imagined a normal life; a life that he used to see many other people live together with their children.

Learning about his wife's pregnancy

Not much time had passed since that New Year's Eve toast, where they had decided to start trying to have children, when his wife told Fred that she was pregnant. The news swept Fred off his feet. Neither Fred nor his wife could believe that they were going to be parents, so they decided to double check by taking a second pregnancy test. The moment is clear in Fred's mind, and when the news was confirmed he was jumping of joy together with his wife. Even though they were eagerly waiting to become parents, they had not anticipated that it would be happening so soon.

The 9-month wait

Fred was eager to know about the sex of the baby. As soon as he had found that he was going to father a girl he started imagining her future. Since he was an animal enthusiast, he thought that his daughter would be just like him and even grow to

become a vet. He started making plans and also had a lot of dreams of how she would turn out to be and also about their father-daughter relationship.

During the nine months Fred also was concerned about the wellbeing of his daughter. He was thinking about what could go wrong and that there could be a possibility that he would be the father of an unfortunate child. He thought of many things, such as the possibility of his daughter having Down Syndrome. However, it had never crossed his mind that his daughter would be autistic.

The birth

Some of his fears came true when at the moment of his daughter's birth she experienced complications related to asphyxia. Fred was really scared when she was born as he noticed that his daughter could not obtain sufficient oxygen through breathing, and he saw her grasping for air. She then spent 5 days at the SCBU (Special Care Baby Unit). There was a lot of tension and preoccupation that day when his daughter was born. However, in the end, things turned out to be ok.

Becoming a father

The moment his daughter was born was magical for Fred. Fred and his wife named their daughter Mary. The instance Fred held Mary in his arms for the first time he immediately, and very naturally, felt that he became a father. For him fatherhood was instantaneous and it was magical. He immediately felt that he had bonded with his daughter and immediately felt emotionally attached to her.

His life changed immediately after Mary's birth. He started to stay more at home and help his wife with his daughter's care and upbringing. For him it was a big change in his life as his family suddenly expanded and consisted now of three people. His wife helped him a lot to cope with the change. She used to spend a lot of time with Mary in the nursery so that Fred could have a good night sleep and have the energy to go to work the next morning. However, after work Fred used to try his best to rush back home to see and care for his new baby.

Even though the change was sudden, the family's needs and Fred's responsibilities started to increase slowly. Due to the increasing demands of family life and increasing needs of his daughter, he gradually became busier whilst his life slowly became more hectic.

The first year

Mary's first year was relatively normal. She appeared to be reaching her developmental milestones at a very regular pace and in a timely fashion. Fred recalls that during the first year Mary had started babbling and vocalising. He remembers her smiling a lot, and also remembers that she was a very happy baby. During the first months Fred was used to enjoying making her laugh and seeing her smile. Even though it was not very clear, at seven months she said "papa", which made Fred very happy. Back then it never ever crossed his mind that she would be on the autistic spectrum.

The first concerns

The first time that Fred noticed that something was "wrong" was when she was eleven months of age when Fred and his family went on a cruise with two of their friends. Their friends also had a son who was nearly Mary's age. What was puzzling for Fred

was that whilst their son used to respond immediately to his name, Mary did not always answer or even look at Fred when he called her name. Why was she not answering, he asked? He remembers that it was really easy to take a photo of their friend's son, whilst it was very difficult for him to take a photo of his daughter as she never looked at the camera when asked. He started to notice that his daughter was not looking at him and not orienting towards him when he called her name.

Initially he had thought that her difficulties were due to a delay in her development. This hypothesis was reinforced by the fact that Mary was not able to crawl at the time. Rather, she used to move by carrying herself on her bottom. However, as she started crawling, Fred suspected that a delay in development did not account for all of the symptoms that she was presenting. Fred was also noticing that his friend's son was already starting to use an iPhone and other equipment, whilst his daughter was not anywhere close to that. When he saw this, Fred started asking many more other questions.

Fred's wife had questions that were similar to his. She was always suspicious about there being something wrong with Mary's development. The paediatrician they used to consult with at the time however used to tell them that they are overly obsessed and that their worry was blown out of proportion. The paediatrician used to tell them that they were actually fussing over nothing.

The first time he heard the word autism

On one occasion, whilst discussing what could be wrong with Mary's development, his wife asserted: could she be autistic? That was the first time Fred heard about the condition. The moment that he heard that, he was shocked. That word seemed to generate something resembling an electric shock all over his body.

Fred's wife worked in the medical sector and was involved with a lot of special schools in Malta. She was informed about such issues and was knowledgeable about the subject. So when he heard the word he asked her: "what are you talking about? What is autism?" She told him that autistic children were those who used to stare at the washing machines. She also told him that it was either autism or she had to be deaf.

Stress and self-blame

When Mary was young, Fred and his wife used to show Mary a lot of BabyTV. As they noticed that many children the same age of Mary started talking, whilst Mary had not, they started blaming themselves for their daughter's lack of speech. This was the cause of arguments and a lot of discussions, which in turn was a cause of stress. They also found themselves blaming each other for this, and as a consequence had a lot of guilt feelings. They started thinking that Mary was presenting with such difficulties because they weren't spending enough time with their daughter and that they were not working to encourage her to talk.

On one occasion, whilst Fred was at a BBQ with friends, his wife called him to tell him that she was really very apprehensive about Mary not taking much notice of her and that she thought that she was deaf. At the time Mary was not responding at all to her mother's attempt to engage her. For this reason Fred decided to try out an experiment. So whilst she was in the kitchen and not looking at the TV he turned on the TV and put the channel on BabyTV. When he did this she immediately came to

the living room. She had heard the sound of the TV and went looking for it. So that seemed to prove that Mary was actually hearing well.

The straw that broke the camel's back came in summer, when Mary was attending nursery. It was October when members of staff at the nursery told Fred's wife that they felt that there was something wrong. At the nursery she was spending a lot of time on her own and was not interacting with other children or with adults at the nursery. His wife was really distressed about this and called Fred. Whilst she was crying she told Fred that they had some trouble.

The diagnosis

Mary was two years of age at the time when she was seen by the paediatrician at Child Development Assessment Unit (CDAU). The paediatrician informed them that she thought that Mary was evidencing communication difficulties and that she lacked in role-play and imaginative play. At the time Fred was expecting a harsher diagnosis, so he was surprised to hear that she had communication difficulties.

In that period Mary was presenting with a lot of hearing problems. She had 'glue ears' and was prescribed with a treatment for this. As her hearing improved she also started improving in terms of behavior and reciprocity. When Fred and his wife were sure that Mary was hearing well, after around three months, they went to a psychologist. It was the psychologist who told them that it was ASD. That is when they realized that they had to start learning about the condition. From that point on Fred's life changed again. He initially was heading towards one direction. Very abruptly, from the next moment, he had to make a change of plans.

Learning about the condition

At first the word autism did not mean anything. At the age of two years Mary was manageable in her pushchair. At the age of three Fred and his wife also went abroad together with their daughter. They went for a week in Sicily, and things were ok. They were able to cope with their daughter's behavior and her needs. However, from then on things changed. So Fred started reading, on You-Tube and all over the Internet. He started learning more about the condition and sought ways to help his daughter and his family. In the mean time, as Fred learnt about his daughter's autism, there was a lot of advertising from INSPIRE foundation that highlighted the services they provided. So he got to know that he could send Mary to INSPIRE, and consequently signed her up.

Difficulties related to the condition

Fred has experienced difficulties because of his daughter's condition and has had to adapt himself and his life for him to be able to cope. An example of this is when he had to go to the beach at 7pm and not earlier like he used to because of crowds that he found earlier at the beach. He decided to go to the beach in a time where there were not a lot of people around, as Mary was not coping well with crowds. He also has had to adapt and cope with situations when Mary has had a tantrum. When she did have a tantrum, she usually lied down on the floor screaming and shouting and banging her hands. In such cases, she also threw the first things that she found close to her. During tantrums she was also noticed twisting and turning on the floor. Furthermore, Fred feels that the more attention he gave her, the worse things became. Sometimes tantrums like these even spanned over 5 minutes. In some occasions Mary screamed so much that she started sweating.

Fred has learnt from these experiences. He has also learnt to plan his life and also his days, and has learnt that preparation is crucial. Today Fred has also learnt that he cannot tell Mary that she was going to grandma, and then decide to take her to the swings instead. "That is not going to happen", he asserts. It takes a lot of alienation and redirection for Fred to get away with something like that. Fred feels that if he told her that she was going to grandma, her brain would then be programmed to go to grandma, and that programme would be very hard to change.

Fred feels that he has had to develop a skill to be able to cope with such a condition, as he was not born with such skills. Rather, it is all about trying it out and practicing such skills. Fred asserts: "if you are lucky you are able to cope with your child and hopefully you reach your goals". These days Fred tries to anticipate Mary's needs and her behaviors in order to make sure that she is happy and also to try to prevent a tantrum.

Society and autism

The reason that he has chosen to start going to the beach when there were fewer people is also because when Mary had a tantrum or behaved quirkily he used to notice a lot of people staring at her. They used to look at her as if she was an alien. Fred used to feel slightly uncomfortable when he knew that there was a beach full of people who stared at his daughter whilst she was flapping. People never seem to have understood why she was behaving in such a way.

