

## **University of Strathclyde Department of Counselling**

**Institute of Counselling and Psychological Studies** 

### "How Parents of High Functioning Autistic Children Experience Gordon's PET: A Qualitative Analysis"

by
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A thesis presented in fulfilment of the requirements for the degree of Master of Science in Counselling



# M.Sc. in Person - Centred Counselling & Psychotherapy

M.Sc. Thesis

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20th Group

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#### **ABSTRACT**

The present study touched upon autism, its definition and flexures, as well as its reflection on parenthood. Parenting issues relating to diagnosis, distress, family bonds, and personal growth were reviewed and programs like ABA, TEACCH and PET were briefly presented. Using the IPA qualitative method, the experiences of six mothers of high functioning autistic children under 12 years old -who successfully participated in a Parent Effectiveness Training (PET) seminar conducted in Greece, extending over ten three-hour sessions- were analyzed based on the question: "How parents of high functioning autistic children experience Gordon's PET?". The initial efforts of the interviews were focused on their experience from the program and their thoughts and feelings regarding the appropriateness of PET for the autistic community as a valid alternative to behavioural programs, as well as any changes they noticed in themselves, their children or their common interaction. Findings revealed three themes: a) from lost to found, b) beyond the parents known comfort zone, and c) within and between. In more detail, the findings discussed the participants' journey through their understanding of PET and the attributes they allocated to the seminar, their trip down memory lane describing an inner incongruence when realizing that they were trying to adopt communication skills they themselves had never experienced growing up, to finally unveiling this inner process and their efforts of growing out of it. Further, the findings highlighted the mothers' new way of interacting with their autistic children, using 'Active listening' and 'I-Messages' as well as through an internal shift that seems to have diffused in all of the mothers' human interactions. Lastly, limitations of the study e.g. chosen method and small number of participants amongst others, were considered.

**Key words**: autism, autistic child, high functioning, Asperger, parenting, parent effectiveness training, PET, Thomas Gordon, treatment.

#### Introduction

For many people, childbirth can be the trigger to a transitional phase. Parenthood, as a newly acquired configuration, however rewarding it might be, it can also challenge the positive self-concept in various ways (Mearns, Thorne, & McLeod, 2008). Many parents are faced with the task of balancing the needs of a new identity against the needs of a fully dependant significant other. This effort can become overwhelming when combined with the diagnosis of a child in the autistic spectrum disorder – ASD (DSM-5; APA, 2013).

Parents nowadays might be trained and competent professionals of all sorts but they seem to lack various forms of parenting skills. Adults are not born parents; they give birth to parenthood in an instant. However natural this may sound, the psychological endeavour behind it is rather complex and can become overwhelming (Mosca & Garnier, 2015). For parents dealing with an ASD diagnosis on top of it, things might become even trickier, because -as in any other condition and/or disorder- the fragile balance can get easily destabilized. After a diagnosis, parents go through a period of readjustment (Lee, Furrow & Bradley, 2017), being challenged to configure their own definition of autism, indulge their self-image as well as their perception for their child, during which time they need to prepare themselves for action (Fleischmann, 2005). Seeking for parenting solutions seems inevitable and PET is one of the available options; even though not one of the evident ones.

#### Aim of the Study

This study's objective is to acknowledge the experience of parents of autistic children from Parent Effectiveness Training - PET, validate their struggles and triumphs, and highlight the personal shifts and practical skills acquired from their participation based on their storytelling.

#### **Significance of the Study**

Herein lays the ambition that, by featuring the positive outcomes from the parents' experiences, PET will be gradually introduced to the autistic community as a valid alternative to the current behavioural parenting trends for addressing issues of autism (e.g. ABA, TEACCH etc.). Apart from Prouty's pre-therapy (Prouty, 1998) and Warner's fragile or dissociative process (Warner, 2000) or Gendlin's Children Focusing (Stapert & Verliefde, 2008), the acceptance of a different way of being (Rogers, 1980) as a therapeutic approach is not often encountered in autism. The Gordon Training International Organization itself, being of fundamental person-centred origins, didn't deem it necessary to address the autistic

community directly, since the program is undoubtedly open to everyone. Maybe this study, will be able to highlight the confusion and the amount of stress on parents' shoulders while trying to make the best possible choice for themselves and their children's future as well as the positive experiences of the parents that opted for PET, and communicate this to everyone who is ready to set sail for this journey of self-actualization - autistic or not.

#### **Literature Review**

This part refers to the current literature on autism and parenting. A definition of autism will be attempted, witnessing all the aspects that were deemed relevant to the present study, as well as an approach to parenting in general as compared to parenting an autistic child. Specific parenting programs will also be briefly introduced.

#### What is Autism.

The society's conception of what autism is has vigorously shifted since the beginning of the past century. The term, 'autism'-etymologically originating from the Ancient Greek αὐτός (autós, "self") and the Latin -ismus ("-ism") (Hornby & Crowther, 1995)- was firstly used by a Swiss psychiatrist to describe symptoms of schizophrenia (Bleuler, 1911), and was then reclaimed by Kanner to describe children with a distinct psychiatric syndrome he referred to as "infantile autism" (Kanner, 1943). During the same time, Asperger used the term to describe a group of children with persisting deficits in social relationships, obsessions that impeded their ability to learn, peculiarities in communication and narrow interests (Asperger, 1944). Following in their footsteps, Bettleheim also used the term to portray an emotional disorder apparently stemming from parental rejection (Bettleheim, 1967). In the following decades, research provided evidence that supported the validity of the condition, which led to its inclusion in the Diagnostic and Statistical Manual of Mental Disorders (DSM-III; APA, 1987), officially deeming it a medical condition. Currently autism is also featured in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, 2013) after undergoing several revisions.

Specifically, DSM-5 introduced two fundamental changes in the diagnosis: firstly, it assembled previously distinct autism subtypes into one unifying spectrum and secondly, the three symptom domains of social impairment, communication deficits and repetitive/restricted behaviours became two (social communication impairment and repetitive/restricted behaviours), also including a diagnostic specifier based on severity level and the level of support needed. The single diagnosis of Autism Spectrum Disorder, caused a tumult amongst clinicians, researchers, autistic individuals and parents alike (Kite, Gullifer & Tyson, 2013; Linton, Krcek, Sensui, & Spillers, 2014), whereas the constant changes seemed to underline our society's -still- limited understanding, knowledge and perception of autism.

Another important factor demonstrated in literature is the dramatic increase in diagnosis in comorbidity with attention deficit and sensory integration issues (Lin et al., 2017). In his

research on the changes in autism, Rutter (2005) reports that true proportion of autism spectrum disorders is likely to be within the range of 30–60 cases per 10,000 -a huge increase over the original estimate of four per 10,000, 40 years ago. He attributes this increase in the improved ascertainment and awareness among parents, paediatricians and educators as well as the considerable broadening of the diagnostic concept without ruling out the environmental risk factor. This coincides partly with Grinker (2016) who mainly attributes the increase in autism diagnosis in the way American doctors are diagnosing the disease, thus reflecting changes in culture and not biology. In their research Pellicano & Stears (2011) mention the overwhelming consensus among researchers that autism is a heritable disorder of neural development. The technological advances in molecular genetics, neuroimaging and neuroscience in general as well as the possibility on detecting autism via genetic test before or right after birth along with the spreading public agitation about autism prevalence has led to previously unrecorded governmental interest in autism research, i.e. funding (e.g. US - Combating Autism Act with US\$950 million to autism research; UK - Medical Research Council with £2.5 million within the past decade).

Still, whether biologically explained by the medical model, talking about disability and cure, or socially constructed by a social model, speaking about acceptance and conformity, the challenges seem to be present both to the individuals and their families and this apparently affects many of the attributes defining 'personhood' as our society understands it (Silverman, 2008).

Autism and Linguistics. The different social and ideological beliefs about autism seem to have an impact on the language people use to describe the condition (Kenny et al., 2016). Kenny at al. (2016) conducted a large online survey with the participation of 3,470 UK residents seeking to find the views and preferences of UK autism community members about their preferred ways of describing autism as well as their rationale behind it. The results indicated that people tend to characterize autism differently based on their role and involvement. More precisely, the term "autistic" -as opposed to neurotypical- was endorsed by a large percentage of autistic adults (61%), family members/friends (52%) and parents (51%) but by considerably fewer professionals (38%). In contrast, "person with autism" was endorsed by almost half (49%) of professionals but only by 28% and 22% of autistic adults and parents, respectively. The reasons behind these decisions, retrieved by the qualitative thematic analysis conducted in the framework of the same study, seem mainly conceptual. Autistic adults tended to consider autism as intrinsic to the person, renouncing the notion of a

disorder, and favouring a different way of seeing the world. Some described their autism as a disability, while others accentuated the role of society in creating and/or maintaining that disability; others noted reluctantly the need to describe autism as a disability in order to gain access to services. Many professionals indicated that person-first language (e.g. 'person with autism', 'has autism') should be used to describe autism because the person should always come first and the condition second. Still, they were uncomfortable with the use of the terms 'disorder' and 'disability' which could falsely suggest that it is something that can be cured. Strikingly enough, the most divided group was that of the family members mainly disagreeing on the extent to which autism was considered a part of a person's identity. For some family members, autism was inseparable from their child, others felt it should not define their child whereas others preferred to view it as something that is treatable. Leaving social commentary aside, these findings demonstrate that there is no single way of describing autism that is universally accepted and preferred and they also highlight the power of language both on reflecting as well as in shaping perceptions, e.g. observing the use of storytelling and metaphors to describe autistic people as 'aliens from a different world', or 'being locked inside' (Broderick & Ne'eman, 2008).

Autism and Self-advocacy. A significant shift of the past decades is the outburst of (auto)biographies, articles and social media references drafted by autistic people and/or their family members. These self-advocates are mostly promoting the notion that autistic people have social and sensory attributes that are so foreign to neurotypical experience as to be characterized extra-terrestrial. In the past years, many self-advocates like Jim Sinclair (1993), Martijn Dekker (1999), Temple Grandin (2004), Amanda Baggs (2007) and Grinker (2016) -among many others- have demonstrated their autistic experience as a different -yet still valid- way of interacting with others in terms of neurodiversity as opposed to neurological disability (Baker, 2006). Members of this autistic culture are also rejecting the notion that the autism spectrum is separated in categories of 'low-functioning' and 'high-functioning', stating that intelligence is underestimated and widely misinterpreted in autistics (Dawson, Soulières, Gernsbacher, & Mottron, 2007). Literature on psychological testing suggests, likewise, that estimates of the level of mental retardation in the population diagnosed with autism may be a reflection of the testing instruments, which demand performance in areas that are most affected by autism and devalue those domains that reflect autistic strengths (Dawson et al., 2007). Self-advocates also dismiss the idea of primary deficit in empathizing (BaronCohen & Wheelwright, 2004) as well as the idea of emptiness and isolation which is commonly connected to autistic people (Nickrenz, 2007). Still, in this context, we should take into account that a large number of autistic individuals are non-verbal, thus are unable to participate in this debate. We should also bear in mind those self-advocating individuals who wish to get 'rid of autism' and just 'be normal' (Humphrey & Lewis, 2008).

On these grounds, perhaps we should consider and maybe (re)define the terms 'diversity' or 'difference' as a society. Since the autism riddle is yet to be solved, juggling between a diagnostic category, a neurological disorder, a mental state, or a species in the neurodiversity frame, Silverman suggests (2008) that research on autism should not be limited to psychology, but also dive into the fields of genetics, neuroscience, linguistics and immunology including professionals in developmental paediatrics, neurology, behavioural\occupational therapies, and alternative medicine and combine the results.

#### **Treatment Suggestions in Autism.**

Among medical historians it is commonly acknowledged that the anticipated efficacy of various therapies alters over time. From Bettelheim's 'Empty Fortress' (1967) to Henry's 'Pathways to madness' (1973), Welch's 'Holding time' (1989), Maurice's 'Let me hear your voice' (1994), Esch & Carr 'Secretin as a treatment for autism' (2004), Golan & Baron-Cohen 'Systemizing empathy' (2006) etc., there are many controversies over autism therapies. As Silverman & Brosco (2007) state, maybe we should look into how therapies emerge as preferred options and/or how various techniques are set out. Maybe it would be safe to say, that in autism there is one set of therapies and approaches addressed directly from a professional to the child and another set of programmes addressed to the parent-child relationship and/or the parents' enhancement as such. Parents are the ones to decide on the appropriate approach to tackle the autistic manifestations of their own child as well as themselves. A research by Wilson, Hamilton, Whelan and Pilkington (2018) identifies that severity of the behavioural problems, parental stress, and parent beliefs about ASD are associated with the choice of treatment which is greatly complicated by misinformation and easy access to low cost ineffective treatments. Or as Edwards, Brebner, McCormack and MacDougall (2018) put it, this decision making is evolving over time as parents are transformed from parents to experts and consider seven core aspects: values, experience, information, motivation, understanding, needs and logistics.

