

Dublin Business School

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When Words Fail;

An Explorative Study of the Experiences and Impacts on

Families living with a child diagnosed with Autism

Spectrum Disorder.

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Abstract

The research project was an exploration into the impacts and experiences on families living with and raising a child with a diagnosis of Autism Spectrum Disorder. The specific aim of the study was to explore how parents and siblings in the immediate family of the autistic child were affected, if at all, by living with the child. The study method was qualitative, and involved qualitative structured interviews with a sample of 4 service providers who have had or are working with children with autism, and/or have had or do have experience of point to point daily or weekly contact with the families. Each of the participants detailed comprehensive perspective of the impact on families during the duration of a 45-minute interview, which posed questions specifically on marriage impact, sibling impact, symptomatology of autism, coping strategies, gender roles within the family and service provision within the Irish State. Mothers were found to feel under a greater deal of stress than fathers. A significant financial burden was found, along with concerns around services for their child when they reach the age of 18 and a theme of frustration around alleged lack of services in general. It was also found that parents are reluctant to seek social support from neighbours and extended family members due to embarrassment around symptomatology, and also due to a sense of responsibility over the child. It was also found that a diagnosis is more difficult to accept if the child is high functioning on the spectrum. Parents with more than one child were reported to focus more energy and time to the autistic child resulting in less energy and time into siblings, however it was reported that siblings generally respond well and adjust well to the autistic child. Counselling services were not availed of by families, nor were the families offered counselling services during the diagnosis process. The traits and symptoms of autism were concluded to cause a great deal of stress to the families.

CHAPTER 1 INTRODUCTION

1.1 Outline.

This Thesis explores the impact on the families who live with and raise a child on the Autistic Spectrum Disorder. The aim of the research was to gain an in-depth insight into the world of the families. The earliest theory of the aetiology of autism was that mothers had failed to facilitate their child's psychological development, an unproven, speculated theory which placed heavy burden on parents who were presented with a diagnosis and told they were to blame (Kring *et al* 2010). In 1998, Dr Andrew Wakefield published 'The Lancet', a paper that linked autism to the Measles, Mumps and Rubella (MMR) vaccine, a theory that instilled fear into parents and despair into parents of autistic children (Sanchez and Rose, 2010). Dr Wakefield has since been struck off the medical registrar after it was found that his research was unethical and misleading (Sanchez and Rose, 2010). Nonetheless, autism continues to be linked to the MMR vaccine. To date, there has been no proven cause of autism, although evidence points strongly to genetic components (Kring *et al* 2010). Much uncertainty around the cause and treatments of autism remain, and it is the families who are at the heart of this uncertainty. The current research attempts to explore how life following autism diagnosis impacts on the family system. Global literature will first be examined, followed by how the study was designed. The researcher then presents the findings of the research, followed by a discussion which examines themes and relates back to the review of the literature. The Thesis concludes with recommendations for future research. The research may be beneficial through what is outlined in its' findings. The research also highlights a need for sufficient support such as counselling and psychotherapy for families reported to feel isolated and unsupported, and indeed

more awareness around the benefits of counselling and psychotherapy.

CHAPTER 2 LITERATURE REVIEW

2.1 Introduction.

Autism Spectrum Disorders (ASD) refer to a wide range of complex developmental disorders that typically appear during the first three years of life. The American Psychiatric Association (APA 1994) DSM 4th edition identifies the developmental disorder as a qualitative impairment in social interaction, communication, and behaviour with delays in social interaction, language and play (Kring *et al* 2010). These impairments are pervasive, although the way in which autism manifests itself varies from individual to individual. The prevalence of autism is between 60 and 100 per 10,000 children under the age of ten, and in Ireland there has been a rise of 1,868 in the year 2006 to 2,741 in 2008 (National Council for Special Education, NCSE 2008/2009). Currently, 70% of pupils on the ASD attend mainstream primary schools, while 24% attend mainstream post-primary schools and 6% attend non autism specific special schools (NCSE 2008/2009). Bee and Boyd (2007) state that just under 1% of children in the United States of America have some kind of autism or Aspergers Syndrome. Both ASD and Aspergers Syndrome, a mild form of autism, come under the term of Pervasive Developmental Disorders (PDD). Parents tend to report that they notice their child's peculiar behaviour during the first few months of life, but they will typically begin to notice that their child is displaying behaviours not typical of their repertoire by the age of two (Kring *et al* 2010). They may notice that their child has ceased to use the language that they had previously acquired or perhaps they might notice unusual repetitive and disturbing behaviour such as ritualistic behaviour. What strikes these parents is their infant's apparent lack of interest in people. However in most cases, the disorder is not definitively diagnosed until the child's