Fred insists that it is not exactly embarrassment that he feels, as whatever Mary does, she is still his child. However, he feels very uncomfortable when he notices people staring at him and his daughter. He is not shy or embarrassed because his daughter has the condition. Rather, he describes what he feels as the feeling that a person would feel when he notices people staring at him whilst entering church in the middle of mass. He states that it resembles the feeling that a person feels when he hears people say: "why did this guy come in now, so late?"

In certain instances when Mary misbehaved Fred has tried to calm her and quiet her down. However Mary sometimes could be noticed ignoring Fred. When this happened, people sometimes thought that she was just defying Fred. In such occasions he feels that people don't need to say anything to express what they are thinking, rather, their looks says it all. In light of this, Fred believes that people do say things about him being a bad parent.

What reinforces this notion is his experience with his father-in-law. His father-in-law was not always informed about Mary's condition. So sometimes, when he used to see Mary behaving inappropriately, he used to get angry and tell Fred and his wife that they did not know how to raise their child. He used to tell Fred that if it were his child, he would slap some sense into her. He feels that if people do not know about the condition then that is what they are going to say. This is why he feels uncomfortable with people's stares, as those words keep resonating in his head. He feels that people do not empathise with him and his daughter and tend to blame his daughter's behavior on himself and see him as a bad parent. Today both his and his wife's parents empathise with Fred and his wife and are more aware of what autism is about. They also try to give Fred various suggestions on what he could do or try to cope with his daughter's behaviors. Fred feels that even though they mean well, they cannot actually understand him. Even though some people actually know about the condition, they are most of the time misinformed. In fact, when people try to give

Fred suggestions, they rarely know what they are talking about and rarely know exactly what he goes through. Fred tries his best to try to explain to people what autism is and what the difficulties are. However it is very difficult for them to understand, as they are not in his shoes. People sometimes try very hard to sympathise with him, however he believes that a person has to be in his shoes to really understand. Sometimes, people's lack understanding, their stares, and their bad looks are things that really hurt Fred.

Autism and schooling

Inclusion is a very important concept for Fred. It is also a big issue in schools. Nevertheless, schools did not always help a lot with including Mary in mainstream education. For Fred it is important that his daughter is included in school; is supported; and also understood. However, in the past, this did not always occur.

"How can you tell a child who only drinks cola to not have any cola at school", Fred asks? "How do you expect my child to participate in the school play if you don't give me the script beforehand to practice it with her at home" he questions? This happened two years ago when Mary went on stage and started crying instead of doing what was expected of her. There was not sufficient support from school, and Fred was not in a position to help his daughter in this situation. Furthermore, on the day of the play Mary had to be at the venue an hour before hand. This was something that really stressed her. There was no way that she was going to wait for such a long time. This angered Fred a lot, as he felt that the school were not trying to include his daughter in the play by placing unrealistic expectations on her. In light of the difficulties that children with autism have, he feels that the way they treated his daughter was really unfair.

Hyper vigilance

Fred also feels that ever since he has known about his daughter's condition he has become more conscious of people's perception of the condition. He also feels that he has become "hyper-aware" of his daughter's behavior, and also very mindful of people who could be staring or looking at his daughter's behavior. He feels that this is an action-reaction phenomenon that is a product of thoughts, feelings and experiences he has been through.

Trying to understand his daughter more

Sometimes Fred is stressed and frustrated because he does not know what goes in his daughter's mind. He is curious to know about what goes in the head of children with autism. He frequently finds himself asking: "why do they do the things they do? Why do they have a tantrum?" He however has not been able to find an answer to these questions. Fred would love to understand better the condition and it's implication. However he feels that unless it is explained by a person with the condition, then no one can gain such understanding. Today Fred feels that the people who could understand children with autism best are the parents who live with the person.

Why me?

Fred occasionally is angry, particularly when he goes through some of the trying experiences mentioned previously. For example, when he is at the beach with his daughter and sees his daughter behaving the way she does, he asks: "why does she do what she does?" However this is not the only thing that angers him.

When his wife goes abroad she asks Fred to go pick her up at the airport and to bring with him their daughter. Fred says that he is not very happy about that. This is because of a machine there is at the airport that sells small balls for children. Mary seems to be obsessed with these balls. Whilst at the airport she keeps asking for Fred to buy her all the balls. It is hard to explain to Mary that he doesn't have all that money and that she cannot have all the balls. Furthermore, when Fred buys a ball that she does not like, Mary insists to throw the ball back in the machine and get another one. She cannot understand that she cannot do that. So when Fred is at the airport to pick up his wife he ends up picking Mary up and taking her outside, as she tends to cry and misbehave at the airport. Such moments anger Fred a lot.

When these things happen he finds himself asking...“why me?” However, this is yet another question that he does not have an answer to. He then finds himself thinking about things which are related to the “why me” question: “Why was I born in the first place? To have a child with autism?” He also asks why his daughter is autistic? Did nature or god pick him to be the parent of this child? This is when he stops posing himself questions and asserts: “so be it!”.

Everything happens for a reason

Fred however is a staunch believer that everything happens for a reason. He always had this point of view, even before his daughter was born. He believes that god has a plan for everyone and that he just has to go through it. He is sure that his plan was written for him the day he was born. Part of the plan specified that he had to have a child with autism.

The responsibilities of fatherhood

Fred strongly feels that his role is to help his daughter to feel loved. So he tries to find time to spend with his daughter, to interact with her and to see to her needs. He tries to make himself as helpful as possible to all his family; so much so that he sometimes feels like a butler.

However today Fred is not just the father of Mary. Rather, Mary also has a newborn sister. Having a second child has also effected Fred's perception of fatherhood. Fred today feels that making sure that both of his children feel loved is part of his role and responsibility as a father. For this reason, when he kisses one of his daughters, he makes sure that his kisses her sister.

For him to carry out his duties as a father he feels that he requires a lot of time, a lot of patience and a lot of sacrifice. He feels that he probably requires more time, patience and sacrifice than a father whose child is more independent and who has better developed self-help skills. He feels that his daughter needs a lot of time and attention and definitely needs constant supervision. Mary as yet still could be noticed mouthing a lot of objects, and this tends to be very unsafe for her. For this reason Fred needs to be on his toes to make sure that she does not ingest anything that could be hazardous. In more than one occasion Mary got a cuddly toy and started eating the filling of that toy.

Showing his love towards Mary is very important for Fred. He feels that, because of the difficulties related to autism, he cannot just tell her that he loves her. Rather, due to the Mary's difficulties in receptive language, he has to show her that he loves her. He thus tries to give his daughter a lot of importance, especially now that she has a baby sister. Another job he feels he is responsible to carry out is that of showing Mary

what is not obvious. Fred feels that what is obvious to him is definitely not obvious to her. This, according to him, is a difficulty related to the condition. He is conscious of this when he compares her to other children.

Crying of joy

Fred feels that notwithstanding the difficulties that he has faced, there have been times when he was so happy that he cried with joy. This occurred whenever Fred noticed her doing something new. Fred celebrates all of his daughter's achievements; be it big or small. When she accomplishes something he feels emotional and happy.

The future

Fred is very positive about Mary's future. He has had a lot of discussions with his wife and about this subject; the future. Fred feels that she will be able to advance in life, and will have a good future. He thinks that she is an intelligent girl and sees a lot of potential in her. Fred will do anything for his children and is committed to help Mary reach her potential. He is also committed to help Mary overcome the obstacle that is autism. From his experience he has learnt that with autism there are no big steps. Rather, it is all about small steps. For this reason, he always finds himself evaluating the present accomplishments, and asking what is next?

He feels that this is the attitude that a parent should take when he has a child with autism: the attitude of identifying short-term goals and moving one step at a time. Fred feels that if a father with a child with autism has high expectations, he is going to be crushed and also let down. In fact, Fred asserts that he has expectations with regards to his daughter's future. However the future is very uncertain for him.

An aspect about the future that he is concerned about is the issue of inclusion. He states that many parents who have children with a disability are concerned about their children's inclusion in today's society. He feels that life is scary for people with no difficulties, let alone for children with this condition. Fred sees his daughter as being very vulnerable, and that is something that concerns him. For this reasons, he hopes that she will be able to cope with the demands placed on her by society, and also hopes that she will be included in society; make friends; and also find the right support. Fred feels that if Mary shall be brought up in an inclusive environment, then her future would be much brighter. If society is inclusive, Mary will be able to cope and face the challenges of the future.

Jesmond's Story

The first concerns

Jesmond and his wife were concerned about their son Aaron ever since he was very young. Aaron is the couple's youngest son. Jesmond remembers that his wife used to be concerned about Aaron even when she was breast-feeding him, as he would not react when she called him. She used to tell Jesmond that she sensed something different when compared to their elder son. Jesmond also remembers that when he was young Aaron did not cry or make any eye contact with him or his wife.

In the beginning Jesmond and his wife thought that he was deaf. They also suspected that he could have had a speech delay. Jesmond initially had assumed that it was something typical, as he himself had a speech delay when he was young. Nevertheless Jesmond and his wife together decided to carry out the relevant tests to see if there was anything wrong with Aaron's development.

The diagnosis

The news of the diagnosis was a difficult moment for Jesmond. The moment that the professional who was assessing Aaron met with his son, he immediately informed Jesmond that it was autism. It was an instant shock for Jesmond, particularly because he had never heard of autism before. Jesmond's first reaction was to ask, "what is autism?" The news of the diagnosis was traumatising. Both Jesmond and his wife were unaware of the repercussions of such a diagnosis. Furthermore, they were left alone to find out and discover for themselves what autism was all about.