**Recommended Programs for Parents of Autistic Children.** ABA and TEACCH are among the most visible and frequently cited autism intervention programs in literature, as well as among the most broadly implemented in public treatments by service providers, teachers and parents (Choutka, Doloughty & Zirkel, 2004; Callahan, Shukla-Mehta, Magee & Wie, 2010).

**ABA.** A commonly recommended and widely used form of treatment for parents and/or professionals advocating in favour of the medical model is a broad set of principles and guidelines called ABA - Applied Behaviour Analysis (Vismara & Rogers, 2010). ABA is not a therapy for autism (Chiesa, 2005), but a range of techniques for a variety of diagnoses and it is addressed mainly to the diagnosed children and not directly to their parents. In their article Axelrod, McElrath and Wine (2012) define ABA as the direct application of behaviourism to the improvement of human behaviour as the philosophy of the science of human behaviour and contends directed by Skinner (1975). 'Applied' stands for trying to cause positive change in socially significant behaviours, 'Behaviour' is what changes over time by observation and measurement and 'Analysis' refers to the way the evidence is collected and evaluated to show results (Dillenburger & Keenan, 2009). ABA is a one-onone, intensive, structured teaching program based on behaviour modification and reinforced practice of different skills. ABA models include specific programs like Pivotal Response Training (PRT), Floor Time (FT), Early Start Denver Model (ESDM), Discrete Trail Training (DTT) etc. and cover areas like functional communication, script/script fading, selfmanagement, behaviour chaining, errorless learning, reinforcement systems and activity schedules (Masgutova, Akhmatova, Sadowska, Shackleford & Akhmatov, 2016). Other ABA associated models are Lovaas Therapy (Lovaas & Smith, 1989), Developmental Individual-Difference, Relationship-Based (DIR) Therapy (Pajareya & Nopmaneejumruslers, 2011), Augmentative and Alternative Communication (AAC) (Beukelman & Mirenda, 2005) etc. In a study on parental assessment of behavioural interventions (Shepherd, Landon, Goedeke, Ty & Csako, 2018), parents reported the highest expectations, satisfaction and stress reduction rates with intensive ABA.

**TEACCH.** Another fairly new alternative -again behaviourally based- is the public health program of North Carolina, USA, called Treatment and Education of Autistic and Communication Handicapped Children - TEACCH (Schopler, Mesibov & Hearsey, 1995; Panerai, Ferrante & Zingale, 2002). It is an integrative, evidence-based training and research program for ASD individuals of all ages and skill levels developed around the idea of

structured teaching. The main goal is to maximize independence and the main innovation is including the parents as well (Mesibov, 1997; Mesibov & Shea, 2010).

Humanistic Approaches for Parents of Autistic Children. Apart from Prouty's pretherapy (Prouty, Van Werde & Pörtner, 2002) and Warner's fragile or dissociative process (Warner, 2000) or even Gendlin's Children Focusing (McGuire, 1986), the acceptance of a different way of being (Rogers, 1980) as a therapeutic approach, is not often encountered as a valid alternative to the current behavioural trends for addressing the issue of autism. For example, PET is not primarily -or even at all- addressed to the autistic community. Still based on the three core conditions of empathy, congruence and unconditional positive regard (Cooper, O'Hara, Schmid & Wyatt, 2007), PET seems to be touching upon one of the main debates in autism, i.e. the empathic (or not) ability of the autistic people. Recent social neuroscience studies have attempted to explore the three conditions from this perspective by studying the neural mechanisms of empathic brain responses and by outlining neuronal networks of affective and cognitive processes (Silani, Zucconi & Lamm, 2013)<sup>1</sup>. From the theory of mind and the extreme male brain theory identifying two psychological dimensions

Rogers' concepts	Cognitive processes	Brain areas
Empathy	Emotional sharing Self-other distinction Perspective taking	AI, MCC TPJ, PFC MPFC, TP, TPJ
Congruence	Self awareness Self-other distinction	MPFC, TP, TPJ TPJ, PFC
Acceptance	Emotion regulation	DLPFC, OFC

Al: anterior insula, MCC: mid cingulate cortex, PFC: prefrontal cortex, MPFC: medial prefrontal cortex,
TP: temporal poles, TPJ: temporo-parietal junction, DLPFC: dorso-lateral prefrontal cortex, OFC:

orbitofrontal cortex

(Silani et al., 2013)

(empathizing and systemizing), suggesting that autistic people show an exaggerated male profile (S >> E). (Baron-Cohen & Wheelwright, 2004) to the intense world syndrome talking about hyper functionality and a hyper responsive amygdala suggesting that autistic people use avoidant patterns of attention to restrict empathic arousal due to empathic surfeit (Smith, 2009), the issue of empathy in autism remains an open question.

#### **Brief Presentation of Parent Effectiveness Training (PET).**

Rooted in the teachings of Carl Rogers (1951), Dr. Thomas Gordon's Parent Effectiveness Training (PET) utilized this material to create a communication method divided into five well-defined areas of concern depending on who owns the problem recommending a different set of skills for each area (Gordon, 1970; Gordon & Sands, 1976). It offers a set of communication and conflict resolution skills for helping parents develop and maintain mutually satisfying relationships with their children. The basis of the conceptual model is formed by following principles (amongst others): behaviour window for dealing with all kinds of behaviours, idea of problem ownership, active listening, 12 communication roadblocks, congruent expression of true feelings, avoidance of labels and/or judgments, 'I' messages vs. 'You' messages, modification of physical environment for prevention of conflicts, 'No Lose' method of conflict resolution, no problem area, handling of values differences through modelling and/or consulting, specific non-verbal communication for infants etc. The intensive PET training consists of brief lectures, workbook exercises, demonstrations, role-playing, coaching, homework and small group discussion resembling encounter groups (Lemmens, 2011) spanning over ten three hour sessions in Greece.

Although the model was deemed revolutionary for its time as Cedar and Levant suggest in their meta-analysis on the effects of parent effectiveness training (1990), there is limited published research literature on PET. The most recent papers, reported greater confidence of the parents in their abilities (Rob & Norfor, 1980), acquiring new abilities in communication, problem solving and conflict resolution skills (Wood & Davidson, 1987), and also changes from the traditional role of parent to a newly acquired attitude which encourages emotional competence and self-control in children (Wood & Davidson, 2002). Criticism on Gordon's PET mentions that it technologizes the parent-child relationship and presents a simplistic way for handling all sorts of parent-child problems (Doherty & Ryder, 1980) or that it represents a prevention rather than intervention effective model with questionable outcomes (Cedar & Levant, 1990).

A couple of surveys - like Pinsker & Geoffroy (1981) comparing PET and behaviour modification parent training, and Mooney (1995) reviewing Adlerian, parent effectiveness and behavioural training - came to the conclusion that no particular parenting program was deemed significantly better than the other due to their very different philosophical backgrounds, thus making it difficult to compare them as a whole; each program evidenced different highs and lows in the various scales.

#### Family and Autism.

The importance of parents in the lives of their children has been so accented nowadays, that common sense approaches to parenting appear hopelessly simplistic and inept, even reckless (Golding, 2000). Adults become parents in an instant and what may seem as a natural transformation is in fact the result of a complex psychological endeavour, with dangers and snags, but also evolution possibilities (Mosca & Garnier, 2015). This transition to parenthood is not only manifested in a person's life, but also in the couple's life. Many couples struggle to adjust to parenthood and report feelings of dissatisfaction with their relationship (Miller & Sambell, 2003). And these are all parents not faced with a diagnosis - yet-, because parenting a child in the autistic spectrum seems to be bearing an increased risk factor for high levels of stress in comparison to parents of children with other and/or no developmental disabilities (Davis & Carter, 2008; Hastings, 2003).

Parenting an Autistic Child. The difficulty that an ASD child displays in relating to others is unique to the diagnosis of ASD. This feature is manifested with impairments in socialization skills, joint attention skills, communication skills, functional play, sensory processing, self-regulatory problems, behaviour problems and/or even tantrums and public outbursts (Estes et al., 2009; Hastings, 2003; Lecavalier, Leone, & Wiltz, 2006; Trillingsgaard, Sørensen, N´emec, & Jørgensen, 2005). All these combined with increased time and effort demands on the parents correlating to participation in various therapies (e.g. occupational, speech therapy) have been associated with higher levels of reported parental stress (Davis & Carter, 2008; Brobst, Clopton & Hendrick, 2009; Sawyer et al., 2010). Talking in numbers, in the quantitative study of Mori, Ujiie, Smith, & Howlin (2009) on parental stress associated with caring for children with Asperger or autism, the researchers resulted that 67% of parents in their Asperger group and 57% of parents in the autism group scored total parental stress at or above the 90th percentile compared to the normal parental stress scores. Unexpectedly, the total parental stress levels indicated higher rates in parents of

children with Asperger syndrome than in parents of children with autism. This particular finding is also backed up by another study on parenting stress and high functioning autistic children, which resulted that apart from their practical and emotional well-being, these parents expressed many concerns regarding their children's' behaviours and needs (Bundy & Kunce, 2009). The results of another study (Sigurðardóttir, 2017) conducted in Iceland on stress, anxiety, depression and social constraints in parents of children with autism indicated, due to elevated parental stress of 79%, the need to provide these parents with training and support as well as access to an intervention to reduce their stress, anxiety and depression levels. Similar suggestions in assisting parents to develop psychological resilience while dealing with the stress associated with parenting their autistic child were made by Bitsika, Sharpley, & Bell, (2013) in their study on resilience upon stress, anxiety and depression in parents of ASD children.

Marital Relationship of Parents of Autistic Children. Acute and/or persistent stress has a negative influence on the parents' relationship (Meadan, Halle, & Ebata, 2010) and is related to higher divorce rates (Hartley et al., 2010) or even lower relationship satisfaction than other parenting couples (Brobst et al., 2009). This means that parents of children in the autistic spectrum are more likely to experience divorce (23,5% as compared to 13,8% of couples without the ASD factor) and decreased relationship satisfaction in terms of harmony and agreement than parents of children with other or without disabilities. Karst and Van Hecke (2012) reported that the parental role confidence is challenged in parents with ASD children who seem to undergo higher risk for mental health disorders, such as depression and anxiety.

Several other studies strongly suggest that a marital relationship might start deteriorating under the pressure and the energy required to raise an ASD child because of their apparent focus into the needs of the child and away from their relationship (Churchill, Villareale, Monaghan, Sharp, & Kieckhefer, 2010; Daire, Dominguez, Carlson, & Case-Pease, 2014). In their recent study on EFT for parents raising an ASD child, Lee et al. (2017) resulted that all their couples struggled to maintain emotional connection while serving parental demands linked to caregiving. According to the study's thematic analysis, wives expressed feelings of loneliness in bearing the primary responsibility for medical treatment and caregiving, while husbands seemed to consider this as over involvement on their wife's side, which gradually led them to emotional check-out. Alienation, isolation, disconnection within the couple due to their experience of parenting and special caregiving progressively

led them to put their relationship on hold. Some partners, extended these feelings of alienation to relatives and friends outside their relationship, who according to them withdrew and failed to understand what the couple was struggling with on a daily basis, leading also to social isolation, frustration and a generalized feeling of lacking support. This finding is conforming with literature indicating that these parents often encounter family and friends who withdraw, instead of creating and maintaining a much-needed support network (Boyd, 2002; Dunst & Trivette, 1994). In "living in a world of our own," parents described a world of isolation. (Woodgate, Ateah & Secco, 2008). Another survey on parents of autistic children (Gray, 2002) results that parents still experience stigma, even though somehow minimized, e.g. due to recent findings on the genetic basis for autism shifting the stigma away from parents and towards factors beyond their control.

Siblings of Autistic Children. These stressors might not affect only the couple's relationship but also the siblings' role within the family (Tomeny, Barry & Fair, 2017). In their research on siblings of ASD children, Tomeny et al. (2017) state that the life of ASD siblings can be negatively influenced, ranging from behavioural problems and feelings of rejection to severe psychopathology lasting into adulthood, all related to their parentification within the family (Hooper, 2012). These early childhood experiences seem to have both current and lasting impacts on these children (Portner & Riggs, 2016). A qualitative study on siblings' perspectives found that brothers -in particular- reported their struggling with aggressive behaviours, whereas sisters reported difficulty in coping with communication shortfalls (Ward, Tanner, Mandleco, Dyches & Freeborn, 2016). Still, not all findings are negative. For example, a qualitative study focusing on adolescent sisters of ASD children reported both feelings of under-appreciation and burnt-out related to their care giving roles, as well as positive feelings and pride simultaneously (Cridland, Jones, Stoyels, Caputi & Magee, 2015).