failure to develop normal language skills make it apparent that they are on an atypical developmental path-this usually occurs between the first and second birthday (Bee and Boyd, 2007). Autism is life-long and there is no treatment that is curative, however early intervention can significantly improve social, cognitive, communication and emotional development and these interventions include speech and language therapy (SLT), occupational therapy (OT) and medication. Behavioural strategies such as Applied Behavioural Analysis (ABA) have been the most widely acclaimed (Kring *et al* 2010). It is difficult due to the very nature of autism to gain insight into the thought patterns and behaviour of individuals, but there are cases where individuals with a diagnosis have been able to express themselves to a point where a glimpse of how it is to be autistic can be seen. Temple Grandin describes her experience of autism thus;

“My emotions are simpler than those of most people. I don’t know what complex emotion in a human relationship is. I only understand simple emotions such as fear, anger, happiness, and sadness. I cry during sad movies and I sometimes cry when I see something that really moves me. But complex emotional relationships are beyond my comprehension” (Temple Grandin, as cited by Rowe, 2007; 77).

The literature review aims to examine the following;

1. The Consequences for the Family following a Diagnosis of Autism.
2. Sibling Impact.
3. The Effects on the Parental Subsystem.
4. The Impact of the Symptomatology of Autism and the Coping Strategies employed by Parents.

5. The Use of Counselling and Psychotherapy by Families.
6. The Current Position of Services for Children and Families in the Irish State.

2.2 The Consequences for the Family following a Diagnosis of Autism.

Recent literature based on qualitative and quantitative studies have focused on the effects that having a child with autism has on the family. A wide range of this literature appears to indicate that the consequences for the family cause a great deal of stress related problems. This may be due to the typical traits of autism which can include poor sleeping patterns, self-harming behaviour, absence or lack of typically developing language skills and disruptive behaviour. Together with these traits, delays in diagnosis and lack of social support, there may be an impact on the immediate family. Children on the autistic spectrum display challenging behaviours and often disrupt daily family life, such as public sexual behaviour, physical aggression, stripping of clothes, spitting and screaming. Families are reported to feel guilt, desperation and shock following a diagnosis with mothers more likely than fathers to report that their emotional well-being is seriously affected, particularly as a result of their child being unable to express the most basic need (Gray 2003). Because the onset of autism appears at around the age of 2 years and typically not before, it would appear that parents of the child go through a period of shock and grieving in the initial aftermath of the diagnosis. Indeed Boushey (2004) states that parents of children with disabilities go through a grief cycle just like that of the grief cycle of a death or divorce which could include denial, anger, bargaining, depression and acceptance (Kubler-Ross and Kessler, 2005).

In Ireland, diagnosis of the spectrum remains to be problematic, mostly due to delays of the actual diagnosis. The 2001 Task Force on Autism refer to this delay as