So Jesmond searched online for information about the condition. On the Internet autism was depicted as a condition that made children incapable of feeling sensations. He also came across a video clip in which a child with autism was filmed having a tantrum and banging against the ground. Both Jesmond and his wife felt disturbed by the audio clip. He assumed that his son was affected by the most terrible and severe of conditions.

Jesmond vividly recalls the feelings that accompanied those first days when he started learning about autism. Those days were extremely distressing. For Jesmond, it would have been less stressful if someone had diagnosed Aaron with Down Syndrome, as he was better informed about the condition. But it was autism; and that made things worse since he was clueless about such a condition.

Looking back at the way that he was given the news about his son's diagnosis, Jesmond feels disappointed. He does not approve of the method used by the professional to break the news. Eventually Aaron was assessed by a psychologist and was later given the support of an LSA. He also started attending therapy sessions.

Anger

Initially, the diagnosis was first met by a lot of anger from Jesmond. He found himself asking how come this had to happen to his son. Jesmond posed himself that question often, and every time this upset him. His anger was exacerbated when 10 years ago he came across statistics that illustrated that autism was present in around 1 in 1000 cases.

Autism

Today Jesmond is rather knowledgeable about autism. He has come to see and understand that a child with autism reacts differently than any other person would react when confronted with similar circumstances. He has come to understand that a child or person with autism could live, think and understand things in his own special way. Jesmond has also come to see that there are various degrees of autism. His son Aaron has a number of difficulties, particularly with communication. However, he is very cooperative, and this makes his condition much more manageable. Jesmond believes that if Aaron were a nervous or hyperactive child it would have been more difficult to control him.

Relationship with his son

Jesmond describes his relationship with Aaron, who today is a young teen, as a very good one. Jesmond enjoys his son's company and feels that he gets along very well with him. Aaron enjoys going for walks and on outings, and Jesmond tries to accompany his son to many of his outings. He prefers to walk, together with Aaron, to catholic doctrine classes and to other activities. He prefers walking rather than driving, as a short drive would prevent any possible conversations from developing with Aaron.

Nevertheless, his relationship with his son requires a lot of effort, particularly because Jesmond at times finds it difficult to fully understand his son. The difficulties with communication that Aaron presents, according to Jesmond, impinge on their relationship. Nevertheless, Jesmond feels that Aaron seems pleased with his relationship with his father. Jesmond is particularly fond of the moments Aaron approaches him and spontaneously kisses him. He appreciates it because Jesmond knows that Aaron does this when he is happy. In fact, when he is sad or feels let down, he does not approach his father to kiss him. For Jesmond it is as if Aaron is giving him kiss as a sign of appreciation.

Yet, Jesmond is also aware that ever since his son has turned fourteen, kissing is inappropriate, especially in public places. For this reason he has tried to explain this to Aaron that he should avoid doing this in public. Nevertheless he consents that he kisses his father when indoors.

Communication

Jesmond feels that his son, and also he himself, would lead an easier life if Aaron's communication improved. Today Aaron understands language and comprehends conversations. Nevertheless he does not respond age appropriately. One has to be patient and wait for his reply. In many occasions Jesmond is able to deduce what his son feels and what he wants to say by observing his manners. All the same other people, who are not as familiar to Aaron as much as his parents are, are less likely to understand his thoughts and feelings. He also feels that notwithstanding his best efforts, there are times when Aaron is sad, and this sadness goes unnoticed.

Even though he is autistic, he still manages to understand his father, and that's one of Jesmond's greatest satisfactions. Jesmond also notices that his son is able to interpret his facial expressions. This could be noticed when Aaron misbehaves and is given an intense glance or look by his father. Aaron is mindful of such a "look" and knows that this means that he is doing something wrong and that he has to stop.

Frustration

The difficulties with communication, as well as Aaron's lack of attention, have an emotional impact on Jesmond. Such difficulties also make Jesmond nervous. At times Jesmond asks Aaron to describe the day's weather: a task that he knows Aaron is capable of doing. Aaron is able to describe the weather, yet he refuses to do so when asked. Aaron easily gets distracted and stares instead of responding to his father's request. This behavior irritates Jesmond so much that as a result he occasionally finds himself raising his voice at Aaron. Aaron on the other hand is a very sensitive boy who dislikes being shouted at. He is not used to anyone scolding him and is easily frightened when he is yelled at. He consequently urges his father to stop shouting.

Jesmond asserts that he does not raise his voice frequently with Aaron. When this happens it is usually the last resort. He however does not apologise for shouting or being assertive with Aaron, as he strongly believes that he is doing the right thing to discipline him. Jesmond is angry when he is sure that Aaron is capable of doing something and refuses to do it. He feels even more frustrated when he considers all the time, energy, and money spent on therapy sessions for him to improve. Consequently, when he fails to show his progress it makes Jesmond feel frustrated, angry and upset. Furthermore, he feels that it is important that Aaron follows his instructions and also answers his questions, as that would be a step forward for him to advance and improve.

Difficulties related to autism

Communication is not the only difficulty presented by Aaron. An example of another difficulty is when on one occasion whilst on a family outing at the beach Jesmond nearly had the fright of his life when Aaron seemed to have disappeared. Jesmond and all the family had only placed their belongings on the ground, when Jesmond noticed that Aaron was nowhere to be seen. The whole family immediately thought that the worst had happened. They immediately started searching for him. They soon found him swimming in an area that they had frequented on previous occasions. Aaron was familiar with that area, since he was accustomed to swim in those whereabouts, and had decided to go for a walkabout

Another difficulty is when Aaron opts to get out of the house wearing only his underwear. Occasionally Aaron is so eager to go for a walk that he hastily forgets to check that he is wearing the appropriate clothes to go outside. When this happens Jesmond gazes at him and reminds him to check if he is wearing appropriate clothes.

Socialisation & Schooling

The condition of ASD brings about a lot of difficulties, particularly in the social domain. For this reason Jesmond chose for Aaron to attend a state school and not a private one. The reasoning behind this decision was to make sure that Aaron would get to know the people who live in his town and also make sure that the people themselves are aware of Aaron's condition. Jesmond reasoned that in each scholastic year 125 new children attend his town's public primary school. Thus, by sending him to a public primary school he would be increasing the chances of people in the area getting to know about Aaron and about autism. So if someone encountered him when he was alone at the promenade, someone could easily contact Jesmond or his wife.

However, when it came to secondary school Jesmond was a bit sceptic about sending Aaron to a large public secondary school. Especially since the new "College System" was put in place, Jesmond feels that Aaron would have felt lost and out of place in such a large school. For this reason Aaron attended a private secondary school where Jesmond hoped he would be given more individual attention.

With regards to other activities, Jesmond makes sure that Aaron participates in as many activities that children Aaron's age generally participate in. For example, he makes sure that Aaron attends catholic catechism classes, which many children his age also attend. He also encourages Aaron to attend social activities that the Chaplain of the area organises for youngsters. Jesmond feels that Aaron's participation is very important especially for his social development.

Strengths

Jesmond discovered through experience that when working with Aaron, he tends to spend six entire months without showing any results at all. But all of a sudden or in a span of fifteen days he learns the whole lot. This encourages Jesmond and also makes him feel really fulfilled.

Today Aaron is able to pay for his purchases on his own. He is also able to swim unassisted in deep sea and is also able to walk and cycle for long distances, whilst enjoying it. Jesmond spent a lot of time teaching Aaron how to swim, as he was initially worried that he would drop into water or into a pool and drown. For this reason Jesmond taught his son how to swim at a very early age.

Fathering a child with autism

Jesmond tries to ensure that all of the outings and activities the whole family participates in are adequate for Aaron. If the place or activity is inadequate, then he and his wife opt to change it. Notwithstanding this, Jesmond feels that he did not have to change his life style because of autism. Jesmond feels that both his wife and himself lead a normal life, and having an autistic child did not impinge on their daily lives. For instance when Jesmond trained for the marathon he practised athletics on a regular basis, and was able to follow a strict training regime. Aaron's condition did not inhibit any of his accomplishments.

Jesmond however feels that he has had to adapt somewhat to his family's circumstances. He has learnt that one has to live according to his own current circumstances. In fact, a lot of his schedule revolves around his son's requirements. For example, on Sundays the whole family attends mass at eight o' clock; subsequently they are off to their favourite place in the countryside where they can play ball games and also prepare some food. Jesmond states that he has consciously devoted himself to Aaron. Through a lot of hard work he has seen a lot of good results. However he also feels that there are still a lot of things that need to be done for Aaron to keep progressing.

Working to help his son

Jesmond and his wife invest a lot of money and time on Aaron's needs. During wintertime Aaron frequents school, and every Tuesday he attends therapy sessions for ninety minutes. It would have been much easier for them if they chose a nearby institution for his therapy, yet they opted for one that is eighteen kilometres away from their town.

Besides the therapy sessions Jesmond also drives all the way to Valletta for speech therapy and also drives Aaron to frequent sport sessions all throughout the year. During the summer Aaron goes to a summer school three times a week from 9.30 hours till 12.30 hours. Jesmond states that such chauffeuring around could be stressful for him, however he does not mind it since he is sure that such input helps his son's development.