#### Receiving a Diagnosis.

The couples of the EFT survey (Lee et al., 2017) also portrayed their initial joint efforts of making sense out of how their lives as a couple and as a family had been influenced by the ASD diagnosis, making reference to a survival mode and constant anxiety. According to the study, they also expressed the need to grieve over the loss of not having a normal child or parental role, as well as the need to give a new definition to this unexpected experience. This diagnostic process factor, arose as a theme in other studies as well. Unlike other diagnoses

(e.g. Down syndrome), the diagnosis is not provided immediately and the families experience strenuous processes (Braiden, Bothwell, & Duffy, 2010; Moh & Magiati, 2012), involving attaining opinions from multiple professionals which may even be contradicting when the importance of effective partnerships between parents and professionals should be highlightened and even strengthened (Gavidia-Payne, 2013). Da Paz, Siegel, Coccia, & Epel (2018) are questioning whether the maternal adjustment on an ASD diagnosis will set on acceptance or despair, resulting in their study that the whole process has significant implications on the parents' health. In their research they identified three dimensions of adjustment (acceptance, self-blame, and despair) among which acceptance was deemed protective -despite the limited research on how to increase acceptance of one's child's diagnosis- whereas increasing levels of self-blame and despair about the diagnosis led to worsening of mental health and satisfaction with life. In their research on parent mental health and its relationship to a trauma-based conceptualisation, Stewart, McGillivray, Forbes & Austin (2016) suggest that this parenting experience may be directly related to anxiety, depression, anger-hostility and somatisation due to their exposure to traumatic events (e.g. ASD child's self-injury, suicidal ideation, etc.). Another survey (Casey et al., 2012) supports this claim as well by researching the parental symptoms of posttraumatic stress following a child's diagnosis of ASD and finding that it reached about 20%.

In a survey conducted in UK by Crane, Chester, Goddard, Henry, & Hill (2016) using an online sample of 1,047 parents and measuring their experiences of autism diagnosis, the results revealed that the average 3.5 years process from first encountering a professional till actually receiving a diagnosis (with Asperger diagnosis experiencing an even longer diagnostic delay due to their intellectual ability) led -amongst others- to parental frustration, trust issues and high levels of dissatisfaction with the whole procedure. In this regard, Moh and Magiati (2012), resulted that if parents were included in their children's' diagnostic process (e.g., if the information gathering process was explained) the likelihood of elevated stress was diminished. Furthermore, the survey indicated that taking into account the information currently globally available regarding ASD parents were to 61% unsatisfied with the post-diagnostic information received - which is generally a major area of parental concern (Jones, Goddard, Hill, Henry & Crane, 2014).

#### Parents' Cognitive Processing of the Experience.

The mothers of autistic children storytelling in the research of Marshall and Long (2010) revealed a meaning-making processes that surfaced over time, as mothers came to terms with their children's autism. Generally, when encountered with a stress factor such as an ASD diagnosis, parents may come across one of the most demanding disorders in terms of threats to parents' well-being and mental health (Seltzer, Krauss, Orsmond, & Vestal, 2001). Their beliefs may inevitably undergo a revision process in order to enhance survival. In cognitive terms, this process may follow several procedures, e.g.: a) the "Stress, Appraisal and Coping Model" of Lazarus and Folkman (1984) focusing in cognitive processes of dealing with a stressful situation by adopting an attitude of a continuous effort to balance the demands with the available resources, b) the "Dual-Process Model of Coping with Bereavement" of Stroebe and Schut (1999) bearing as central component the dynamic, backand-forth process of either confronting the loss or avoiding the memories and seeking relief elsewhere (Shear, 2010), and c) the synthetic "Meaning-Making Model" of Park and Folkman (1997) which is sorted in two categories, the global meaning for life and the situational meaning as well as the inconsistency between these two (Park, 2010; Park & Folkman, 1997). In their research Costa, Steffgen & Ferring (2017) also reported how different factors that are related to having a child with ASD interact and can determine parents' stress and well-being.

As stated in literature, this process initiated by a traumatic event or stressor (e.g. diagnosis) is ever evolving and not necessarily permanently detrimental. In his qualitative research on post-traumatic growth in a person-centred context, Makris (2017) mentions four major milestones in this regard, namely (a) growing through trauma, (b) importance of human connection, (c) growth as a process and (d) reinventing one's self mainly focusing on the importance of developing a protective and facilitative frame to permit growth enhancement as such. Similarly, in his research on the effects of PET beyond communication skills, Papagos (2014) observed a process of change and becoming, suggesting the existence of a process of personal growth in line with the principles of the humanistic approach and the characteristics of a fully functioning person as described by Rogers (1995): increased openness to experience, increased existential living and increased trust in the organism.

#### Parental Copying Mechanisms and Group Imprint.

In tune with their organismic selves and their actualizing tendencies towards expansion, effectiveness as well as survival (Rogers, 1957; Brodley, 2000; Mearns & Thorne,

2000), parents of autistic children utilize a variety of coping strategies to encounter diagnosis and autistic manifestation, some of which seem common to the parents of children with other disabilities, (Landsman, 2005).

On a fairly recent survey conducted in Greece by Papageorgiou and Kalyva (2010) on the self-reported needs and expectations of parents, most of them mentioned that their reasons for participating in groups were that they wanted to be informed about developments in the area of ASD, socialize with other parents that face the same situation, receive practical support and advice as well as psychological support. The survey revealed that 1/3 of the parents had not disclosed to people from their work environment that they have a child with ASD afraid of stigmatization. Another finding was that parents of girls expressed the expectation to improve their child's condition, whereas parents of boys felt a bigger urge to meet with other parents in order to gain a better understanding. The authors argued that the parents of girls had reached faster the acceptance stage of mourning, compared to the parents of boys who were still in the denial or bargaining stages of mourning and were looking for an explanation for what was happening to their children, rendering this to the deeply rooted gender division of the Greek society.

Amongst the various coping mechanisms, including a range of narrative strategies for conceptualizing their child's autism and their relation to it, Gray (2002) mentions attempts to restrict information or even opt for selective disclosure of the situation, efforts to give the impression of a normal family, restriction of social life amongst understanding friends and/or relatives or joining of self-help groups. Parents of children with self-injurious behaviour, sleep problems or severe language deficits were more likely to take part in support groups. (Mandell & Salzer, 2007). Bristol, Gallagher, and Holt (1993) found decreases in depression symptoms of mothers following psycho-educational programs and Feldman & Werner (2002) report that parental levels of self-efficacy increased following parent education programs. Mothers reported, however, how they constantly have to balance between doing everything for their child with ASD and being a normal family (Meirsschaut, Roeyers, & Warreyn, 2010). Mackintosh, Myers, and Goin-Kochel (2006) report that seeking support from other parents helped these parents reduce levels of stress.

Huws, Jones and Ingledew (2001) in their survey on parents of autistic children using an email group indicate that the group functioned mainly in making sense of autism, i.e. seeking help in looking for meaning, adjusting to changes, providing support and sharing experiences. Examining 33 self-published websites by parents of autistic children by means

of grounded theory, Fleischmann (2005) reports a process that parents undergo which relates to the description of Catford and Ray (1991) regarding hero's development. After diagnosis, parents go through a period of readjustment following which they prepare themselves for action as stated by Fleischmann (2005). According to the study, the internet allowed them to liberate themselves from their isolation, undergo an emotional metamorphosis, changing their perceptions of autism, their self-image, their perception for their child and celebrate this change by reaching out to help others. In order to realise an optimal development for their child with ASD, parents become 'super' parents, trying to learn everything about autism in order to be prepared for everything and adjust their life to the needs of their child (Woodgate et al., 2008). Mothers' experiences suggest that advocacy and activism may be experienced on a continuum. For many mothers, advocacy and activism are a major part of the experience of mothering a disabled child, i.e. their parental configuration. (Ryan & Cole, 2009).

#### **Research Question.**

Pursuant to the above-mentioned literature review, congruence, unconditional positive regard and empathy (Rogers, 1959) as embedded and dispersed through PET can potentially create a safe enough environment of a parent-child relationship, to support parents in order to help their autistic children unleash their full potential by testing new communication tools connecting them to the rest of the world. The model's philosophy also addresses the experience of the parent, whereas in the other models like ABA this parameter seems underestimated.

For this reason, the present research addresses following research question:

"How do parents of high functioning autistic children experience PET's Parents Effectiveness Training?"

#### Method

This section is dedicated to the method and the methodology tools that were selected for the completion of the present study. Ideally, the methods implemented should be fully substantiated by the relevant methodology and, vice versa (Carter & Little, 2007), so this part will attempt to establish that.

As aforementioned, the aim of this research is to shed light on how parents of high functioning autistic children experience Gordon's PET. A qualitative analysis giving form and meaning to mundane experiences (McLeod, 2011) seemed like the best alternative, since it offers an accessible approach to analysing and understanding unique, personal, subjective experiences in fields marginally researched (Creswell, 2013). Displaying the way the participants comprehend and analyze their own experience, as well as the sense they make out of it (Merriam & Tisdell, 2016; Willig, 2008) based on their own perception (Denzin & Lincoln, 2013), lays in the heart of a qualitative analysis. Relating the fields of qualitative analysis and counselling, Thorpe (2013) claims further that the experience of conducting a qualitative research is enriching the therapeutic competencies of the person conducting the survey, while Bowers, Minichiello, & Plummer (2007) report that the findings and the realizations which emerge through a qualitative analysis constitute reflection material of vital importance for the developing counsellor. McLeod (2001) agrees also stressing the fact that the deconstruction and reconstruction procedures taking place while conducting such a survey are an asset in the field of counselling and psychotherapy in general.

#### Sampling.

For the purposes of sampling, as suggested for an undeviating research (Creswell, 2013), I contacted some autistic organizations (e.g. Greek Autistic Adults) but unfortunately none of them were familiar with PET. I also contacted Gordon Hellas to introduce me to instructors and direct candidates as well as fellow colleagues who are regularly conducting PET seminars to help me identify, narrow down and select prospective candidates that seem particularly related to my field of interest (Creswell, 2013). I needed i) parents, ii) who had fairly recently concluded a PET seminar, iii) had at least one autistic child under 12 years, iv) which preferably classified in the high functioning/Asperger spectrum. It turned out that no sampling strategy was going to be necessary as the number of likely candidates amounted to a round zero. Apparently, there had never been a PET seminar addressed particularly to parents of autistic children in the past and parents attending the regular seminars didn't

identify themselves as such. So, according to Gordon Hellas, there was no way of knowing amongst the approx. 4,500 Gordon's graduates of Greece who was a parent of an autistic child. I addressed Gordon Training International in the USA with the same question, and I got the same answer.

#### Recruitment.

While searching for ways to identify potential candidates, I contacted several personcentred counsellors that specialize in autism but none -apart from one- could suggest a suitable candidate. Only one fellow person-centred counsellor who has a previous background in special education, is a certified PET instructor and works exclusively with autistic children and their families was excited with the idea and assumed without hesitation the role of the recruiter. We did a screening of potential candidates together and decided on six people that qualified. She contacted them immediately and they were all more than willing to offer their insight. After her initial introductory phone call, I contacted each participant separately by phone providing a detailed description of the study's scope as well as the interview's procedure, highlighting issues regarding confidentiality and risks as well as assets deriving from a potential participation. We set a convenient date and place for our meeting and I sent them the information sheet (Appendix 1) as well as the interview questions (Appendix 1) per e-mail in advance.

From the six contacted candidates, all six were willing to participate. They were all women aged from 38 to 45 years old, with at least one high functioning autistic/Asperger child, that had successfully concluded a PET seminar within the past two years. Five out of six children were at the time teamed up by the aforementioned counsellor to a social skills group meeting every Wednesday for two hours, so five out of six mothers met each week. For this reason and for avoiding any compromising, all interviews were conducted within one week between the Wednesday meetings.

Some demographics regarding the sample of this study are offered in the following Table 1. All names were deleted and replaced by acronyms to avoid identification.