“unsatisfactory and unacceptable.” Oppenheim and Goldsmith (2007) studied mothers and fathers of pre-school age boys regarding the diagnosis of ASD, using the Reaction to Diagnosis Interview (RDI) with a view to illustrate resolved and unresolved acceptance to the diagnosis. They found that those who were resolved with respect to the child’s diagnosis changed their perspective from the time of diagnosis to the time of the RDI. Some parents began to accept that this was still their child whom they loved very much, and that positive progress in the child enhanced their feelings from shock and despair to acceptance. This set of parents also ceased to search for a reason for the child’s autism. Oppenheim & Goldsmith (2007; 117) maintain that it is not that they cease to “seek information about the disorder or treatment options, but rather not being preoccupied by this search”. The set of mothers who were unresolved with respect to the child’s diagnosis were described as not being able to allow themselves to “express painful emotions in reaction to the diagnosis or are still absorbed in the initial response to the diagnosis” (Oppenheim and Goldsmith, 2007; 122). This set of parents appeared to be angry, shocked, depressed and in denial. The study found that 33% of mothers were classified as resolved. However, the length of time it may take to receive a diagnosis may impact on how the mother or father can resolve themselves to the diagnosis particularly if the diagnosis has taken so long that it has impacted on the child’s right to early intervention (Oppenheim and Goldsmith, 2007). Gray (2003) found this delay to be a struggle for the family, in particular the mother, with the long referral process having negative effects. Mothers felt that the absence of a diagnosis resulted in accusations of ‘parental incompetence’ by the wider family (Gray 2003). It would appear then that some parents feel relief at receiving a diagnosis, and can then account for disruptive behaviour and possess explanations for these unusual and at times, socially inappropriate behaviours. However, it is chiefly noted that the process

of diagnosis is a major source of stress. Wing (1985 p. 61) states that “the problem is made worse by the fact that parents are likely to meet many different theories on their travels and they may become confused and depressed”.

Schloper and Mesibov (1984) suggested that there is a lack of acceptance of the diagnosis from the extended family and society, perhaps due to a lack of knowledge on autism and poor social awareness. Messenger (2009; 88), supports this finding and states; “all I ever wanted was for my little girl to be treated like a little girl. Not like a granddaughter, niece or cousin with autism”. Whilst many parents wish for their child to be treated as though they were a typically developing child, Holmes and Carr (1991) found that friends and neighbours were often reluctant to offer help. Whitaker (2002) stresses that exercises to combat stress and self-care regimes should not come too soon after the diagnosis, due to the presence of shock. In contrast to other developmental disorders, the families of children with autism are at a greater risk for depression and isolation (Heiman and Berger, 2008). Anecdotal evidence suggests that the stress is indeed overwhelming for parents and many suffer a financial burden. There has been little researched on a national level around the financial burdens. However, research has been widely developed in the United States where it is found that there is a considerable amount of financial burden on parents (Jarbrink, Fombonne and Knapp, 2003). Sharpe and Baker (2007; 248), found that some parents experience bankruptcy due to private Speech and Language sessions and various other treatments, adding that “the educational programs that are provided are rarely sufficient to address the needs of school aged children with autism and are not available to young adults with autism”. It would also appear that financial impact of autism is greater than the financial impact on families with a child with other special health care needs and who do not attend respite care (Kogan, Strickland, Blumberg,

Singh, Perrin, van Dyck, 2008). With regards adolescence, there is evidence of further stress when the period of puberty arrives, and parents have been reported to endure worry over respite care and long term residential provisions for their adolescence. Lord and McGee (2001) found that the demands on parents to provide for the needs of each individual in the family and indeed their own needs can cause a substantial amount of stress as they attempt to raise their child with autism and negotiate their own feelings of sadness and disappointment.

2.3 Sibling Impact.

Although the parents do suffer a great deal of emotions and stress, siblings also are impacted. Research shows that siblings with a brother or sister on the autistic spectrum are correlated with various negative and positive effects. These siblings appear to possess an awareness of the unusual behaviours displayed by their sibling from a young age. There is a mixed response to how this awareness affects the siblings, and findings tend to be associated with whether or not the siblings had access to adequate support from both peers and professionals. Kaminsky and Dewey, (2002) found that being in a large family helped facilitate adjustment. Positively, this same study found that siblings were well reported low levels of loneliness and adequate social support (Kaminsky and Dewey 2002). This same study found that if it were the case that the sibling was isolated and suffered loneliness, it may be due to lack of social support. Research has tended to focus on psychosocial adjustment and correlations with the number of children in the family. As may be the case for parental stress, the greater the symptomatology and severity of disability, the greater the effect on the sibling. Literature shows that less parental attention to the sibling is not correlated with jealousy or feelings of neglect; in fact findings conclude that the

siblings feel very positive about their relationship with both the autistic sibling and with parents. Roeyers and Mycke (1995), found that siblings of autistic children understood the disorder well which enhanced the quality of the relationship. It appears evident from this literature that research has tended to focus mainly on the relationship between the sibling and the autistic child and social adjustment and skills gained from being the sibling of an autistic child.