In the mean time Jesmond is also trying to teach and encourage Aaron to walk home on his own when returning from Christian Doctrine lessons. He is aware that crossing the road and coping with directions poses a big challenge to Aaron. However he also believes that this is an important skill that he needs to learn. In most occasions

Jesmond follows and supervises Aaron from a distance to make certain of his wellbeing.

Effects of autism on his relationship with his wife

Jesmond does not feel that the diagnosis of autism has affected the relationship that he has with his wife. Aaron is part of every aspect of their life and they both feel that the condition has not impinged on their life. Rather, they even go to public places where there is live music and crowds with their son.

Inclusion

Aaron is an essential part of the family and thus Jesmond and his wife try to include him in every activity. Aaron attends weddings and even goes to watch movies with his parents. Jesmond remembers the first time that he went to the movies with Aaron. This was when he was very young. Jesmond had opted to watch Mission Impossible; he had reasoned that in the eventuality that Aaron misbehaved they would have left the theatre. However this did not happen and they all remained watching the movie.

Jesmond refuses to leave Aaron an entire day at home watching a DVD. He makes sure that his schedule includes time for going out. At public places there are times when people look awkwardly at Aaron's peculiar behaviors. However, Jesmond's strong character precludes grief caused by people's stares or glances. He closes his eyes and ears to outsiders' opinion.

Autism and society

Jesmond feels that society has not always been so kind with children who have difficulties such as Aaron. A good example would be at Sunday's mass when he would kneel down, gaze backwards and shush off some of the people who were participating in mass. Jesmond used to hear people commenting on Aaron's. He occasionally heard people say things like: "what a shame, he is a careless parent, he is not vigilant and tolerates that his son misbehaves during mass". Jesmond states that in an ideal world a boy would be motionless in church, but in Aaron's case he tends to be restless. However Jesmond feels that he has to focus on his son and his needs and not on strangers' observations or comments.

The future

Jesmond is conscious of the fact that he will one day kick the bucket. This thought, and that of leaving Aaron on his own, makes him very apprehensive. He occasionally finds himself pondering on Aaron's future and asks himself whether he would be able to lead an independent life. Jesmond is hopeful that he would see Aaron develop his capabilities later on and also lead an independent life. However he is aware that one cannot predict the future.

He would love to see Aaron get a job and be able to earn money for himself. Jesmond describes his son as good at doing tasks that are repetitive, and says that he would be able to have a job that requires him to do repetitive tasks. However he feels that Aaron must be monitored as well. He also believes that in the future Aaron will keep himself busy in a way or another even though he has some difficulties that limit him. He however tries to avoid thinking about the future because it is so unclear and because he has no answers to questions about the future.

Jesmond hopes that once Aaron finishes his compulsory schooling he will not be left to stay the entire day at home watching YouTube or playing PC games. He is really upset by people who leave their children with special needs at home just because there are no places to take them. He hopes that by the time Aaron is older, there will be facilities that he could attend where his needs are being met.

Jesmond also feels that the needs of physically disabled people, who use wheel chairs, differ from those of autistic individuals. He cannot imagine Aaron passing an entire day in a room with physically disabled persons doing nothing. Jesmond feels that there are people with different needs, whose needs should be specifically catered for. Jesmond would like to group people who have similar difficulties together and make sure that their needs are being met and that they feel good about their placement.

Luke's Story:

Perchè tutte capitano a me?*

Family planning

Soon after Luke got married, he and his wife started thinking about having children. However, he was initially conscious of the additional financial demands and responsibilities that children would bring. Luke and his wife both wanted children and wanted a large family. However, in light of such financial concerns they waited for 5 years before having children, as they first wanted to be more financially stable. After the five years, his wife was worried about them both being too old to have children. Both had concerns related to potential fertility issues that were related to age, and thus were very keen to have children.

Family

Today Luke and his wife have two children: Alex the youngest of the two and is diagnosed with autism and also with Global Developmental Delay (GDD). Alex is a very active boy. In fact, Luke spends a lot of time running after Alex, whether he likes it or not. Ever since he has been diagnosed with autism Luke feels that Alex has progressed a lot. However, as yet, he does not use verbal language to communicate.

Fear of having other children

The possibility of having children that had certain difficulties was something that Luke and his wife were both aware of. Luke states that before having children he thought about the health and wellbeing of his children. He however could never know beforehand what sort of difficulties those children would go through once brought into the world. Having a child, Luke says, is like having a closed box; you never know what you are going to find once you open it.

* An Italian phrase that means: why do things always happen to me. The phrase is a humorous phrase, and as a title has a sarcastic tone.

Luke would have liked to have another child after Alex was born. However, both Luke and his wife were afraid about the possibility of having another child with autism. Since he learnt about Alex's diagnosis, Luke did a lot of research about the subject and got to learn new things. In his research Luke learnt that having a child with autism, increases substantially the possibility of having another child with autism. For this reason, he did not want to take this chance, as the risk was too big to take.

Luke also reasoned that, besides the possibility of having another child with problems similar to Alex's, having three children would be a lot to cope with. Alex already required a lot of attention and a lot of work, whilst his eldest son still needed a lot of help at school. Furthermore, they both were still growing up. So Luke asked; how was he going to cope with a newborn at this point in his life? Furthermore, how would he cope if his third child also had autism?

A long journey towards a diagnosis

The road towards a diagnosis of Autism Spectrum Disorder (ASD) was a long one. It started when Alex was 8 months of age. At the time Luke's wife felt that Alex did not always take notice of her. She thought that this was rather strange. She also noticed that he did not answer when his name was called. Luke also noticed this occurrence and recalls that was a while before he answered to his name. It also took a while before he could see him sitting down on his own. Luke and his wife also noticed other things such as a lack of social reciprocity, particularly when they used to compare his development to that of his sibling. However, Luke also felt that they were worrying too much and that it was too early to conclude anything.

When Luke noticed that Alex had turned one and had not as yet seen any progress, his concerns grew further. In light of such this lack of progress Luke decided to seek the advice of a specialist. The first specialist Luke spoke to was a paediatrician when Alex was around 1 year of age. In view of Alex's delay in walking, they also sought the advice of a physiotherapist.

During the numerous consultations that occurred with these professionals Luke was confronted with a lot of challenging news. A particular professional also told him that Alex would never get to walk. This however did not materialize as at the age of 1 year and 6 months Alex started walking. Soon after, he also started running. Luke and his wife breathed a sigh of relief. This however did not last long, as Alex was noticed refusing to climb up stairs. Luke's wife started worrying again here. Why isn't he going up the stairs, she said? Luke figured that he probably did not have the strength to go up the stairs. Nevertheless the family again went back to see the specialist.

The diagnosis

After a lot of tests, assessment, hypothesis and speculation and after two years of waiting, Alex was diagnosed with ASD and with GDD. This occurred when Alex was three years of age. The Psychologist at Child Development Assessment Unit (CDAU) made the diagnosis.

The diagnosis did come as a surprise for Luke, as he was of the opinion that the delay was his biggest problem. Luke believes that even though his son is diagnosed with autism, the biggest of his problems is the Global Delay, and not autism. According to Luke, if it were "only" autism, then his problems and difficulties would actually be

less pronounced, and Alex would have progressed more than he has done today. Unluckily, Luke asserts, his son has two conditions.

Questions raised about the diagnosis

The diagnosis of ASD brought about a lot of uncertainty and also a lot of questions. Furthermore, Luke feels that the manner in which his son was assessed and diagnosed was not done in a professional manner. At the time of the diagnosis, and also to this very day, Luke is uncomfortable with how the assessment actually unfolded. One of the professionals who first mentioned the word autism presented Alex with a board with objects that turned or spun. Alex was then observed spinning the wheels that he was presented with. According to Luke, this is what spurred the professional to conclude that it was ASD. The manner, in which the diagnosis was done, rather than the diagnosis itself, is what really annoyed Luke.

He feels that if he were presented with such an apparatus he would also have started spinning the wheels. “So would that mean that I also am autistic”, he asks? At the time Luke felt that it was unfair and even excessive to ascertain that his son was autistic solely by observing him spinning a wheel. Notwithstanding his scepticism, Luke is aware that there could have been other symptoms that could have been indicative of ASD, which he could have been ignoring. However, at the time he felt that the way his son was diagnosed was rather unprofessional.

The word Autism: learning about it.

Luke had heard about the condition of autism before. However, up until his son was diagnosed with ASD, he had never looked into what ASD actually was. Luke feels that when something doesn’t affect a person’s life, then that person tends to be unaware of it. However, when he heard for the first time his son’s diagnosis, he was initially shocked and frightened. What exactly was autism, he asked?

That question brought about a lot of hazy yet daunting information, such as: autistic children do not speak; some are intelligent whilst others are not; some have certain skills whilst others have other skills; some even are isolated and refuse to have any contact with people. As Luke heard these things he asked himself: “ow, my...what is coming my way?” Was he not going to be able to hug his son anymore? Was Alex not going to ever hug him?

In the face of such uncertainty, Luke sought refuge on the pages of the Internet. Today, he considers himself lucky to be living in this era of technology. However, he also feels that the Internet is a doubled edged sword, as he feels that in many occasions the internet actually has the potential to misinform the public rather than inform them. For this reason, the Internet also tended to be the cause of a lot of pain and anxiety. Nevertheless, he started searching on the Internet with the hope of finding answers to his questions. In his case, he feels very lucky to incidentally have come across a couple of sites where the information presented was genuine and legitimate.