**Table 1**Participants

Acronyms	Age	Education Level	PET	Marital Status	Number of children	Number of autistic children
SWT	38	Higher educ.	successfully	Married	2	1
		(Bachelor's)	concluded			
SPR	45	Higher educ.	successfully	Married	2	1
		(Phd)	concluded			
GDS	40	Higher educ.	successfully	divorced	4	3
		(Bachelor's)	concluded			
LST	40	Higher educ.	successfully	Married	2	1
		(Master's)	concluded			
TTP	43	Higher educ.	successfully	Married	2	1
		(Master's)	concluded			
EXT	39	Higher educ.	successfully	Married	1	1
		(Bachelor's)	concluded			

#### Interpretative Phenomenological Analysis (IPA).

Profoundly phenomenological, hermeneutical and idiographic (Pietkiewicz & Smith, 2012; Smith, Flowers, & Larkin, 2012), the Interpretative Phenomenological Analysis (IPA) was deemed the most appropriate amongst the various qualitative methods to approach the scope of this particular study leaning on the aspiration to fully comprehend the holistic way parents of autistic children make sense of their own experiences (Barker & Pistrang, 2015) and link those to my research question by unavoidably including my own frame of reference while interacting one-on-one or through interview transcripts (Willig, 2013). The IPA method underlies the dynamic and active role of the researcher (Smith, 2004), acknowledging the centrality of her role throughout the whole the research process, the hermeneutic stage and the analysis (Brocki & Wearden, 2006; Finlay, 2002; Pietkiewicz & Smith, 2012). Bearing that in mind, the research result is conceived as a co-creation of the participants, the researcher and their interaction (Finlay, 2002).

The effort to indulge in the participant's subjective interpretation of a phenomenon (Creswell, 2013) and simultaneously decode that given meaning for one's self is one of the

most important characteristics of an IPA study (Smith & Osborn, 2008). The term "double hermeneutic" is widely used to describe this process of making both sense of the participant's and the researcher's experience at the same time (Smith, Flower & Larkin, 2009). This dynamic and dual facet process (Smith, 1996) involving both the participants' ability to adequately and lucidly articulate (Baillie, Smith, Hewison, & Mason, 2000) as well as the researcher's skills to reflect and analyse was the main reason IPA was chosen for this study.

In an IPA study, whether directed to an individual or a very small group, it is imperative for the participants to have common experiences (Smith & Osborn, 2004). The topic should be clearly defined and addressed to a limited appropriate target group of six to ten participants (Creswell, 2013). The interviews ought to be semi-structured allowing the participants to fully express all aspects of their experiences, which at a later stage are in depth analysed and ideographically processed and blended together by the researcher (Willig, 2013).

#### Interviews.

A pilot was conducted for the testing of the questions and the general flow of the interview in order to avoid and/or prevent any misunderstanding or confined answers from the participants (Fassinger, 2005). Since I wasn't acquainted with any participant, I took some time at the beginning of each interview meeting to introduce myself and repeat in more detail what I had already explained over the phone, regarding confidentiality, potential risks and probable benefits from the participation. I particularly stressed out the factor of voluntary participation and indicated that they would be able to withdraw their participation at any time prior to the submission of this study without stating any reason. One copy of the information sheet (Appendix 1) was then thoroughly read by me out loud, I answered all questions and both copies were then duly signed by both me, the researcher, and the participating party and each kept a copy. All interviews were conducted face-to-face and lasted from 45' to 1h 45' and were digitally recorded with the participants' permission.

During the interviews I used the semi structured questions I had already sent to the participants for reference. According to the IPA bibliography (Smith et al., 2012), the questions should be open-ended and non-directive with the purpose of facilitating the participant's own flow and storytelling. Still, the drafting and later on using of the questions during the interviews was a riddle to me and I found little comfort and guidance in the IPA bibliography. The reference to 'minimal probes' by Smith and Osborn (2004) was pretty

ambiguous to me, so after thoroughly discussing it with my supervisor I came up with 11 questions (Appendix 1) which I thought would provide some sort of guidance to the participants without interfering. Amongst others, these included the meaning they would give to the polysemous term 'autism' according to their experience, the reason that led them to PET, their experience from the program, any particularly helpful or none helpful aspects for autistic children, any noticeable changes in them or in their relationship with their child upon completion. During the interviews, I tried to follow each participant's flow and adjust, delete or add clarifying questions (e.g. "You mean... did I understand that correctly?" or "Could you tell a little bit more about that?") when I felt it was necessary (Pietkiewicz & Smith, 2012). Upon completion, I dedicated again some time to check with the participants how they felt about the whole experience and answer any newly arisen questions.

#### Textural analysis.

As a first step of data analysis, all digitally recorded interviews were downloaded on an especially dedicated and password secured folder on my PC and were transcribed. I listened to each voice file while reading through the transcript several times trying to optimize omissions, make sure I had noted changes in hue and all the non-verbal signs I could remember. I also made sure I had left a margin on the page for later comments.

In an IPA analysis, the focus should primarily lay on the participants world since "there is no attempt to test a predetermined hypothesis [...]; rather to explore" (Smith and Osborn, 2004, p. 53). Another prerequisite is the close interaction between researcher and text (Smith et al., 2012). Bearing that in mind, I read through all transcripts over and over again, keeping notes on the margin of each one separately. I underlined words and/or phrases and noted anything that sounded important or intriguing or related to my study question. I also noted my own thoughts, feelings and insights as well as ideas. During this process, groups of related issues I thought I had detected in more than one transcripts started forming in my mind as different units and I created little trees of thoughts and phrases in an extra spreadsheet, thus giving it some sort of form or structure (Willing, 2013). After the initial brainstorming, I started experimenting with labelling and the formation of ordinate and subordinate, i.e. more in depth, subjects focusing mainly on recurrent concepts. During this synthetic process, I tried to decode each participant's saying and go a step further each time. Anything new that emerged was noted as a different concept and was compared to the previous one. After several and pretty complex attempts, I created a draft structure by blending together what I

thought captured the essence of all the different transcripts, which was later on finalized with the help of the incredibly helpful insight of my supervisor.

#### Researcher Reflexivity.

The present study was my first effort to conduct a qualitative survey and it was a challenging one. After conducting the first interview I realized that I struggled to find my centre and/or my role and I was balancing between the empathic counsellor and the intrigued researcher for quite some time. I realized I needed to develop a new way of listening as well as responding, and thus quickly. The fact that I took six interviews -lasting up to almost two hours- in eight days was a rather ambitious plan due to inexperience. It was very demanding, both physically and mentally, and it almost caused me a burn out before I even began.

I have to admit that I wasn't initially aware of the amount of time and commitment it would require on my behalf and I found myself juggling between that and my daily obligations in numerous occasions and with dubitable results.

The fact that I'm also familiar with the issues of parenting and autism -both personally and professionally-was another initial concern. I was concerned whether I would be able to keep the necessary distance and avoid feeling sympathetic instead of empathic or even speaking on behalf of the interviewees instead of with and/or through them. Taking a step back on various occasions was important. On the other hand, this is exactly what helped me to skilfully avoid pitfalls like the autism jargon or the babbling around on interesting still irrelevant issues to my research question. I found it easy to spot the potential areas of interest, politely inviting the participants to further elaborate on that, especially during the interviews. Further, the fact that I've been trained as a person-centred counsellor, Emotionally Focused Couples' therapist, focusing companion -both for adults and for children-, as well as a PET certified instructor gave me a wider perspective of issues encountered by the parents of autistic children and it guided me through this whole procedure.

Being able to discuss this whole process with friends and colleagues as well as with my supervisor and my personal therapist was a blessing. I don't think I would have been able to do it otherwise.

#### Ethical issues.

The interviews assessment was conducted bearing in mind the Yardley (2000) criteria referring mainly to sensitivity to context, commitment and rigour, transparency and coherence and every effort was made to adhere to these principles. Further, according to

Yardley (2000), a research is deemed as important if it has an impact on the actions of the people it is directed to and if it offers new ways of comprehending the topic. Indeed, regarding their impact and importance, the findings of the present study have substantial information to offer and could potentially alter the way parents of autistic children regard parenting and what they deem as helpful. The present research has also a lot to offer to colleagues working with clients like that. The credibility and the validity of the method is based on the prerequisite that the research is conducted in an ethical manner (Merriam & Tisdell, 2016). In the framework of this study, I made every possible effort to ensure confidentiality and retain the anonymity of the participants. All the names were replaced by acronyms -even in the transcripts- and I tried to avoid mentioning any other characteristics that could lead to their identification. Still I made sure to inform them and get their consent on the fact that any data appearing in this thesis may be used in subsequent studies, publications and/or presentations.

I informed the participants that it was on their absolute discretion not to answer any question they didn't feel comfortable with or even withdraw their participation without stating any reason. Given the very personal nature of the research question, I was concerned that there might be issues they didn't want to talk about. I was also concerned that issues might arise that would require follow up meetings and/or even counselling support by a colleague, so I also prepared for that. Luckily, although all of them got deeply emotional at some point of the interview, none of them mentioned that they wanted to withdraw and all of them mentioned a feeling of relief, revival and/or hope for the future during our closing conversation. I noted some of these comments down and kept them in mind during the data analysis in order to be reminded of the general state of mind of each participant.

The proposed research design was approved by the Ethics Committee of the ICPS College for Humanistic Sciences before any interview was taken.

#### **Findings**

Aim of this part is to dive into the answers of the participants and analyze how they experienced their participation in a PET seminar as parents of autistic children. The initial efforts of the interviews were focused on their experience from the program and their thoughts and feelings regarding the appropriateness of PET for this particular target group as well as any changes they noticed in themselves, their children or their common interaction. The following analysis is based exclusively on the participants' answers to the question: *How do parents of high functioning autistic children experience Gordon's Parents Effectiveness Training?* 

In the Findings section below, the reader will follow the participants' journey through their understanding of PET and the attributes they allocate to the seminar, e.g. them picking almost the same PET features to label as useful, as well as referring to the PET group dynamics between parents. Following on, the survey accompanied the participants' trip down memory lane, where they described some sort of inner incongruence when realizing that while they were trying to adopt communication skills they themselves had never experienced growing up. The survey follows the unveiling of this inner process and their efforts of growing out of it. Lastly, this paper will discuss the participants' changes in the way they experience both themselves as well as their relationship with others due to their participation in the PET seminar. The findings revealed a new way of interacting with their autistic child; but not only that. According to the findings, the PET features seem to have diffused in all of the parents' human interactions. Some of these may be deemed the reasons for the positive evaluation of their whole experience with PET that sums up this section.

All names have been replaced by acronyms, namely SWT, SPR, GDS, LST, TTP and EXT to preserve the participants' anonymity.

The themes and subthemes that emerged are stated in the following Table 2.

Table 2
Themes and Subthemes of the Analysis

Themes	Subthemes
I. From Lost to Found	A. In Search of a Meaning to Begin with
	B. On the PET Ride
	Active Listening: A New Challenge
	I-messages as Communication Bridges
	C. Stumbling on & Reinterpreting Autistic Traits
	D. A Sense of Belonging
II. Beyond the Parents' Known Comfort Zone	A. Personal Experiences Interrupting PET
	B. Facing Incongruence: Old Experiences vs New
	Learnings
	C. Encountering One's Self
	D. Processing Progress into Personal Growth
III. Within and Between	A. A New Way of Being
	B. Regenerated Interacting with the Evolving
	Superman
	C. Over and Above Parental Interaction
	D. Evaluating the Experience as a Whole

#### From Lost to Found.

This theme addresses the participants' journey from the initial shock of being faced with diversity, towards accepting it and the effort of trying to comfort themselves and help their child. It follows through their understanding of PET and the attributes they allocate to the seminar based on their experience as parents, but also as parents of an autistic child. Although none of them was familiar with the person-centred approach, most of them identified and mentioned all three core conditions as the theoretical basis of the program and deemed them helpful and liberating. Apart from that, they picked almost the same PET features to label as useful. All participants made also reference to the PET group dynamics between parents while exchanging experiences.

In Search of a Meaning to Begin with. When asked to offer their own personal definition of 'autism', all six participants starting describing some sort of inner process initiated by a shocking common realization: my child is "different". "Think of a parent, who is uninformed, has a diagnosis in the hand, is lost in space -literally- has lost the earth beneath his feet, doesn't know what autism is, cannot comprehend it yet..." (GDS). Almost all participants referred to a state of confusion and helplessness dealing with "(...) some sort of disorder nobody explained to us" (TTP) that sank them in despair "I was crying night and day, I couldn't understand" (EXT) and self-pity "why me, why our child (...) I was angry and scarred [and] in pain" (SWT), crying out that "not a single person was there to tell me, why this is happening. [I thought] I can't stand this, I feel like drowning" (SPR). Like one of the participants vividly describes: "Parents are alone, tangled up and there is no obvious way out (...) they need to be very lucky not to end up in the hands of a quack" (SPR). Four of the participants addressed the Greek Healthcare System and the other two turned to private counselling in an effort to encounter the diagnosis and find their inner balance in parenting. After "many disappointments" (GDS) they all seem to have found comfort in the private special educator and PCA counsellor that kindly referred them to me for the purposes of this survey.