2.4 The Effects on the Parental Subsystem.

There appears to be some consistency in the literature that mothers experience greater impact than fathers. This may be due to the evidence that shows that mothers tend to leave full-time employment to care for their child. Brobst, Clopton and Hendrick (2008), compared 25 couples with child or children on the ASD with 20 couples of typically developing children. Comparisons were tested on stress and relational variables with results indicating that the parents of children with ASD experience greater parenting stress and lower marital harmony. Hartley, Barker, Seltzer, Ffloyd, Greenberg, Orsmond and Bolt (2010), compared divorces of 391 parents of autistic children with parents of typically developing children. The divorce rate of parents of autistic children was 23.5%, significantly higher than the 13.8% divorce rate of the comparison group. Gray (2003) also outlined the difference in impact between mother and father and found that fathers tended to acknowledge that the mother endured stress and that this had a negative impact on the marriage. Mesibov and Schopler (1984), state that coping with the reaction of the diagnosis could test the most solid of relationships, adding that couples may either turn to each other for support or turn their pain on one another. Fathers and mothers express their difficulties in different manners while mothers express emotion through crying and anger and fathers either

claim that their child's disorder had little effect on them, or that they suppress their emotions. Gray (1993) suggests that this may be partially due to gender roles. Mothers report significant changes in their lives with regards to their careers, responsibility, relationships, and their ability to modulate stress arousal (Gray 2003). The literature suggests that mothers tend to be expressive in their emotions, relaying their grief and sadness to family members and friends with fathers showing more commitment to their careers, and suppressing emotions related to the initial diagnosis, and the aftermath of the diagnosis.

2.5 Symptomatology of Autism and Coping Strategies employed by Parents.

Added to the long process of receiving a diagnosis, the financial impact, the feelings of grief and loss, it would also appear that the level of symptomatology is linked to parental stress (Hastings and Johnson 2001). That is, the greater the symptomatology, the greater the parental stress. Dale Gardner, (as cited by Gardner, 2007; 334), a young boy with autism describes how hearing the words 'proud' or 'OK' would frustrate him to the point of self-harm;

“Words like ‘proud’ – if I didn’t understand what they meant, it really frustrated me and gave me the same irritating feeling in my head. That’s why I would hit my head with my fists or bang it off the wall, to get rid of this weird irritation these words caused”.

Such behaviours are not uncommon in children with autism. Luther, Canham and Cureton (2008), identify a need in parents to acquire social support as a coping strategy for the behaviours manifested in autism, whereas others use denial or social withdrawal in their attempt to cope (Luong, Yoder and Canham 2009). Abbeduto, Seltzer, Shattuck, Krauss, Orsmond and Murphy (2004), conducted a comparative study in which the psychological impact on mothers was examined in mothers of

children with Fragile X syndrome, Down Syndrome and Autism. It was found that the psychological wellbeing of mothers of children with autism was mostly compromised, and what was the most consistent predictor was the symptomatology of their child's autism.

Gray (2003) looked at coping strategies in a qualitative study among a sample of parents with autistic children. Stressors that the parents attempted to cope with included the lack of normal language, disruptive and violent behaviour, inappropriate eating and toileting and inappropriate sexual expression. There does not appear to be any one particular coping mechanism widely used by families, although family support seems to be widely cited and appears to be the most successful strategy for parents to use. Sharpley, Bitsika and Efremidis, (1997) found that 81.9% of parents felt overwhelmed by their daily lives around the typical traits of autism, with the lack of sufficient support of respite adding to the stress. It has also been reported that higher levels of symptomatology are consistent with higher levels of stress in parents (Hastings and Johnson, 2001). What appears most commonly in the literature is that families feel that the alleged lack of services contributes to their feelings of not being able to cope and in not knowing how to deal with decreasing behaviours. Indeed, this alleged lack of available services combined with the lack of public awareness impact on the parental subsystem and wider family to make coping difficult. Despite the evidence to support the theory that many parents use social supports, many of them state that isolation is still very much present in their daily lives as a result of symptomatology (Dunn, Burbine, Clint, Tantleff-Dunn, 2001), which highlights the imperativeness of social support as a coping strategy. However, acceptance, spiritual enlightenment and engaging in peer relationships have also been found to assist in ways of coping in parents (Luong *et al*, 2009).