The more information he found the more he searched. In hindsight, Luke could say that the information that he got from the Internet was actually good and honest information. Through the Internet Luke also came across some information that depicted autism as having no cure. Despite this piece of information, from that moment on, Luke vouched to do all that was in his power to try to help his son Alex reach his potential.

Priorities

The diagnosis of ASD made Luke reorganise his priorities in life: both as an individual and as a father. For him, the priorities today are different from what they were before he had children. They are also very different from those that he had before he found out about his son's autism. In fact, before getting acquainted with autism, Luke had actually started reading for his Masters degree. However, three months into the course he realised that his priority had to be his son, who required more attention than he had previously figured.

Furthering his studies was one of Luke's long time dreams. Luke loves his profession, and thus, furthering his studies would have meant a lot to him. However, a Masters degree would have taken a lot of time to complete and would have required that he dedicated a lot of his time studying. Because of Alex's needs, Luke did not find the time to pursue other objectives of the sort. This was something that has frustrated Luke a great deal.

Having two children and having one of them with autism limited Luke's time considerably. He previously had the time to enjoy doing "Do-It-Yourself" (DIY) activities at home. However, in view of his current responsibilities, whenever he practices such a "hobby" he feels as if he is "stealing time" from his children. He in fact tried to do such activities when his children and his wife are asleep at night. Ever since his son was diagnosed with autism Luke has in fact stopped doing some of the things that he used to do which he really enjoyed, such as DIY. Time has now become an issue. Today he spends more time with his son, and this has considerably reduced the time he spends pursuing his hobbies and ambitions. That is how autism has changed his life mostly.

Difficulties brought about by the condition

Apart from a change in priorities, Luke experienced Alex's condition in other ways. He however feels that the difficulties are not many. The demands of the situation made Luke and his wife more susceptible to stress. There were many times when he was sad and had negative thoughts. Caring for a child with autism is very tiring, and at times the lack of progress is saddening. In fact in some moments Luke felt extreme sadness and helplessness.

However he has always tried to do his best to wipe out such negative thoughts out of his head. He reasoned that feeling sad about his situation was not going to solve anything. So now he reasons that his life is what it is, and that he should concentrate on making the best out of it. He does acknowledge that there are limitations and that there are bad moments. However, he is realistic and feels that there are good moments as well.

Lack of verbal communication

The lack of verbal communication is an issue that concerns Luke. As yet Alex does not use words to communicate with his father. However, he communicates a lot using gestures. In fact, when he wants something, such as a particular drink, he grabs his hand and takes his father next to the fridge. He also places Luke's hand on cold water when he would like his father to pour him some cold water. Alex's lack of communication occasionally is also a cause of stress. However, this is not because he does not talk to Luke. Rather, it is because there are times when Alex is hungry, thirsty, sick, or in pain and unable to express himself in a verbal or nonverbal manner.

Help for his son

Luke's first priority has always been to help Alex reach his potential. Luke has worked towards this by searching for treatments and therapies that could help Alex maximize his potential. In fact, soon after the diagnosis Luke decided to have Alex attend a specialised programme for children with ASD. Here he received a lot of good professional input and support. However, after some time attending the programme and in view of an apparent halt in Alex's progress.

In the mean time, Luke incidentally found out that Alex was lactose intolerant. This occurred whilst he was in hospital and whilst he was seeing his son's hospital file. There he noticed that Alex resulted positive in the lactose-intolerance test. Luke knew that it had something to do with milk and dairy. For this reason he asked the doctor who was seeing to Alex's case what that meant. To his surprise he found out that his son was lactose intolerant. Luke was angry that no one had ever pointed out this to him before. However, this actually explained the tantrums that Alex used to have after he was given dairy. From then on Alex was not given anymore dairy.

On one occasion Luke came across a foreign doctor (DAN Doctor - Defeat Autism Now) who specialized in ASD and who used to visit Malta every other month. Luke and his wife made an appointment and went to meet with him. The doctor did a number of tests to try to get a better picture of Alex's needs. He then prescribed for Alex a cocktail of dietary supplements and medications. Luke was open to try new things, particularly if these things could help his son with his development. So he purchased the prescribed supplements over the Internet, as they were mostly unavailable in Malta, and had them shipped to Malta. This doctor also suggested Luke to stop providing his son food containing gluten, as gluten could negatively affect children with autism. So Luke decided to put Alex a gluten free diet. The gluten free diet was really difficult to adhere to particularly because Luke and his wife could not find many gluten free products in Malta.

Luke strictly adhered to the doctor's prescriptions for two whole years. He also adhered to the gluten free and lactose free diet for that period. After the first four months of such a regime, Luke saw some improvement in Alex's behavior and in his development. However, after that, they stopped seeing improvement. Alex was growing up and time was passing, and he was not improving as much as we hoped. Luke was expecting Alex to improve so much that he would actually start reading. But nothing of this happened. For this reason, they decided to stop the supplements prescribed by the doctor as well as the gluten free diet. However, till this very day Alex is still on a lactose free diet.

When the diet and the supplements were stopped things did not change. Things remained the same. Alex did not regress. Rather, he kept progressing at a slow pace like he always did. Today Luke feels that the diet and supplements were not very helpful and were not a good investment. However, besides the nutritional and supplementation advice, this doctor also suggested "hyperbaric oxygen therapy". In Luke's opinion this was a very good suggestion.

Luke consequently decided to look into this. However, he quickly realized that the government in Malta did not offer such an intervention. So what he did was search for this therapy in the UK. In fact, in the UK he was able to find a lot of private hospitals that could provide such a therapy. Luke and his wife then contacted a particular private hospital in Leeds and started flying off to the UK for months at a time. They

used to fly to the UK in July and in September so that neither of their children would miss out on days of school. The centre that they visited in Leeds was a private hospital that actually catered for multiple sclerosis. However they also treated children with autism. Each session costed around ten British Pounds. Alex used to have two sessions every day for a whole month, so this therapy was rather costly.

Immediately at the start of the therapeutic intervention Luke started to see some results. However, they soon discovered that the improvement was temporary. The doctors and nurses who used to oversee the procedure suggested that for this therapy to be effective Alex had to attend all through the year. They believed that the intervention should not just be a one-off thing. This was difficult for Luke, as this would have lead the whole family to move to the UK.

The last time Luke and his family went to Leeds for the treatment his wife befriended a married couple from Sweden. The couple recommended to Luke and his wife to take their son to a German hospital to make use of stem cell therapy. As soon as Luke heard of this possibility he again started researching the treatment. Luke was able to find the German hospital's representative in Malta. So Luke made contact with this person, who in turn told him what was needed. After the preliminary tests were done, the hospital informed Luke and his wife that the intervention was possible and informed them of the costs. The operation alone costed around ten thousand euro and was performed in Dusseldorf.

After the intervention, Luke cannot say that Alex did not improve. However, the progress seen was gradual. The question that Luke asked, as with every intervention he tried before, was if the progress could actually be attributed to this intervention?

What would improvement mean?

Seeing his son improve means a lot to Luke. Alex's improvement – in terms of behavior, communication, and independent living skills – would affect all the family and not only Alex himself. Luke feels that any sort of improvement would also improve Luke's life, his wife's and even Alex's elder brother's life. It would also have a positive impact on Luke and his wife's parents and all their other close relatives.

Father-son relationship

Luke is the type of father who wants to spend as much time as he possibly can with his family. The situation is not any different with Alex, as he would like to be with him all the time. Luke would like to think that he could be with him forever. However he knows that this is not possible.

Luke feels that he has an excellent relationship with his son. This is probably because he is the one that actually spends the most time with Alex. Alex's sibling receives a lot of help with schooling from his wife. Consequently, Alex tends to spend a lot of time with Luke. When he is with Luke, Alex seems to be very happy.

When with his father, Alex is encouraged to do educational exercises like matching and sorting. Luke enjoys working with his son and would like to find time to do more of this kind of work with him. Sometimes, in a very spontaneous manner, Alex approaches Luke to hug and kiss him. These are the moments that Luke enjoys the most: the moments when his son is affectionate towards him. Moments like these are the ones that Luke really treasures.

Husband or father?

Luke feels that his role as a husband and that of a father are on the same level. His number one priorities in his life are his wife and his children. Both priorities are seen to be on the same level. His work was very important for him before he had children. However, today work is not anymore his priority. This does not mean that he takes his job lightly or that he approaches it less professionally. Rather, he still works hard and tries to perform at the best of his abilities. However, his roles as a father and as a husband are the most important roles for Luke.

Why did it have to be this way?

Ever since finding out about his son's diagnosis there have been moments where Luke was angry about the situation. Sometimes he even asked himself why things had to be this way. However he also makes a conscious effort to look at the positive side. He reminds himself that his son walks, and reminds himself that not all parents are able to say that about their son.

What makes Luke angry is when he sees parents with six children who do not care about their children. So he asks; why do they have 6 children with no difficulties, whilst he and his wife, who actually love and take care of their children, had to have it so tough. But then again, Luke quickly says to himself: it is tough, but "it could have been much worse". Luke also reasons that this is a question of 'chance' and that this is how it turned out to be.