On the PET Ride. Acknowledging that in the issue of an autism diagnosis in parenting "the most important thing is the parental support [and] soothing" (GDS), all participants had some short term counselling sessions and worked together with the aforementioned counsellor on an individualized basis expressing their concerns, filling cognitive knowledge gaps and addressing the needs of their own child, prior to being prompt to attend the PET seminar to address their personal parenting needs as well.

All participants were able to track down specific PET concepts that they labelled as particularly helpful, especially for their autistic children. In particular, all six participants referred to 'Active Listening' and the different 'I-Messages' as crucial and life changing and some of them also commented on the usefulness of the 'Changing of Environment' (GDS, EXT, SWT), the '12 Roadblocks' (LST, SPR, SWT), the 'Method III conflict resolution' (LST, TTP), the 'Problem ownership' (SPR) and the 'Values Collisions' (LST). One participant (GDS) also referred to the use of non-verbal communication as described in PET for infants or toddlers under two years old, which she is using with her two non-verbal autistic children, deeming it as very useful and, in parallel, liberating for her.

Active Listening: A New Challenge. I was impressed to hear by all six participants the effects of Active Listening both on them but especially on their autistic children. "The child is who he is! He was telling me clearly what he wants and what he needs, I was just not listening! (...) he was introducing me to active listening way before I encountered that in PET!" (SWT). Most participants were able to identify that communication problems with their children, originated from their misinterpreted notion of 'listening': "I was the one not listening... Em... I was hearing the first phrase and then I would start looking for the solution in my head without paying attention to what my child was telling me" (TTP). After realizing that and implementing the skill of active listening, a participant mentioned "I think he feels I understand him better now, so he is relieved and trusts me more. The result is mind blowing!" (LST). All participants mentioned that active listening made a huge difference with all their children, autistic or not. But especially with autism, active listening with all its attributes seems to be easier welcome, quicker in response and less complicated to use.

My [not autistic] son was even defensive at first. He has the sleight of mind of the neurotypical child that dictates that when you notice the other person behaving in a different way, you ought to put up your guard... at least at the beginning. My [autistic] daughter was more open and innocent, she was pouring everything out from the very first time I tried active listening (...) as if she had finally found an outlet! The problem was to stop her! (TTP)

Another participant made the same comment, even more vividly by sharing her inner dialogue as well as the outcome:

Asperger has its own frame; the child will get angry and upset very easily if you don't respect it. I used to hear a distressed child telling me all the time 'You always do that! You tell me what to do! Don't do that!' (...) and PET kept stressing 'Don't judge! Listen!', so I said to myself 'Wake up! You've been taught this, use it!' and the moment I started active listening, the tension disappeared! (...) As if the child had unlocked! He is lighter now... there is no tension cause I'm not questioning him anymore... (...) It almost feels as if he has become an easier child to communicate with compared to my [neurotypical] daughter... [laughter]. (SWT)

*I-messages as Communication Bridges.* Another PET skill all participants referred to and described with bright colours, were the 'I-Messages'. On a personal note, many parents appreciated the fact that they were for once 'granted the right' to an opinion or even a feeling "The acknowledgement towards me and the sharing with the child. It's not a bad thing to be

angry... I was feeling guilty for that too... (SWT)" and commented on the effects of expressing that to an autistic child: "My autistic child understands my sharing through I-Messages much better than my other child. If you tell him how you feel and where you stand, all is fine!" (SWT).

The participants vividly described one of the main communication blockages with autism, the perceiving and reflecting emotion, as being very smoothened through this process. "When I explain myself with the I-Messages, it cuts everything down for him in smaller and precise pieces making it easier to understand and copy it" (SPR). And the participant explained further: "Things like these comprehensive procedures are not automated in autism, so [I-Messages] take over this task" (SPR). Almost all participants mentioned as problematic the fact that autistic people will not place you in the frame of their story telling, they will just take it from somewhere as if everything else is taken for granted. According to these participants, reflecting this back through I-Messages seems to help them adopt a new and very liberating tool of expression: "I-Messages were of great importance for my autistic son because he managed to overcome his inability to express his feeling (...) he can now put it into words! This was very important!" (SPR) or "He understands and even copies after me now!" (LST).

**Stumbling on & Reinterpreting Autistic Traits.** Although none of the participants was previously familiar with psychology, psychopathology, theories of personality and/or the person-centred approach, while describing their experience as PET participants, they were all able to pick up the person-centred origins of the PET model. They also expressed their surprise when they saw their autistic children not only take these in but also reflect them back.

Throughout their storytelling, the parents identified qualities of the program that they deemed helpful while communicating with their autistic child. The three core conditions of empathy, congruence and unconditional positive regards were acknowledged as helpful, especially when dealing with autistic traits. "In autism it's all about action and reaction. Metaphors are not comprehensible. Everything is pure reason. [You have to] be authentic in expression. PET gives the perfect tools." (GDS) This particular participant, also mentioned other parenting programs addressed particularly to the autistic community and expressed her disapproval due to the lack of positive regard: "Autism doesn't need ABA. No. It doesn't need TEAACH. Autism needs freedom. With limits [...] It needs acceptance" (GDS).

Commenting on empathy, one participant mentioned: "Every autistic child has speech, an internal dialogue. Empathy and love will help him express that [...] I talk to all of my children as if they were all verbal and would reply back" (GDS). Yet another participant expressed an inner dialogue regarding the wide spread assumption on the lack of empathic ability in autism:

The paediatricians and everyone else used to tell me that my child has empathy issues... and I was trying to comprehend that, because my experience with my child was different... she would continuously surprise me... and trying to comfort me when I would be sad. And I would think to myself 'How is this possible? What lack of empathy are they talking about?' (...) PET opened new ways for me (TTP).

A Sense of Belonging. Most participants appreciated the group dynamics of PET as well. The PET model draws upon a 'united we stand' notion and by all means uses these dynamics during the course. Likewise, these parents -having already participated in several individual sessions- they apparently found comfort in a sense of belonging to a wider group of people, either as parents of autistic children or as parents in general: "We all felt like parents in the group (...) you are amongst people who are potentially prone to this kind of procedures" (SWT) or "all parents need a support group, parents of autistic children even more" (GDS).

When parents realized that they were not alone they referred to this as both empowering and relieving. "I still meet with two people from my group and it's nice. There is a warmness between us. Something like a bond. (...) It feels like support to me..." (SPR). This participant, as well as others, appreciated the possibility of having an honest conversation with someone apart from her counsellor; someone that would not be judgemental because (s)he is going through the same or has already been there: "This sense of belonging... you need that throughout your life. [These are] my comrades [laughter], my classmates" (SPR).

According to another participant, listening to others describe even more difficult situations than one's own puts things into perspective and you become more realistic: "Listening to her and then seeing her smile... well, this is a life lesson!!" (SPR).

The idea of a group was almost an invitation for most participants who were longing for a sense of belonging: "Entering the group, you take for granted that the people there will want to learn how to cope, regardless of norm and diversity. We are all parents, we all have children. (...) there is a common need of belonging" (TTP). Of course, there are always people who don't find sharing or participating in a group comfortable, like one of the

participants here: "It was hard for me... role plays were hard for me... (...) it was helpful still straining for me..." (EXT).

Another participant, shed light to yet another aspect. She claimed that in order to feel comfortable in their role as parents, this particular group of parents of autistic children have another barrier to tackled first, i.e. acceptance. They need to have accepted the fact that they are parents of a child labelled as autistic or at least find themselves amongst others who accept autism as a whole- and not only the stereotype of it.

It was nice to talk to the parents of the group, cause when someone comes there... (s)he has accepted... You take it for granted, that the other thinks a bit outside the box... or at least doesn't look at this with a critical eye... (...) you are not afraid of how you are going to sound! It becomes a safe frame for discussion and understanding (...) you are not an alien! [laughter] (SWT).

Although most participants seemed to have appreciated the role plays in a non-therapeutic but educational parenting group, three of them (GDS, SWT, SPR) made a reference to the tendency of other PET trainees to over share or monopolize the sessions. "This is not a therapy group but people tend to misinterpret that, which can be annoying!" (SWT) Or like another participant put it: "[I'm telling you] ZERO, she had zero problems! And everything had to be MAJOR. She had an opinion about everything and there were other people there too... pfff!" (SPR).

### **Beyond the Parents' Known Comfort Zone**

This theme discusses the participants' uneasy feelings when realizing the effects of their own childhood on their parenting styles drawn to the surface from their participation in the PET seminar. All participants went a trip down memory lane at some point during the interview and most of them got pretty emotional. This was not intrigued by a particular question, still all six participants related to their childhood one way or another. They all described some sort of inner incongruence when realizing that what they were currently trying to adopt communication skills they themselves had never experienced growing up. They also referred to the inner -and outer- challenges this process was veiling, their growing extent of awareness, their ways of dealing with it as well as their growing out of it.

**Personal experiences interrupting PET.** During the interviews, all six participants - most likely inescapably- experienced a throwback to their childhood years. For some instances, they stepped out of their parental roles - and everything this brings along- and

became children themselves. "While working with PET... inevitably, you will get pictures from your own childhood as well" (SWT). Or as another participant put it "These had become my nature and as soon as I realized that they were wrong, I tried to limit them... " (EXT).

All six participants also stated that none of them was brought up with the principles resembling the ones they were now trying to invoke:

I cannot trace it back experientially! (...) It is as if I am... as if I have a standardized model for child education, the way I learned it as a child, the way I live. (...) There is an inner incongruence between my experience, the beliefs I was brought up with and this PET thing (...) cause what I know is 'you are a good kid, if you are obedient' (...) and I was just that (LST).

Going through the PET seminar, all participants were faced with their past and went through a flash back procedure bethinking: "We thought our parents had acknowledged things, but they actually didn't. We were a bit like "Shut up, I'll do the talking", right?" (SWT). They all seem to acknowledge their parents efforts growing up "(...) with a mother that sacrificed a lot for me (...) she had good intentions but I still remember the tension and the burden I felt back then, I still feel it" (TTP). Yet there were emotions of anger and regret "(...) I used to see my faults as very bad, because that's how my mother used to mirror them back to me" (SWT) and pain "my mother is carried in my subconscious, I even use the exact same phrase and when it's out I go 'Oh, God!' and then 'Ok, relax, that wasn't you!'" (SWT) but maybe also feelings of purification and/or defensiveness like the here and now it's not all their fault after all "I was holding the finger up, like I was raised" (SWT).

Most of the participants referred to the circumstances that are uncontrollable by notion and dictated by experience: "There are many times that I address my kids and then I say "Aha! My mom just came directly out of me!" (TTP) which leads to guilt and remorse, as if they did something purposely wrong. In the best case they are now able to acknowledge that something out of their control just happened:

And then I realize that something steps out of ME and reaches my child (...) I cannot control it, it's out there" (LST) or even " (...) the way I lived as a child and it is automated. It's instinctive and it's what I'm also prone to use as a mom (LST). PET seems to help the parents bridge past and present experiences without judgement: PET understands both the parent and the child and it doesn't judge the parent actually! That's the key! A simple seminar would bring the other person into a defensive state

(...) You are being judged! PET has the magical touch to make you feel like you are not being judged, you are being understood, and let's see what the deal is here (SWT).

After experiencing a sort of internal journey, the parents seemed to be returning to their current state of reality as parents. One participant referred to this whole process like this:

How much we destroy their psychology...em, we realize, maybe, when we do a flash back, let's say, of how much our parents used to listen to us... and how this might have hurt us at some point that has for ever been engraved in our soul... that when I was listening to her, my mom wasn't listening... and unfortunately, you know, mistakes tend to get repeated, cause the way they raised us it's not their fault... (...) you are not born a parent, you became a parent in one minute at some point of your life... (GDS).

Facing Incongruence: Old Experiences vs New Learnings. This experiential course of thoughts and actions that PET induced in all six parents seems to have liberated some "You see what mistakes your parents did and how easy it would have been to do it a bit differently! It's not mission impossible!" (SWT) but also to have debilitated or even discouraged and dumbfounded some others "When I listen to other people do it, then I realize what I'm also doing - I have to learn it from scratch... what saves me [and keeps me going] ... is my guilt" (LST).

All the above-mentioned realizations and inner processes were captured in comments like:

There is an inner incongruence between my experiences growing up, what I've learned and PET, which I'm learning as a technique for now (...) I have to read the book over and over again to understand that kids need to comprehend and negotiate, not be ordered around... (LST).