2.6 Counselling and Psychotherapy for Family Members.

There is little researched on both a national and international level about the benefits of counselling for family members and the use of counselling by family members. Heller, Miller and Hsieh (1999), found that family support programs can assist with the family's ability to cope with care provision. In addition, Bitsika (1999) carried out an exploratory examination of the effects of group counselling on the well-being of parents. Fourteen parents of children with autism attended group support and the study found that the support group provided additional support for the parents but they did not find any significant benefit due to the lack of stress reduction skills. Gray (2003) found that mothers tended to seek the services of counselling more so than fathers, whilst Bromley *et al* (2004), found that 50% of mothers in a quantitative study were found to be positive for psychological distress. Literature tends to focus on the use of counselling to enhance the life of the child. This includes directive therapy (Coplan, 2000), and therapies that assist in how to deal with symptomatology (Akkok, 1994). Whilst these forms of counselling may be very beneficial with regard managing behaviour, there has been little published on the benefits of humanistic and psychodynamic counselling which would provide a listening space and containment for both parents and siblings. Literature also tends to focus on counselling for individuals with autism and whether psychodynamic approaches can be applied to these individuals or not. Nuala Gardner, (2007; 340), a mother of two autistic children states; "Parents in similar situations to ourselves are still driven to the brink of suicide because of lack of support and understanding". Given the demands placed on parents coupled with grief following the diagnosis and a lack of social support, it seems imperative for there to be some focus toward the use of counselling as a source of support. However, there appears to be a considerable gap in the literature around

counselling and psychotherapy for families and in particular for siblings of the autistic child.

2.7 The Current Position of Services for Children and Families in the Irish State.

In recent years autism has been one of the most marginalised developmental disorders in the education sector, and indeed it has shown to be one of the most stressful developmental disorders for the family system. Counselling and Psychotherapy or any other means of support do not appear to be widely recommended within the delivery of the diagnosis. Centers which provide diagnosis and services for children with autism in Ireland have in recent years begun an individual counselling service for parents of children with autism, and more recently a relationship counselling service. The significant demand for the service coupled with demands for support groups could be a sign of the distress and despair that parents are sometimes faced with. The 2001 Task Force on Autism stated that the establishment of its report meant that education and support for persons with autistic spectrum disorders could be comprehensively explored for the first time in Ireland. It included its intention to have regard to the distinct needs of certain children with autism, and to the commitment to the special educational needs of children with autism. This report emphasised ‘urgency’ that research be conducted into the prevalence of autism (ASD, PDD and Aspergers). However, there has been a need for review on education policy, research and awareness. The European Autism Action Conference (Autism 2010) took place on 29th November 2010. This event launched a ten-year strategic public health plan, 'European Autism Action 2020' and the European Autism Public Health Alliance. During the meeting autism was described as “a significant public health challenge” in Europe and concluded that there is a lack of research funding or collaborative efforts

to identify risk factors for ASD. It was also concluded that no consensus exists on how to educate people with ASD. A vast amount of positivity has been invested in the latest strategic plan and the response of parents is generally of optimism and hope. Additionally, there has been a commitment in Removing Barriers to Achievement by conducting a four-year programme to continuing professional development, which is hoped to meet the needs of Special Education in mainstream settings. The President of the United States, Barack Obama recently declared April 2nd as World Autism Awareness Day and also declared it long overdue. It would appear now that on a national and international level, awareness around autism and the needs of the child and the family are much improving, and it would be hoped that this can impact positively on the families.