Society's perception

Luke is of the opinion that most of the general public is not informed well about the subject of autism. Some people are actually very insensitive towards autism and the difficulties brought by the condition. He has experienced this lack of sensitivity towards the condition directly. An example of this is when on one occasion Luke and his family attended church to hear mass. Alex is not a child who just stays in one place and stays still. Rather he tends to move around all the time. There are times when he is active in moments when he should be quiet. Because of this, Luke and his family had decided to stay in the "crying room", which is a room specifically designed using sound proof material and used by families with young children who want to hear mass without having their children disturb the general public.

That day Alex was very active and energetic and was making a lot of noise. So Luke's wife, in order to keep him quiet and amused, opened a packet of crisps. When an individual, also seated in the "crying room", saw this she arrogantly told Luke and his wife: "do you think that you are at a restaurant?" Luke immediately replied that he is only a child. This was not a good enough reason for this individual. Luke then tried to explain that Alex is autistic, and occasionally needs a packet of crisps to keep him amused. Notwithstanding Luke's best efforts to explain the complexity of the situation, this person in particular did not seem to understand and just continued complaining.

On another occasion, Luke and his family were taking a walk on a public promenade. Whilst they were on their walk, they encountered another man who was walking his dog. As the dog brushed by, Alex noticed the dog and was fascinated by it. When this happened, Alex instinctively pulled the dog towards him. This is when the dog's owner started shouting at him. Luke immediately tried to explain to the owner that

Alex did not do this on purpose and that he was autistic. Nevertheless, the man found it very difficult to understand this.

It is moments like these when Luke feels that people do not know enough about the condition. However, he sympathises with these individuals, as he feels that if his son had not been diagnosed with the condition he would have not been aware of the condition. Luke is of the opinion that when something does not affect individuals personally, the like the way autism has affected him and his son, they do not take an interest in learning about that condition. Sometimes this “phenomenon” actually happens to Luke himself, when he is faced with conditions that people are experiencing that he never heard about before and does not know anything about. This is why Luke understands and sympathises with this lack of awareness about the condition. “If they do not know, then they do not know” he asserts.

Looking towards the future

The thing that hurts Luke the most is when he hears someone saying that he can place his son in a home or an institution. This thought upsets him a lot. Luke is not even comfortable leaving Alex under the supervision of a family member or of a professional at “Dar il-Kaptan” for an hour or so every once in a while, let alone having his son institutionalised. The thought of that happening also distresses him a lot. Luke wants to be with his son as much as he can. Alex is his son and thus, Luke wants to be there for him as much as possible.

The first time that “Dar il-Kaptan” was mentioned was by his wife who was concerned about what would happen to Alex when Luke and herself would not be able to take care of him anymore. She had suggested that they take Alex for a one-off visit to the home. “Dar il-Kaptan” is a residential home that could provide families and carers with respite, and look after children who are experiencing such difficulties.

Luke did understand his wife’s point. He also feels that this could be a good idea, particularly in light of his parents’ age and his wife’s parents’ age. Both their parents are in fact elderly people who have the will and motivation but not the strength to take care of their nephew. Thus, Luke feels that he and his wife cannot depend on anyone to take care of Alex, not now and neither when they are gone. This is something that is always on Luke’s mind: what will happen to his son once he and his wife pass. This concern is also a very current concern. Luke feels that in the present they also could need such support. If something would happen to anyone of them, it would be difficult for them to cope with the situation on their own. So Luke feels that they should have a backup plan.

The future for Luke is distressful especially because of such uncertainties. His son will grow just like he himself will grow up. Luke affirms that when Alex will be thirty years old he will be sixty years old. He is concerned about this, particularly because his son is a big kid, and needs a lot of support and supervision. Luke also tried to look towards the future and start saving some money for Alex and have also put a savings plan in place. In the future the bank will take over the management aspect of the funds saved when they both are no longer alive. The bank will manage the funds and will make sure that Alex is being taken care of. They will also be making sure that he has everything that he needs. This is somewhat reassuring for Luke. What is also reassuring is the fact that Alex has a brother. His brother could help Alex later on in his life. However, one can never say what happens. However, Luke hopes that his brother will still take care of Alex in the future.

Trying all that he could

Looking back at his son's past, Luke would never want to say that he did not try all he could to help his son. In fact, Luke never minded the costs incurred by all the treatments and therapies administered. The expenses of all the treatments amounted to a little fortune. However, that didn't matter for Luke. He reasoned that even though treatments were expensive, he had to try. If he didn't try it then Luke would have always had that difficult question at the back of his mind: "what if?" Like that Luke feels that he and his wife have tried all that is in their power to help their son.

Luke believes that money comes and goes. Expenses are very high, however, if he just puts money away in a bank, that would not yield the results that he desires for his son. In the end, Luke feels that he has done his utmost. Now it is not anymore up to him or his wife. After all this work, anything can happen. However, he cannot say to himself that he did not try. Notwithstanding all the expenses incurred and the sacrifices made so far, Luke feels that he will not stop here. Rather, he is prepared to keep exploring other possibilities. If he also hears of something else, he will also look into it for sure.

William's Story

Family planning

Whilst growing up, the age gap between William and his brother always bothered him. Thus, his wish was that if he ever had more than one child, they would be brought up together. So soon after their daughter was born, William and his wife started planning for another child. Consequently, it wasn't long before his wife was pregnant again.

Finding out he was going to father a boy

William always wanted to have a boy. His dream was to take his son to the nursery and to see him playing soccer. He thought of how proud he would make his parents when he told them that they were going to be grandparents of a boy for the first time. However, no matter what the sex of his second child was going to be, all that mattered was that the baby was healthy. His first reaction to the news of him having a boy was sheer joy. For him, it was like scoring a goal. His reaction to the news was "Oleeeeeee". He immediately started picturing himself taking his son to soccer practice.

The birth

His son was born two weeks premature and was called James. He recalls this vividly. William recalls that he was watching Manchester United playing against West Ham when his wife started having labour pains. They initially dismissed it as flatulence. However, as the pain increased, they realised that she could be actually going to deliver the baby. Her water broke in the car on their way to the hospital. They initially thought that she was going to give birth to their baby in the car. However, this was not

to happen, as William's wife gave birth to a boy as soon as they arrived at the hospital.

The first year

James's first year was normal. William and his wife were told that boys took longer in some aspects of development when compared to girls, so they were not worried. William describes him as a very normal child: he used to look at people, smile, and also wave his hands to say goodbye. He even used to say bye and look towards a camera to get his picture taken.

Regression at the age of two

As James approached the age of two years, William started to notice him flapping. Initially William thought that the flapping was a game that his son played. As time passes, it became harder for William to take a photo of him, as his son started displaying poor eye contact. He started biting his hands, touching his private parts, licking the wall, and feeling the texture of labels. As he grew older he also started manifesting severe tantrums.

The diagnosis

After James was one year of age, William took him to see a doctor, who suggested speech therapy. Shortly after, William and his wife took their son to CDAU to have him seen by a team of professionals. The process at CDAU was laborious. Initially, the professionals hinted that he might be on the autistic spectrum. William did not know anything about autism, and asked a lot of questions. Another hypothesis was that of it being a developmental delay. Again, this brought a lot of uncertainty. William asked: "what is this delay?" At this point, he started searching for information on the internet. As the professionals realised that he started to understand what the problem was, they started to ask him more specific things such as: if he flaps or if he hums. They asked about if he looked in his eyes when being spoken to? This is when William started observing James's actions even more.

The diagnosis was officially given by the paediatrician and the clinical psychologist at CDAU, and it changed William's life completely, from day to night.

Difficulties with getting an LSA for his son.

One of the difficulties William encountered was that of obtaining an LSA for his son. The statementing panel was hesitant to assign James an LSA on a one-to-one basis. Nevertheless, the 'statement' was confirmed when his son was three years old. As James started attending school in kindergarten-1 he was supported by an LSA. The provision established that the LSA should be shared in the same class. However, the school provided James with an LSA who he was to share with other children within the school. In this case, the LSA was responsible of supporting James and also other children who were not in his class. This meant that at times James was going to find himself without individual support and supervision.

William did not accept this. He was worried that his son would not be able to cope at school if he was not supported and supervised continuously. Notwithstanding the fact that the school was a small one, William reasoned that in view of James's difficulties, he should not be left alone whilst the LSA supported other children. What would his

son do in the mean time, William asked? Would he be a danger to himself and to others?

Difficulties with the LSA

Another problem William encountered was that of the LSA. William states that the LSA assigned with James did not know the meaning of autism. He was extremely disappointed about this. He believes that children should not be just supervised, and an LSA should not just be a babysitter. Rather, children with autism should be thought, and therefore require someone with the right knowledge to teach them. He however was heartened to see this person work hard and strive to see his son progress. He was also pleased to see the LSA make a serious effort to get more informed about autism.

Difficulties encountered in school

On one occasion, his wife's niece overheard a member of staff, who occupied a high position in his son's school, claim that children like James should be attending a 'special-school'. That angered William a great deal. William states that members of staff at James's school claim that they do not discriminate. However, he feels that the school occasionally give people like himself, who have a child with a particular difficulty, a hard time just to force them to seek alternatives. An example of this was when the head of school asked William to come pick up James from school as his LSA called in sick. William did not do so, which in turn enraged further the school administration.

William feels that schools need and should get better equipped to cope with children that have specific difficulties such as his son. If they do not, he fears that James and other children with autism risk to achieve nothing. William would love to see things such as special rooms for children with autism, particularly because children with autism necessitate an environment that is less stimulating.