This inner incongruence between 'what I've been taught' and 'what I have come to realize I wish to implement now' awoken by PET, also triggered one participant to start personal psychotherapy sessions: "I want to try and so I started counselling to unlock my issues, to balance and be more functional, more complete. " (TTP) and two others to seek out group psychotherapy for their personal growth and support after the completion of the course. two of the participants were already in personal therapy and one -the one that encountered the most difficulties in implementing the newly acquired tools- did not consider personal therapy at the time of the interview but chose to continue searching academically and do lots of reading.

**Encountering One's Self.** Going through the interviews I got the impression that the participants decided to attend PET in order to learn new communication skills to cope with their children. After completion, it seems to me, that not only did they find new ways of encountering their children, but they also ended up encountering themselves; their past and their present state of mind and consciousness: "PET is a way of life" (GDS).

Most participants, appreciated the systematic conspectus of communication skills stating "PET talks about self-evident stuff, it's just that we have never been taught how to implement them (...) I consider them realistic guidelines not a nostrum or patents that I invented, you know..." (SWT) as well as the labs narrating "through PET some practices got automated. (...) Let's just say I found the tools, the ways. Somehow, I now perceive things experientially" (SPR). Throughout the interviews, I also picked up many generalized comments like "PET smoothened out communication by giving me hands on tools to work with" (EXT).

The program seems to provide the participants both with a theoretical background and some tools to work with: "PET is self-evident, we just haven't been taught the how. And that's what PET does. It teaches you HOW. It's not a new theory." (SWT).

Still, most participants seemed to differentiate between the hands-on tool they expected and the experiential shift they felt, that "just happened" in themselves (TTP).

Some found it easy to adopt "I realized PET gives you the general idea and then you work out your own way" (SWT) or "PET helped me identify mistakes in communication and revise some staff" (EXT) and others not so easy:

PET advocates that you should trust the child to choose but there is a limit when it comes to values - I cannot let the child "choose" to have a tattoo - I HAVE to trick and guide it. (...) It's time consuming and crushing for me. It's not working when I'm using it as a method, as a technique (LST).

Others found it difficult at first but really believed in it and were determined to make it work:

Reading the book at first just stressed me out, I was blocked, I couldn't understand. (...) Most of the time I'm stressed when trying it, slowly, like learning to drive a car. [...] Still, it's not automated but I imagine how it could be and get on it - it needs work from my side. (TTP).

**Processing Progress into Personal Growth.** Whether the PET philosophy was already part of the participants life, e.g. "PET gave names to the ways I already had" (EXT) or not and it therefore introduced them to something new, e.g.

I realised that in order to pit all these wonderful things PET is talking about [laughter] into praxis, I had to find my inner balance first and balance myself as a human being (...) I had to metabolize it, sense it first and then express it... ok? (TTP),

the sure thing seems to be, that all participants gained both experiences as well as an intellectual nourishment: "It gives you food for thought. It all starts from that... if you are in the mood to reflect" (SWT).

There seems to be a leading forward drive taking the wheel, which diffused in the participants everyday life and their relationships. "There is a difference in our interaction... [The kids] are getting more mature and I'm getting more flexible - we are all more open indeed" (LST). Amongst other processes, participants experienced an inner growth "Going through this, I started loving my own little self... and I forgave me ...!" (SWT).

And this seems to be leading the way forward: "I'll do the program again, I'm evolving. I feel optimism and thrills thinking of PET" (TTP) or "I need more follow up training because it's promising..." (LST).

### Within and Between.

This theme dives along with the participants in the changes they experienced both in themselves as well as in their relationship with others, especially with their child. Some also mention evident changes in their child's behaviour. Referring to PET as a new way of being, something beyond a plain parenting program, helped them regenerate their way of interacting with their autistic child, i.e. the evolving 'superman' as one of them called it (GDS). But not only. PET features seem to have diffused in all of the parents' human interactions. Towards the end, they all mentioned their general appreciation and evaluated the whole experience of their participation in PET from very positive to life changing.

A New Way of Being. Most participants found specific concepts of PET very useful but they also sensed something more than that. In their narrative, while trying to elaborate on their PET experience, they swung between receiving a set of useful practical communication guidelines and an underpinning feeling of being introduced to something deeper and broader than that, a new "way of being" (GDS). "PET for me is a technique and a way of living.

Both." (TTP). Another participant, would note: "The effective parent works in me first and secondly on my child" (EXT).

What impressed most of them was the effect it had on themselves and the way the perceived themselves "PET made me feel like a human being with rights... a human (...) I now learned from scratch that I'm entitled to bad feelings and can also share them with my child. I never thought of that before..." (SWT).

Some participants were even able to identify more precise changes, like: "I changed the way I express myself and it's more effective this way" (SPR), "I learned how to listen... it's a personal change" (TTP) or "It taught me how to listen actually. That." (SWT). They all mentioned that there was some underlying characteristics of the seminar in the 'new' way they learned in order to approach one's self or communicate with the child and/or others: "(...) but it also has to do with my emotions... I mean how you are generally made, how you comprehend the world, your life philosophy" (TTP). As one participant eloquently, states: "You need to have a different stance towards the child not like 'OK, it's just a kid' but more like 'hm, it seems like he's got something to say, lets listen..." (SWT).

They were also able to pick up potential difficulties "If you don't have it in you, like that's the way I want to function, you will not be able to implement it" (TTP). Still, even the participant that seemed to face the most difficulty in implementing the tools was able to identify the same: "These are techniques I utilize as if I had been instructed to do so. (...) But it's also more than that; it has to do with the way you see the world, it's an attitude to life, a philosophy" (LST).

This philosophy, whether newly acquired or pre-existent, was to my understanding beautifully summed up by one of the participants in the comment: "You have to trust your child and TRUST it's process" (GDS).

Regenerated Interacting with the Evolving Superman. The parents of the survey, being parents of autistic children, will always be faced with "the challenge of the unknown" (SPR). But going through the seminar, most of them realized that "You don't have to fit into frames, PET unlocks you, takes the guilt away" (SWT). As another participant puts it:

(...) the difference between autistic and neurotypical children is in the evolutionary stages, it's not a matter of can and cannot do... (...) to the contrary, autistic people have assets that other people don't have (...) it's like bring up Superman. Literally. Because, it's as if these children have fallen on earth from another planet to your doorstep and you have to teach them how to live in this world (GDS).

By acknowledging that, the parents made various realizations that affected their interaction with their children even in a practical way like "I was using awards and I added active listening as an alternative" (LST) or "I realized that each child had its own personality, it's not just a little child that doesn't know, it's a human with an opinion and I need to listen to that" (LST) and even

I don't react back anymore, I say 'OK' and let him do his thing... and this seems to be giving him time to self-regulate. (...) what I didn't understand before was that he didn't talk back to me, he was letting steam out and I was pushing him not to! You just let him... (SPR).

These realizations are not always easy to accept, as one participant confesses: "I admit that's the taught way, but it's the only way. (...) every autistic person has two ways: his own and his own! If you don't accept and respect that and just listen, there is no going forward" (GDS).

Most of the participants described in their narrative that with autism, nothing is apparent and undeniable. You need to listen, give time and observe and when this shift happens within the parent, the results are projected on the child: "I listened to her, I probably gave her space to express something I would never have thought of and which can lead us somewhere completely different... (...) I call up and said 'I did it!'" (TTP). This feeling of being proud of managing, is multiplied in autism. "The magic in autism is to witness the evolution of the person..." (GDS) stated one participant, which corresponds to another comment by another participant: "As parent of a different child, I am proud because I have unlocked very special parts in him and that's the essence of every existence" (SWT).

The fact that PET refrained from "just knowledge and solutions" (TTP) and talked about emotions was also key to the personal and interpersonal change between parents and children: "There is less tension amongst us, because the child feels [the difference] ... I was getting angry before! (...) He realizes I understand, I listen and smile without judging, he loves me more now!" (SWT) bringing along a qualitative change that all six participants mentioned and which stretches way beyond: "I am defending him more towards others now, I used to get angry. Now it doesn't matter, I understand him and get angry with the others who don't get it" (SWT).

**Over and Above Parental Interaction.** The internal shifting that to me resembles growth within the participants "I learned and changed a lot, I stopped being afraid through the process" (SWT), does not seem to be limited to the parent-child relationship, as it seemed to

influence almost every relationship of the participants: "It's not just parenting, it's about all sorts of relationships" (TTP), for e.g. "PET is open to everyone and it concerns any kind of relationship. I learned how to communicate with my mother for example [laughter]" (SWT).

Many participants referred to relationship shifts; one aspect they all referred to was their marriage. three participants (EXT, SWT, TTP) had also their spouses actively involved in the PET training, either attending it together or having their husbands attending it at a later stage on their own. These mothers referred to their relationships more affectionately, considering them part of their support system and gave me the impression that their husbands were more actively engaged in their parental roles as well. e.g.

The way we communicate as family is different... other families around us don't act like that, e.g. my sister's family (...) we now have our own communication style the three of us (...) it helped us all as a family, helped my relationship with my husband (EXT). We talked about it with my husband and we both came to the seminar (...) we now apply it as a general frame but while knowing what the other is doing, cause you cannot have one applying PET and the other one going "What's wrong with you?' [laughter] (TTP)

To the contrary, the husbands of the other three participants (LST, SPR, GDS) were either completely absent in their storytelling (SPR) or negatively cited "After the seminar, whenever I hear my husband use that, I then realize what a big mistake that is...! (LST)". One participant even referred to marriage problems that eventually led to her divorce due to the differences in approaching parenthood and autism. According to her she wanted a new way of being and her ex-husband was in favour of more traditional approaches and didn't want to be that much involved: "I resolved my marriage in favour of my autistic children! (...) He never wanted to listen! (...) He couldn't even comprehend all that. We were so very different in the matter of problem solving" (GDS).

PET seems to have favourable influence in dealing with autistic children's siblings as well. Autism affects the whole family -as most of the participants narrated- and particularly the non-autistic children of the family. The younger brother of one family used to complain to his parents that they were always paying attention and were involved with his sister, rather than him, and that would result in panic situations within the household: "PET opened new ways for us, it put us in a different frame" (TTP).

**Evaluating the Experience as a Whole.** All in all, the participants evaluated the experience of their PET participation very positively. Two participants (LST, TTP)

acknowledged the fact that the implementation needs time and that follow up sessions would be necessary. Still, they all seemed to agree in the beneficial and helpful aspects of the program, summed up in one participants conclusion:

Parents need training and mindfulness. Both. (...) Parent sessions and counselling should be going hand in hand with the child's therapies. (...) If PET would somehow manage to become a prescribed therapeutic alternative, noted in bibliography, (...) I think it would be most helpful" (SPR).

Commenting on the program, one participant assumed that "it's not easy for everyone to digest, it's not that commercial, because it needs a hell of a lot of work with one's self!" (TTP) which seems to overlap with the rather visual figurative image another participant gave me, while describing the extensive efforts a parent should make: "it has to do with how much butt you wanna get wet in order to catch the fish" (GDS).

The first participant also mentioned that she wished, she "had discovered [PET] sooner" (TTP), still she was determined to make PET work by starting personal therapy, while another participant concluded "After all the training and the searching I feel proud to have a HFA child. It's not at all what I feared at the beginning" (SWT).

### **Discussion**

The present study examined the experiences of six mothers of high functioning autistic children who opted for the Parent Effectiveness Training and successfully concluded the program. The initial goal was to delve into their experiences, thoughts and feelings by analysing their answers to the question: *How do parents of high functioning autistic children experience Gordon's Parents Effectiveness Training?* 

In the following section, the particular research findings will be discussed along with the literature which has already been presented. The scope is to critically link present with older findings and demonstrate the contribution of this research to the academic community as well as the counselling praxis. Finally, certain limitation and validation barriers will be highlighted and further research proposals will be submitted.

The findings of the present research featured three themes, namely a) from lost to found, b) beyond the parents known comfort zone, and c) within and between. In particular, the participants of the study shared their initial shock and distress, their process of feeling lost until they found a new way of dealing with their situation through the various PET features, the skills they attained and their incorporation in their everyday lives. During their storytelling, the mothers startlingly dredged into remembrance of their past and described a realization process of how their current parental attitude seemed so closely related to their personal experiences as children, which was unexpected and -to some extent- uncomfortable. They also shared a newly acquired way of expressing and experiencing themselves and their children that seemed like a growing extent of awareness and a new way of connecting and relating; both within themselves and between themselves and their significant others.

In the framework of the first theme, congruent to current literature findings, all six mothers participating in this study made gritty descriptions of their initial showdown with the realization of their child being 'different' and later on diagnosed as 'autistic'. Their comments of feeling lost in space and being in a state of confusion correlate with the findings of several surveys on parental autism diagnoses. Lee et al. (2017) for example, also mentioned that the participants of their study referred to survival mode and constant anxiety. Furthermore, present findings referred to a state of grief and self-pity expressed through crying, panic attack resembling symptoms and feelings of helplessness, which also correspond, for instance, to Lee et al. (2017) findings, where the parents expressed the need to grieve over the loss of not having a normal child or parental experience.