2.8 Overview.

For parents siblings and the wider family, it appears that the stress is not only caused by the fact that the child has obtained a diagnosis but also because of the way in which autism manifests itself so disruptively. Added to an alleged lack of support services and alleged poor public awareness, families appear to suffer from tiredness, overwhelming stress and loneliness. In Ireland there has been a difficulty in gaining access to services that can assist the parents in helping their child to reach their maximum potential, such as waiting for the diagnosis, appropriate education and long waiting lists for schools that teach through ABA, a scientifically proven method of teaching. There appears to be a gap in the literature of how the symptoms and traits of autism impact on the family, and whether or not it is these traits that can raise levels of stress and impede the acceptance and resolving of the diagnosis and prognosis.

From the research it could be concluded that;

- 2.2 The process of receiving a diagnosis, coupled with the stress of symptomatology, causes a great deal of stress to the family system.
- 2.3 The impact on siblings is correlated with both positive and negative experiences.
- 2.4 Mothers tend to be impacted a great deal more than fathers.
- 2.5 Although parents attempt to seek social supports, the symptoms and traits of autism makes this difficult to do.
- 2.6 Despite a limited volume of literature on the subject of counselling for families of autistic children, demands for counselling services in Ireland are indicative of the need for more awareness and information of the benefits of counselling for families.
- 2.7 Although there has allegedly been a gap in the education sector for children with autism, the Irish State appears now to be in review of its policies and indeed becoming action orientated in its approach to service provision.

CHAPTER 3 METHODOLOGY

3.1 Aims and Objectives.

This research aims were to explore the impact on the family who live with a child on the Autism Spectrum Disorder, and how the family experience that impact. The specific objectives are to note the experience of the sibling child, marital impact, to examine whether the symptomatology of autism has a negative or positive effect on the marital system and the ways in which the mother and father experience their child.

3.2 Ethical Consideration.

The Belmont Principles of The Belmont Report (1979) were employed by the researcher. This meant acknowledging key ethical principles with regards to respect, beneficence and justice. Therefore the researcher had respect for persons acknowledging that all persons are entitled to autonomy. Secondly the researcher took into account beneficence, which meant that any decisions of the interviewees were respected, such as their wanting to terminate the interview at any time and in addition there were efforts made to include their well-being. The researcher also acknowledged the Hippocratic Oath of Do No Harm. Justice was also an ethical stance; therefore the researcher treated all interviewees equally and fairly, with consideration to each of their individual needs. Interviewees signed informed consent sheets and therefore received the opportunity to consent to the interview as an informed voluntary choice. The researcher also abided by the Code of Ethics of The Irish Association of Counsellors and Psychotherapists. Respect, competence, responsibility and integrity were of paramount important throughout the course of the research project. The interviewees were informed of the limitations of confidentiality and were guaranteed

anonymity.

3.3 Research Strategy.

The research used a qualitative method in order to gain an understanding of experience. Qualitative data is concerned with meanings, with a view of the want for understanding, explanation and interpretation (Crabich, 2007). It was decided to integrate the qualitative method due to its' significant advantages in relation to these particular research questions. According to Bryman (2010; 366), "qualitative research is concerned with words rather than quantification" and will therefore allow for the uncovering of insight through reflective experience. Ritchie and Lewis (2003; 3) describe qualitative research as a "naturalistic, interpretive approach concerned with understanding the meanings which people attach to phenomena (actions, decisions, beliefs, values etc.) within their social worlds." This is what this study aims to do. The researcher used a structured interview method as a means of gathering qualitative information. In addition, the researcher concluded that the method of structured interviews would allow in depth descriptions and for an in-depth analysis of the dynamic of the experiences of families.

3.4 Research Design.

One to one structured interviews were employed by the researcher, which allowed for all interviewees to be each given the same structured questions. Bryman (2010) suggests that the structured interview therefore can be achieved reliably in response to identical cues. The questions are specific and allow for fixed responses, with the researcher gaining access to deeper insight into the impact of families. Each interview was allocated 45 minutes and the interviewees were interviewed separately

by the researcher. They took place at a School for Children with Autism and the interviewees were tutors to these children, and were engaged with point to point contact with families on a daily basis. Questions were direct and specific.