For William this is a constant battle that does not end at the school gate when the day is over. William also encountered some difficulties when he took James to a governmental summer school. In this occasion, for his son to attend, William had to pay the fee of seven hundred euro to have his son supervised by an LSA. At this particular summer school William again found an ill prepared LSA as well as an ill prepared programme. There was no structure and no consistency. James used to come back home covered in urine with his packed lunch still intact, as staff at the summer school did not give him time to eat.

William before autism

William always considered himself to be a "happy-go-lucky" sort of person. Before autism, he was a free spirit. His motto in life was always live and let live and always was an easygoing person. Determined is not the adjective that he would have used to describe himself. However, experiences and circumstances in life changed him.

Determination

The circumstances and challenges that he has been through ever since being faced with the challenges brought about by a diagnosis of autism made William more resilient; more stubborn; and more determined than ever. William believes that in moments like these, as a father he has to step up and fight for his son. He has to be

like a fighting lion. This was never his nature, as he was always a calm and laid back person. However, for his children he would do anything; especially when his son has such difficulties, and especially because he feels that he is the only person that can help his son.

A constant battle

William believes that if he were a parent who was not so determined or even who lacked the right education, then he would not be able to cope with his current situation. He goes further and called his experience a constant battle and a relentless upstream struggle.

The search for solutions

William worked very hard to enrol James in the “Eden Program” from a very early age. This proved to be problematic and required William to fight yet another battle for his son. This was because of the precarious financial state that the organisation found itself in at the time, which consequently led to the unification of two leading NGOs in Malta that offered early intervention services for children with autism; ‘Eden Foundation’ (now known as INSPIRE) and ‘Razzett tal-Hhbiberijja’. However, after a lot of heated debates, conversations and after many phone calls and emails, James was provided with the service that he required.

During an incidental conversation that William had, he was told that through the administration of a very special diet, a child with autism could improve in various areas of development. With the hope that he would see such improvement he approached a foreign doctor who specialised in biomedical treatments. The treatment, which consisted of dietary supplements and medicines, was extremely expensive. William recalls that he was given a lot of supplements to give to his son, such as B12, GABA, ointments and many more. He was overwhelmed with all the supplements that James was prescribed. William felt that the money that he spent on expensive supplements was not money well spent. For him, the only positive thing was GABA (gamma-amino-butyric acid). The doctor also suggested Hyperbolic Oxygen Therapy. However William was very sceptic about this. Instead he opted for more conventional and proven therapies such as occupation therapy sessions.

Difficulties related to autism

William sometimes finds himself thinking of parents that are at the seaside with their children, whilst his son is at an occupational therapy session. He however feels the responsibility of seeing to his son’s needs. He reasons that if he and wife do not take care of his son’s needs, then no one will.

William would like to do different things; things that most families do with their children, such as weekend breaks in hotels. However, he is not very comfortable with this as he feels that hotel settings are not the right environment for his son. In such circumstances he feels that he cannot relax and also tends to become hypervigilant. For this reason he tried to avoid such situations.

James himself is not very comfortable in unfamiliar places such as hotels. He is also not very comfortable in places such as his grandparent’s house, where he only spends a maximum of two hours. William explains that James’s grandparents are not always able to cope with James’s needs, particularly as they are getting older. William also

explain that he also finds it difficult to imagine James on an aeroplane, and for this reason he chooses to not go abroad with his family.

Communication

William communicates with his son with the use of PECS. James however is able to understand certain verbal instructions. An example of this is when William tells him to switch the lights off. James knows where the lights are and goes to switch them off. He seems to understand him more when he speaks in English. However, as instructed by professionals, he tries to speak to him more by using his mother language.

For William communication is very important. In his opinion, before he starts speaking his son will not improve. He believes that children will not speak to James if he does not speak to them. This is why he feels that adults should introduce PECS to the children who are closest to James. In this way they would be in a better position to understand and communicate with him.

William would like it if he would one day hear his son calling him “Papa” (dad). He does say “Papa” occasionally, however he never says it spontaneously. William would also love to hear his son ask him to go for a swim, or to watch a DVD. Most importantly, William would love to hear his son communicate with him spontaneously and with purpose.

Financial aspects of the diagnosis of autism

Apart from the frustration brought about by the lack of communication, William also experiences frustrations brought about by financial burdens linked to autism. He used to employ a professional to work with James individually at home. This service used to cost him 10 euro an hour. James also attends O.T. sessions, which cost 20 euro an hour. William is also trying to introduce James to the iPad. However, in view of the high cost of the hardware, he is currently looking to find a sponsor.

James also attends a private school and also attends weekly session at the INSPIRE foundation. These sessions are not free of charge. All of these fees, as well as that of the private school, are a burden on William and his family and are also extremely anxiety provoking.

William’s relationship with his son

William enjoys doing activities with his son such as wrestling, which James also seems to enjoy. James also enjoys it when William carries him on his back and plays horse. William also likes to take his son for an occasional swim during the summer months. William would do anything for his son. However, he finds it difficult to perform tabletop activities and try to teach him. He finds it very frustrating to remain wedged to a chair and a table. For William, James appears to be uninterested in learning, and this is what frustrates William the most. Furthermore, when he tries building blocks together, James appears unwilling to participate and also finds it very difficult to complete the task.

William feels that at times James is being overloaded with work: by taking him from school to Inspire to OT sessions and to private home one-to-one sessions. He would like to see his son live his childhood and have more fun. So William plays with James and enjoys tickling him and enjoys roaming around the house with him. James, in

return, grabs William's hands and indicates to William that he would like him to continue doing so.

William feels that he currently does not have much quality time for himself or his wife. Notwithstanding this, he still feels guilty leaving his son with someone else. In fact he never does. The fact that people find it difficult to care for and supervise his son makes things even more difficult. Some relatives are willing to take William's daughter out with them, but are unwilling to take his son along. This really is upsetting for William. He, however, acknowledges that people could encounter certain difficulties when going out of the house with his son. When going out with his son, he tends to worry a lot. What if James has a tantrum? What if James encounters difficulties with bladder control, he asks? Hence, he always is very selective on where he goes with his son. William also tries to avoid certain places that may cause a tantrum whilst also trying to think ahead and forecast the difficulties that might occur.

William's description of his son

William describes his son as a quiet boy. He sees him as an adorable and handsome child with a sweet face and charming smile. He also mentions that he has a lot of academic difficulties. A song that reminds William of his son is Pink Floyd's "Coming back to life". The song makes him emotional as it makes him hope that his son will one day come into 'our world'.

Being unlucky

When thinking about his son, William sometimes thinks about how unlucky James is. This comes to mind whenever he accompanies him to sport sessions with other children. This is when he realises that amongst all those children participating, he is the only one with such a problem.

Autism and his son

For William, autism is an obstacle for his son's development. Autism is robbing him of his life. His son reminds him of a star or a comet; its there, its beautiful, it exists. However, he cannot live it.

Guilt, blame and acceptance

Every day that passes William asks himself the question: "what caused the autism?" He says that even though it is a very hard thing to do, especially because he doesn't have the answer, he still has to accept it. In some occasions, William finds himself looking at his son's difficulties and blaming himself for them. He finds himself blaming his son's autism on the vitamins and supplements he used to take when he was younger whilst doing resistance training at the gym. William and his wife sometimes blame themselves. They ask if things might have been different if they hadn't given James the MMR injection. Could the MMR be the reason for all of this, they ask?

Hopes and wishes

William hopes and wishes that he would one day be able to take James to a football nursery and see him playing football. He wishes that he would one day spontaneously call him dad. He also wishes that he could see his son go to school on his own, and that at school he wouldn't need an LSA. He also wishes that he would stop going to

INSPIRE, as INSPIRE means that he is still in need of help. But most of all, his biggest wish is to never ever see or let his son suffer.

The effects of autism on William's relationship with his wife.

As a result of all the stress and pressure they experience, William quarrels frequently with his wife. They find it very difficult to spend some quality time alone with each other and at times do not find the time to go out as a couple. One of the reasons for this is that everyone around them seems to be ok with keeping an eye on their eldest daughter but refuse to be held responsible for their son.

Fatherhood

William believes that before having children, one should be sure that he really wants children. Individuals really need to be prepared, he says. When he was younger he was not prepared for children. He wanted to have the right environment first. He wanted to be settled, and wanted to have the right foundations. William states that, like it happens logically in nature, he needed to prepare his nest before having children.

For him fatherhood means immense love. He started loving his children as soon as he saw them for first time. To him, fatherhood means responsibility and sacrifice. William wants his children to live a fairytale, just like he did. His main concern right now is to provide his son, who suffers with autism with better developmental opportunities, so he hopefully recovers. He also feels that he is responsible to help his daughter academically and wants to see her improve. He believes that he cannot just focus on his son, even though he is aware that at times he does tend to focus on James more.

William also believes that if his first child had been diagnosed with autism, he would not have tried to have a second child.

Lack of awareness of autism in Malta

William believes that in Malta there is not enough awareness about autism. He in fact went as far as to talk to a TV presenter and ask him to make a program about autism. The notion of there being a lack of awareness stems from William's family's difficulties with themselves not understanding autism. In fact some of his family members blame him and his wife for their son's condition. They believe that it is because of the time he spends in front of the TV. Other family members just cannot accept it, and have even sought a psychologist to help them cope with the situation. William is also bombarded with questions from his family, about when or if James will be normal. It is very difficult for William to hear people blame his child's condition on him or on his wife.