It is understandable that the parental role brings along challenges to a person, regardless of the characteristics of the child (s)he raises. Autistic or not, children seem to trigger universal buttons and inner processes to their parents. The quest for balancing the elements that differentiate them as parents of autistic children to the attributes of parenthood as such was an intense procedure I felt these parents were going through. It seems to me that PET helped them somehow connect both endpoints of this pendulum by bringing them in contact with themselves.

Notably, the challenges presented by the mothers of autistic children -i.e. outbursts, punishments, conflict resolutions, etc- did not sound unique, but universal to all participants in any PET seminar worldwide as presented for example in Doherty & Ryder (1980) and Wood & Davidson (1987). Still in this case the challenges seemed more intense, complex and amplified leaving them whirling in confusion (Stewart et al., 2016) and feeling a tad more guilty than an average parent -probably due to the diagnosis. The fact that all apart from one mother, were also parenting a neurotypical child as well as the parameter of whether their autistic child was their first association with parenthood, it seems that it could make a difference to their level of parental distress experienced, like e.g. Bitsika et al. (2013) suggest in their study regarding parental resilience upon stress or other current literature (Davis & Carter, 2008; Brobst et al., 2009; Sawyer et al., 2010).

Further to the diagnosis factor, the mothers of the present study referred to their difficulty in being left uninformed, not being able to fill their knowledge gaps, and not finding comfort in the expert professionals of the Greek Healthcare System in order to cope with their concerns and address the needs of their children. Similar comments on the inflexibility and long duration of the diagnostic process were also noted in literature, e.g. Braiden et al. (2010), Moh and Magiati (2012), and Crane et al. (2016), supporting the experience of a strenuous procedure. There are extensive references in literature that this procedure has significant negative effects of the parental distress levels (Davis & Carter, 2008; Brobst et al., 2009; Mori et al, 2009; Sawyer et al., 2010) and/or their health (Stewart et al., 2016), leading up even to symptoms of posttraumatic stress (Casey et al., 2012).

Complaints arising in the first theme of the present study of feeling left alone or not having a single person to turn to for guidance were also found in literature, e.g. in Woodgate et al. (2008) where a world of isolation is vividly portrayed. Autism tends to be a taboo issue worldwide. Greece in particular, is not celebrated for its well established public sector, health care system or even social progressivism; it is well renowned however for its family support

system. As vividly described in Papageorgiou and Kalyva's (2010) survey, parents in Greece seem to face particular difficulty mentioning the fact that they are parenting an autistic child either way. The parents of the present survey validated that as well.

According to literature, parents of autistic children are confronted with high divorce rates (Hartley et al., 2010). The results of the present study do not necessarily reflect that, since only one participant made direct reference to marital problems due to the differences in approaching autism related issues, which subsequently lead to divorce. Marital discomfort, low relationship satisfaction (Brobst et al., 2009), struggles of emotional connection, alienation and isolation as reported in the Lee at al. (2017) survey could partially be concluded for two of the participants who either did not mention their husband or did not referred to him favourably. To the contrary, PET seems to have positively affected the other three of the participants in terms of affection, alignment and engagement, possibly due to the shift in their communication, both in the way they expressed their needs and, in the way, they started listening to the needs of their partner. Further, the fact that both partners attended PET might to my understanding be an indication of a closer couple's bond and the partners' state of mind prior to seminar attendance which was further strengthened afterwards.

Regarding the rest of the family members, only one participant made reference to a sibling's complaint of feeling neglected, which aligns to the Tomeny et al. (2017) survey reporting behavioural problems and feelings of rejection in neurotypical siblings. The rest of the participants made no reference to other first-degree or extended family members, which may not lead to safe conclusions as to the absence of such problems or their insignificance at the time of the interview.

Actually, the fact that most participants made reference to, and at least three seemed to relish, the group dynamics in PET, might be an indication that their support system was not solid. For precisely, as mentioned again in the survey of Papageorgiou and Kalyva (2010), parents in Greece tend to seek out support groups, because they don't feel comfortable enough sharing this burden with their extended family.

Interestingly, out of the six participants, three of them seemed to be longing for and appreciating more this sense of sharing and participating in a group, lively mentioning warmness, bonding, and a sense of belonging, while the other three seemed to surely enjoy it but be rather neutral about it, i.e. not considering it a milestone or crucial in their everyday life. Intriguingly enough, the first group of participants had little or no personal therapy sessions before or during the PET seminar, while the latter group of parents had substantial

amount of personal therapy years behind them. I cannot help but wonder whether there is some sort of connection between these facts. I also noticed that the first group stumbled a bit in the use of language. While the second group mentioned the word "autistic" without hesitations, the first group was very cautious and defensive. Specifically, when I impulsively used the characterization autistic for a child during an interview, the mother abruptly interrupted me to mention that her son was not autistic, he just had Asperger and she prompted me to be more careful in the use of the correct terminology. The high level of sensitivity highlighted to me the importance of linguistic connotations as indeed referenced in literature, namely in the survey by Kenny et al. (2016). The findings of the present survey reflect this notion of the usage of terminology based on conceptualization and degree of acceptance.

A further alignment between current literature and present findings arose in the second and third theme and referred to the processes of meaning making, successful coping and personal growth of the parents. In their research, Marshall and Long (2010) followed the meaning-making processes of their participants as they managed to adapt to their children's' autism. As mentioned for example by Lazarus and Folkman (1984), Stroebe and Schut (1999) and Park and Folkman, (1997) to name a few, the meaning making process works to my understanding as a human defence mechanism to cope with a stressor factor. According to Papagos (2014), PET in particular leads the parents towards a path of personal growth, a fact which also the participants of the present research were able to identify. They also attributed facilitating characteristics to PET in helping them either realize or come to terms with both with meaning making and with growing. In his research, Makris (2018) identified features like trauma, connection, process and reinvention of one's self as facilitators towards growth, which the participants of this study identified as well even in the same order, i.e. autism diagnosis (trauma triggering factor), PET group dynamics (connection effort), own childhood (own processing) and new way of being (reinvention of self).

Parents of this research mentioned PET as a process for learning to love and forgive themselves, stop being afraid, getting rid of guilt and feel like humans entitled to feelings, even bad ones. They also associated PET with a process of unlocking and learning to accept and respect their child's autistic manners which led to an internal shift of moving forward with proudness and inner balance. In this context PET could to my understanding be labelled as a coping mechanism, also bearing the characteristics of a support group that is so commonly seem in literature for parents of autistic children (Gray, 2002; Mandell & Salzer,

2007; Mackintosh et al., 2006). What was not mentioned in literature however, was the labelling of PET as a way of being, a way of living, an attitude to life, a philosophy that after being metabolised by the parent, it subsequently leads to the child's unlocking according to the participants.

Another aspect of the current findings that I was not able to detect in the literature I retrieved on PET, was the intensity of self-encountering and the inner incongruence between experience and expectation which was introduced in the second theme of the findings. All six participants of the present survey encountered a throwback to their own childhood. Five out of six were so affected by it, that they started crying during the interview. All of them were able to identify that the PET philosophy they were trying to embed in their parental configuration was not supported by personal experience. It seems to me that PET, apart from offering hands on tools, it creates a setting for the parents to connect their configuration of their inner child to that of the adult-parent (Mearns & Thorne, 2000). This experience seemed both liberating and debilitating for the participants, but they were certainly all stunned to make the realization of the effects of their own upbringing on their adult life. This inner shift seemed to help the participants better understand themselves, their inner child as well as their actual one. Still, I was not able to link this finding to the PET literature available to me.

It also needs to be noted, that research on other suggested parenting programs regarding autism, e.g. ABA (e.g. Vismara & Rogers, 2010) and TEACCH (e.g. Schopler et al., 1995), do not mention such a profound impact on the parent him/herself like currently reported for PET. To my understanding, in these programs the locus of interest is the child and not the parent. In contrast, the parents of the present survey seem both to acknowledge and to appreciate the fact that PET offers them hands on tools to work with but at the same time reaches the child through them. They actually seem to become the tool to reach the child. And that to me resembles a very subtle way to work on acceptance; possibly the only one?

Another finding of the present research, which was mainly highlighted in the first theme but was also infiltrated in the other two, which I was not able to align to literature was the effect of Active listening and I-Messages in the parents' communication with their autistic children. There is limited current literature on the PET skills as such and plenty of research material on autism, but since the present research is as far as I know the first to combine the two, I am guessing that this is an original finding.

In particular, these two features that constitute a major part of the PET training seem to be tuning in remarkably to HFA traits. According to the PET theoretical basis (Gordon &

Sands, 1976), a parent that implements active listening prompts the child to go from outside self to inner self, helps him/her understand and deal with his/her own feelings and by hearing out loud subsequently acknowledged thoughts, thus invoking empathy. A parent expressing himself/herself via the various I-Messages, and thus through BEF (Behaviour, Effect, Feeling), promotes his/her authenticity in a comprehensible way. Both features combined enable acceptance. The three core conditions of empathy, congruence and unconditional positive regard (Cooper et al., 2007) and the neuroscience perspective of them stating that empathy is related to emotional sharing, perspective talking and self-other distinction, congruence is related to self-awareness and self-other distinction whereas acceptance is related to emotional regulation (Silani et al., 2013), seem to align with the findings in the present research, at least indirectly.

PET obviously doesn't reinvent the wheel but could it maybe be that it canalizes already pre-existing traits that prevailing literature and experts tend to question in autism, i.e. empathy? The rogerian philosophy in general (Rogers, 1951; Rogers, 1959; Rogers, 1980) and Prouty's research on pre-therapy (Prouty, 1998; Prouty et al., 2002) make direct reference to the three core conditions and the notion of the 'hidden self' in general and in autism in particular.

Language can be versatile and metaphors are complex structures yet embedded in our everyday conversation. Being incomprehensible for autistic children, they tend to be oversensitive to message intaking. The BEF effect seems -according to the mothers of this survey- to cut language into smaller and precise pieces, making it easier to understand and copy it, thus facilitating procedures that are not automated in autism -like metaphor comprehension- helping children overcome their inability to understand context as well as detect and express feelings. Usage of BEF gives a structure and makes the message clear, genuine and authentic, thus trustworthy, and subsequently makes tension obsolete. Mothers of the present research described the use of I-Messages as extremely important -in fact as "crucial", "mind blowing", "life changing" and "unlocking"- with effects including better communication, less tension and elevated trust in their relationship with their autistic children. It seems to me, that further research on this aspect would have a lot to offer.

All parents of the present research are backing up current literature (Bristol et al., 1993; Feldman & Werner, 2002) in the emphatic way they express the need for personal training and parental mindfulness, by even mentioning that PET and the child's therapies should be simultaneously prescribed by the country's health care system. Commenting on the lack of

commerciality of the program amongst the autistic community, one participant assumed that it's not that commercial, because it's not easy for everyone to digest it as it needs a lot of work with one's self and personal involvement and evolvement. Current literature (e.g. Karst and Van Hecke, 2012) is widely establishing, that parenting an autistic child leaves little time and strength to care for one's self. Still based of the present findings, this might also be the first place a parent should start with in order to help the child: with him- or herself.

### Limitations and Validity of the Study

This study, which to the best of my knowledge is the first to associate Parent Effectiveness Training (PET) with autism, looked into the experience of mothers of autistic children following their successful participation in a PET seminar. However, the study experienced certain limitations (Patton, 1999).

Given that the qualitative method chosen as more appropriate to address the scope of this survey was the IPA, the limited sample size does not allow the generalization of the results. Further, the issue of subjectivity, also deriving from the limitation of the chosen method, suggests that the emerging findings are affected by views, perspectives, values and the interpretation of the researcher.

Additionally, the fact that all the participants were referred by the same person-centred counsellor who trained all six of them in sessions held during the past two years, creates several limitations as to the criteria of opting for the particular participants as well as for the variety of the sample in terms of experiences, convictions, views due to being trained by the same person. A more divergent sample might have resulted in more multifarious findings, but since tracking down participants with the particular characteristics turned out to be almost a mission impossible, the sample was again deemed satisfactory.

It should also be noted, that in the absence of a control group, it was not possible to compare the findings to parents of neurotypically developing children and note possible similarities or differences in concerns and/or needs.

Further, the participating mothers were all from Northern Greece, thus restricting the place of residence to the minimum regarding availability of services and the reasons for opting for PET.

In this context, it should also be taken into account, that Greece's particular cultural and current socio-economic framework might not be directly comparable to that of other countries, possibly restricting the findings; still autistic traits tend to be universal.

Finally, the fact that the findings reflect only the perspective of the parents and not that of the children could be a further limitation; yet this was a conscious decision to avoid ethical complications.

Regarding the validity criteria as stated both in Stiles (1999) and in Elliott, Fischer and Rennie (1999) in terms of e.g. participants' accuracy and in depth sharing, potential participants' empowerment after the interview, coherence or consistency of the findings as well as credibility checks and readers' resonance, perspective ownership, examples for grounding, researcher's self-disclosure and reflexivity, etc. it should be stated that every possible effort was made for those to be met.

In particular, It was my conviction that all six mothers that were interviewed shared their most intimate and heartfelt experiences. They were enthusiastic to do so at the beginning and they thanked me for the opportunity to make this mental summary of their experience afterwards. Three participants also invited me to arrange a similar meeting in the future. I did my best to exert myself and honour their trust by interpreting as consistently and coherently as possible, and by giving several examples. The fact that I have been PET trained as a mother as well as a PET certified trainer was the trigger to opt for this study, as both personally and professionally I had witnessed several shifts similar to the ones described in the present study taking place before my very eyes many times. I was curious to see whether these experiences would be further validated. And they did. As a professional person-centred counsellor who received the necessary education, training, supervision and therapy to balance and encounter all that, I hope sufficient affirmations concerning my perspective ownership and self-disclosure in terms of validity for this study have been offered.

### **Further Research**

The results of this study could constitute a starting point for a series of qualitative and/or quantitative methodological attempts. Given the aforementioned limitations, a quantitative study with a larger sample would be a good suggestion for further validating and generalizing the experience of these six women.

A research studying a group consisting exclusively of mothers of autistic children compared to a control group of mothers of neurotypically developing children could also provide valuable outcomes.

Also, a research on the experiences of both parents and autistic children in selfadvocacy would constitute a very interesting prospect and would certainly have a lot to offer to the current literature.

It would also be useful to conduct a study focusing on mothers of non-verbal autistic children under 12, using PET as described for non-verbal children under 2.

Finally, a research combining features with psycho-educational material on autism in cooperation with particular reference to Active listening and the I-Messages as presented in PET in cooperation with insight of therapists from other faculties (speech/occupational therapists, focusing companions, couples' therapists etc.) on a group of parents and/or couples parenting autistic children sharing their experiences and input afterwards, could potentially offer an even more inclusive alternative to stressed out parents, especially at the beginning of their journey.

### Conclusion

This research dived into the experience of mothers who opted for PET in an effort to find support and a way to better communicate with their autistic children. Since communication is one of the deficits in autism, participation in a program on communication skills might seem like an obvious step. But it is not.

PET is not usually offered as an alternative to parents of autistic children and the findings of the present research seem to imply that it probably should. The suggestion is clearly not, that PET should replace other therapeutic interventions and ignore autistic manifestations that negatively affect the life of parents and children. The suggestion is for PET to enable the parents to listen and respect their own inner voices and needs first and foremost and empower them to settle their restlessness to create the necessary distance, in order to make educated decisions for their children. By learning to distinguish through PET which part is their expectation from themselves and which constitutes an expectation from their children, this might help -especially parents of autistic children- distinguish the parts, that however annoying, belong to the personhood of their autistic child (Silverman, 2008) and are not to be fixed, but accepted as such.

As one of the participants nicely articulated: "All these... Asperger... made me a better person... it made me grasp diversity around me and it taught me how to love my own litter self as well..."

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## **Ethics Form**

# Institute of Counselling & Psychological Studies

# Department of Counselling

**Ethics Committee: submission of project for approval** 

This form should be word processed – no <u>handwritten</u> forms can be considered <u>ALL</u> sections of this form must be completed No project may commence without authorisation from the appropriate Ethics Committee(s)

Title of Project:	How parents of high functioning autistic children experience Gordon's Parent Effectiveness Training: a qualitative analysis
Name of Supervisor:	Sophia Balamoutsou
Name of Investigator:	Eleni Maria Katsoura
Date Ethical Approval Given:	19/5/2017
Level of Research: (U/G, P/G, MSc, Staff)	Master of Science in Person-centred counselling. Institution: ICPS-Greece. Accredited by the University of Strathclyde, Glasgow.
Qualifications/Expertise of the investigator relevant to the submission:	
Target Group: Please indicate the population of participants/nature of the subject group and how they will be recruited.	The number of participants to be recruited is six clients. All participants should be parents of children up to ten years old who have received an official and/or unofficial diagnosis of autistic spectrum disorder (ASD). They should have participated and successfully concluded Gordon's Parent's Effectiveness Program (Gordon's PET) under the supervision and/or facilitation of a certified PET instructor.  Prospective participants will be approached through their PET trainer, who will be informed about this research project through me and/or ICPS College. These trainers will give my phone number and my e-mail to their clients and, if they are willing to participate, they'll come in

contact with me. The participants will not be obliged to inform their trainers about their participation.

Please attach the following and tick the box as appropriate:

o ui o	<del> </del>
Outline Summary: Rationale and expected	This research will focus on how parents of high functioning autistic children experience Gordon's Parent Effectiveness Training.
benefits from the study;	
state clearly what you propose to do and how	To my understanding, answering this question will highlight the eventual
	benefits of person cantered parenting which to my understanding are very
	valuable for autistic children and their relationships - firstly, to their significant
	others and, secondly, to the rest of the world. The information received from
	the interviews in this study will benefit all ASD community, providing an idea of
	how Gordon's Model could or couldn't became an alternative approach to ASD
	parenting. The feedback based on the parents' experience is a valuable asset.
	The way I will proceed with my research topic is to collect data from interviews
	with clients and cluster them according to the arising thematics and meanings.
	Then, at the stage of discussion, the elements will be combined with the
	existing literature review, making an effort both to confirm and to enrich the
	existing researches.
Explanation of Method	What I am aiming at is capturing as vividly and accurately as possible, how
	parents of high functioning autistic children experience this configuration of self,
	i.e. being a parent, and particularly a parent of an autistic child. I will try to
	follow their efforts and ask them to share their experience with Gordon's Parent
	Effectiveness Program.
	The chosen method of research will be the Interpretative Phenomenological
	Analysis (IPA), a qualitative research aiming to bring into light the perceptions of
	the participants and link these to the theme of interest of the researcher.
	Data will be collected through semi-structured interviews to give necessary
	freedom of expression to participants within the context of interest of the
	researcher.
Information Sheet for	
Information Sheet for Participants	Appendix 1

Informed Consent Form	Appendix 2
Interview questions	Appendix 3
Details of how information will be held	I will do all that is necessary to preserve participant anonymity and any information obtained during the interviews or otherwise will remain confidential.  The measures to ensure confidentiality are the following:  Any emails exchanged will be erased after serving their purpose.  The interview recordings, once transcribed, will be permanently erased.  The transcripts will be codified without assigning any personal details.  The study will not disclose any details that may lead to their identification.  If quotations from the transcripts are used in the thesis, these will not in any way endanger clients being identified.
Details of how results will be fed back to participants	A summary of the research findings will be available to all participants as soon as concluded and will be sent by email or mail.
Letter of consent from any Collaborating Institutes	n/a
Letter of consent from Head Teacher, if participants under the age of 16 years of age	n/a
Is any other External Ethical If yes, which Committee?	al Approval required? NO

ICPS will only give conditional approval until all evidence is provided and the project cannot commence until approval is granted.

Appendix 1: Letter of Information to Participate in Research

"How parents of high functioning autistic children experience Gordon's Parent

Effectiveness Training: a qualitative analysis"

You are hereby invited to take part in a research conducted by me, Eleni Maria Katsoura, a post-

graduate student undertaking a Master's of Science in person-centred counselling.

Institution: ICPS-Greece. Accredited by the University of Strathclyde, Glasgow.

If you have any questions about the research, please feel free to contact me at:

T: 6944114006 or/and E-mail: emkatsoura@gmail.com.

**PURPOSE OF THE STUDY** 

The purpose of this study is to indulge into how parents of high functional autistic children

experience Gordon's 'Parent Effectiveness Training'. The idea is to investigate the reasons for

choosing this particular parent training program, see if any previous expectations were met during

and/or after the completion of the training and take some time to reflect on the whole experience,

both at a personal level as well as in terms of parent-child relationship.

**PROCEDURE** 

The prospective participants are parents of children who have received an official (state) or

unofficial (private) diagnosis of ASD, particularly in the high functioning end of the spectrum, and

who have successfully concluded the 30 hour training under the supervision of a certified instructor

in Greece.

Should you decide to volunteer your participation in this study, kindly inform me accordingly

via e-mail, phone call or text message and I will contact you to arrange an interview meeting of

approximately 60 - 70 minutes, at convenient date, time and place of your preference.

The interview will be audio-recorded and transcribed.

It might be that a second follow up meeting is considered as required lasting no more than

half an hour, pertaining the above conditions.

Note that the participants will not be obliged to inform their instructors and/or referees

about their participation.

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### **POTENTIAL RISKS AND DISCOMFORTS**

If any discomforts arise, I will personally make all the necessary arrangements together with another colleague and person-centred counsellor so that you are able to discuss whatever might have emerged due to your participation in the research - of course at no charge.

### POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

I hope that participating in the study will provide the participants with the opportunity to take a small step back for a little while, reflect on their experience and evaluate it or even assess their present situation compared to it. It may also be insightful and possibly helpful for future reference. However, this cannot be guaranteed.

The information received from the interviews in this study will benefit all ASD community, providing an idea of how Gordon's Model could or couldn't became an alternative approach to ASD parenting. The feedback based on the parents' experience is a valuable asset.

### **CONFIDENTIALITY**

I will do all that is necessary to preserve participant anonymity and any information obtained during the interviews or otherwise will remain confidential. The measures to ensure confidentiality are the following:

- Any e-mails exchanged between the participants and me will be erased permanently after serving their purpose.
- The recordings -once transcribed- will be permanently erased and -if requested- they will be sent to the participants.
- The transcripts will be dully codified without assigning any personal details as well as code encrypted. Copy of the transcript will be sent to each participant if (s)he so desires.
- Any hard copies of transcripts will be locked in a secure place and permanently destroyed by shredder at the end of the research.
- The study will not disclose any personal details that may lead to a participant's identification.
- If quotations from the transcripts are used in the thesis, these will not in any way endanger a person's identification.

PARTICIPATION AND WITHDRAWAL

Should you decide to participate in this study you may withdraw at any time before, during

or after the interviews but no later than the submission of the thesis. No questions will be asked as

to the reasons of such withdrawal and you will not be held accountable with consequences of any

kind.

During the interviews, it also remains to your absolute discretion not to answer questions

you do not feel comfortable with.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE SUBJECTS

A summary of the research findings will be available to the participants as soon as these are

concluded and will be sent by email.

**SUBSEQUENT USE OF DATA** 

Any data appearing in the thesis may be used in subsequent studies, in publications and in

presentations.

These are the terms under which I will conduct my research.

Eleni Maria Katsoura

Department of Psychology

ICPS College-Greece

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# Appendix 2: Consent Form

I have read and understood the letter of information concerning the study: "How parents of high functioning autistic children experience Gordon's Parent Effectiveness Training: a qualitative analysis" My questions have been answered to my satisfaction, and I hereby agree to participate in this study. I have been given a copy of this form. Name of Participant: Signature of Participant: Date: Name of Researcher: Signature of Researcher:

Date:

## Appendix 3: Interview Questions

First of all, I would like to thank you for accepting my invitation to take part in this survey ....

- 1. As I have already informed you, the goal of this survey is to explore your experience with Gordon's Parent Effectiveness Program (PET). Since you are participating in this survey, I take it for granted that you are a parent of an autistic child. Could you kindly elaborate on that? What does autism and/or being autistic mean to you?
- 2. Since you are participating, I also take it for granted that at some point you sought for some parenting advice. Could you describe to me what urged you to do that?
- 3. Where did you look for help and how was that whole procedure for you?
- 4. What was recommended to you and why did you choose PET?
- 5. What were your initial expectations from PET, if any? Could you describe them in some detail?
- 6. Who was your particular parent's group comprised from? What was your experience on that and how did it affect your participation in the program if so?
- 7. What did you personally experience as particularly helpful and as non helpful in the PET?
- 8. During your training, did you feel that something was missing? Would you like to change anything in the PET? Or, better yet, do you have any particular suggestions for parents of autistic children based on your experience?
- 9. How would you characterize your overall PET experience? Did you notice any changes in your relationship with your autistic child?
- 10. After the conclusion of PET, did you experience any particular shifts in yourself or in your autistic child in general?
- 11. Is there anything else you think is related to the subject of my survey and you would like to point it out to me?

Thank you very much.