The future

William is not the kind of person who takes things day by day. Rather, he tends to think about the future all the time; he is 'all about' planning and safety. In fact he always wanted to meet an adult with autism, as he was always curious to see how his son's future could look like. On one occasion he has met a teenager with Asperger's Syndrome who told him that it would be useful to help his son find out what he was good at. Thus that is one of his aims now; to help James find his hidden talent.

Uncertainty

William realises that notwithstanding his best efforts, he cannot plan ahead for his son. He states that he cannot do what he had always planned or dreamt for his son. All he can do is help him out in his development. Improvement for him is gradual and consists of him starting to communicate and scribble on his copybooks. However William states: “if nothing of this happens...then we will see”.

Appendix 13 - Ethic Forms

SCHOOL OF PSYCHOLOGY

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.



School of Psychology Professional Doctorate Programmes

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

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If you have any special access or communication requirements for your visit, please let us know. MINICOM 020 8223 2853



UNIVERSITY OF MALTA

UNIVERSITY RESEARCH ETHICS COMMITTEE

Check list to be included with UREC proposal form

Please make sure to tick **ALL** the items. Incomplete forms will not be accepted.

		YES	NOT APP.
1a.	Recruitment letter / Information sheet for subjects, in English	<input checked="" type="checkbox"/>	<input type="checkbox"/>
1b.	Recruitment letter / Information sheet for subjects, in Maltese	<input checked="" type="checkbox"/>	<input type="checkbox"/>
2a.	Consent form, in English, signed by supervisor, and including your contact details	<input checked="" type="checkbox"/>	<input type="checkbox"/>
2b.	Consent form, in Maltese, signed by supervisor, and including your contact details	<input checked="" type="checkbox"/>	<input type="checkbox"/>
3a.	In the case of children or other vulnerable groups, consent forms for parents/ guardians, in English	<input checked="" type="checkbox"/>	<input type="checkbox"/>
3b.	In the case of children or other vulnerable groups, consent forms for parents/ guardians, in Maltese	<input checked="" type="checkbox"/>	<input type="checkbox"/>
4a.	Tests, questionnaires, interview or focus group questions, etc, in English	<input checked="" type="checkbox"/>	<input type="checkbox"/>
4b.	Tests, questionnaires, interview or focus group questions, etc, in Maltese	<input checked="" type="checkbox"/>	<input type="checkbox"/>
5a.	Other institutional approval <i>for access to subjects</i> : Health Division, Directorate for Quality and Standards in Education, Department of Public Health, Curia...	<input checked="" type="checkbox"/>	<input type="checkbox"/>
5b.	Other institutional approval <i>for access to data</i> : Registrar, Data Protection Officer Health Division/Hospital, Directorate for Quality and Standards in Education, Department of Public Health...	<input checked="" type="checkbox"/>	<input type="checkbox"/>
5c.	Approval from person <i>directly responsible for subjects</i> : Medical Consultants, Nursing Officers, Head of School...	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Received by Faculty office on	
Discussed by Faculty Research Ethics Committee on	
Discussed by university Research Ethics Committee on	30.3.2012

To be completed by Faculty Research Ethics Committee

We have examined the above proposal and advise

Acceptance

Refusal

Conditional acceptance

For the following reason/s:

of attached letter from UFL Ethics Committee

Signature

Date

To be completed by University Research Ethics Committee

We have examined the above proposal and grant

Acceptance

Refusal

Conditional acceptance

For the following reason/s:

Signature

David Hagan

Date

8/4/2012

Appendix 14 - Overview of narratives' thematic stanzas

<u>WILLIAM</u>	<u>LUKE</u>	<u>OLIVER</u>	<u>ISAAC</u>	<u>FRANK</u>	<u>ALAN</u>	<u>IESMOND</u>	<u>RUPERT</u>	<u>IAN</u>	<u>FRED</u>
Family planning	Family planning	Finding out he was going to be a father	Family planning	Learning about autism	Thinking of becoming a father	The first concerns (1)	Becoming a father	Finding out his wife was pregnant	Thinking about having children
Finding out he was going to father a boy	Family	First time fatherhood	The first concerns (1)	Finding out about his wife's pregnancy	The birth	The diagnosis (2)	Foresight	Providing for his family	Thinking about becoming a father
The birth	Fear of having other children (9)	Having a boy	The diagnosis (2)	Finding out about his son's autism (2)	Changes brought about by fatherhood	Anger (8)	The denial phase (1)	Becoming a father	Learning about his wife's pregnancy
The first year	A long journey towards a diagnosis (1)	Fathering another child	Uncertainty (2)	Search for answers (2)	The first concerns (1)	Autism	The search for answers (2)	Autism (2)	The 9-month wait
Regression at the age of two (1)	The diagnosis (2)	Financial responsibilities	Looking forward (3)	Lack of communication (4)	The diagnosis (2)	Relationship with his son (7)	Perceptions of autism (2)	Search for solutions (3)	The birth
The diagnosis (2)	Questions raised about the diagnosis (2)	The first concerns (1)	Getting acquainted with the condition (8)	Frustration with development (5)	Therapy (3)	Communication (4)	The journey towards acceptance (8)	The effects of autism on fatherhood (9)	Becoming a father (6)
Difficulties with getting an LSA for his son (5)	The word autism: learning about it. (2)	The diagnosis (2)	Difficulties with accepting the diagnosis & labeling (8)	The bigger picture	Search for solutions (3)	Frustration (5)	Looking for solutions (3)	Communication (4)	The first year
Difficulties with the LSA (5)	Priorities (9)	Coping with the news that his son was autistic (2)	Schooling (5)	Expectations	More self-awareness (9)	Difficulties related to autism (5)	Fatherhood (6)	Difficulties related to autism (5)	The first concerns (1)
Difficulties encountered in school (5)	Difficulties brought about by the condition (5)	The difficulties with his daughters	Fatherhood (6)	Difficulties related to autism (10)	The road to acceptance (8)	Socialization & schooling (11)	Difficulties related to autism (5)	The relationship with his children (7)	The first time he heard the word autism (1)
Mark before autism	Lack of verbal communication (4)	Hindsight (9)	Working hard to see progress (7)	Issue of family (5)	Fatherhood (6)	Strengths	The why me question (8)	Fatherhood (6)	Stress and self-blame (8)
Determination (11)	Help for his son (3)	Difficulties brought about by autism (5)	Being cruel to be kind (7)	Autism and love (7)	The effects of autism on fatherhood (9)	Fathering a child with autism (6)	Learning from experience	Authoritarian vs. Democratic parenting	The diagnosis (2)
A constant battle (11)	What would improvement mean?	Communication (4)	The ups and down (7)	Affection or sensory stimulation? (9)	Challenges (5)	Working to help his son (3)	Life besides autism	Concerns about the future (12)	Learning about the condition (2)
The search for solutions (3)	Father-son relationship (7)	Autism and his relationship with his wife (10)	Expression of affection (9)	His son and society (11)	Communication (4)	Effects of autism on his relationship with his wife (10)	The husband and the father (10)	The road towards acceptance (8)	Difficulties related to the condition (5)

Table 1: Analysis of headings of the “thematic stanzas” that composed the 10 narratives

Difficulties related to autism (5)	Husband or father? (10)	Coping with the responsibilities (9)	Benefits of early intervention (3)	Educating the people around him about autism (11)	Autism and the relationship with his wife (10)	Inclusion (11)	Autism and society (11)	Relationship with his wife (10)	Society and autism (11)
Communication (4)	Why did it have to be this way? (8)	Fatherhood (6)	Communication (4)	The question of why my son? (8)	Autism and society (11)	Autism and society (11)	The future (12)	Autism and society (11)	Autism and schooling (11)
Financial aspects of the diagnosis of autism (9)	Society's perception regarding ASD	Family life (7)	Positive affects of the diagnosis (9)	Guilt and regrets (8)	Hopes and wishes (12)	The future (12)			Hyper vigilance (9)
Mark's relationship with his son (7)	Looking towards the future (12)	The future (12)	Changes in his life because of autism (9)	The journey of acceptance (8)	Concerns about the future (12)				Trying to understand his daughter more (4)
Mark's description of his son	Trying all that he could (8)	Wishes (12)	Autism and society (11)	Being a father (6)	Coping and living with reality (8)				Why me? (8)
Being unlucky (8)		Search for solutions (3)	The future (12)	Current Scenario					Everything happens for a reason (8)
Autism and his son (9)		Autism and society (11)		Fear of having another child (9)					The responsibilities of fatherhood (6)
Guilt, blame and acceptance (8)		The question of why my children (8)		The future (12)					Crying of joy (9)
Hopes and wishes				Picture perfect (12)					The future (12)
The effects of autism on Mark's relationship with his wife (10)									
Fatherhood (6)									
Lack of awareness of autism in Malta (11)									
The future (12)									
Uncertainty (12)									

Table 1... continued

<u>Color Key for themes</u>	
<u>Events</u>	<u>Key</u>
First concerns/regression	1
Diagnosis	2
Search for solutions	3
The issue of communication	4
Difficulties contributing to stress	5
Notions of Fatherhood	6
Relationship with the child	7
Coming to terms with their children's condition	8
Affects of autism on fatherhood	9
Relationship with spouse	10
Society and autism	11
The future	12

Table 2: Events identified and color-coded

Appendix 15 - Audit Trail