3.5 Research Sample.

Letters were sent out to tutor staff at a Special School for Children with Autism. In total 20 letters were sent out, and one participant who worked at separate institution was contacted by phone. 2 people declined to take part and 11 did not contact the researcher therefore it was concluded that they did not want a part on the research. The sample size of study was therefore originally 7 participants; however, 3 of the original who had agreed eventually declined, therefore the final sample size who completed interview was 4 participants. The sampling method was a non-probability form and used purposive and convenient sampling. Bryman 2010 (p. 183) states that convenience sampling is “simply available to the researcher by virtue of its accessibility”. Due to the fact that The School for children with autism was a location where the researcher had once been employed, it was felt that a good response rate was highly probable. Purposive Sampling was used because the particular research goals were compatible with, and relevant to the setting in which the interviews took place. The researcher explained the nature of project before the interviews took place.

3.6 Materials.

An iPhone was used to record the interview. Interviewees had control over when they wanted a break or to end and were informed of their right to terminate the interview at any time. The interviews were transcribed verbatim on a PC before being deleted

3.7 Data Recording.

The interview process occurred over a period of two weeks. According to Dey (1993:77) qualitative “data must be recorded fully and accurately.” The analysis was done by hand before being transcribed verbatim. The researcher listened to the recordings 3 times in order to become completely familiar with emerging themes. Transcribing verbatim took a total of 9 hours and 10 minutes, and the content was read several times by the researcher, before listening to the taped session once again to verify the typed accounts.

3.8 Data Analysis.

The data analysis was a thematic form. The themes were identified and interpretation commenced. This was in the form of a thematic table, in which themes were identified as they were coded.

CHAPTER 4 FINDINGS

4.1 Introduction.

The aim of this study was to explore into the lives of families who have a child on the ASD, and how this affects the family. It was intended to be able to view how the mother and father differ in their way of coping and in their way of managing behaviour and household tasks. A further aim was to gain insight into the lives of the siblings of the autistic child and to explore how they were impacted both positively and negatively. Another aspect of the research was to examine if it was the symptomatology of autism that impacted heavily on the parents, and how the current services provided by The Irish State are regarded by the family. It was also intended to demonstrate the use of counselling services by families, their knowledge of the benefits of counselling and whether or not counselling had been recommended by professionals such as their Speech and Language Therapist, the professional who delivered the diagnosis and general service providers. In total, 4 participants took part in the research and completed interviews on a one-to-one basis. Three of these participants, 1 male, 2 female, worked with children with autism through the teaching of ABA and had daily contact with families, whilst 1 participant (female) is a psychotherapist who works with mothers whose child or children are on the spectrum. Each of the 4 participants was asked a total of 15 question which were asked in relation to five different sections: The Family, The Parental Subsystem, Service Provision, Symptomatology and Coping Styles. Questions around counselling services were asked within each of these sections.

4.2 The Family.

The findings of 'The Family' are separated into 5 different headings, namely sibling impact, psychological impact, financial impact, diagnosis impact and counselling services.

4.2.1 Sibling Impact.

When asked about how siblings are affected, there appeared to be a sense of embarrassment and anger around the autistic sibling's (hereafter referred to as 'the child') behaviour and the amount of time parents had to spend with the child. At the same time it appeared that the siblings' are also hugely loyal to the child. One participant suggested that they had come across siblings that have gained a dislike toward the child who has autism, suggesting that it may be because "that child with the special needs has taken up a lot of time in the family and they feel left out and stuff but you know at the same time these same kids are remarkably grown up and they are so good, and do things you know, and take care of them and make sure that they have the best experience and go on school trips with them and they are very supportive of them". Another suggested that "they give up a lot to make life easier". Another participant stressed that parents are completely aware that they need to devote time to their child and therefore sometimes "neglect the siblings". It would also appear that their lives are especially affected when it comes to sibling friendships. One participant commented on this and stated that "a lot of them are embarrassed sometimes, around inviting friends over and stuff. Autistic children don't know anything about boundaries, they might go up a hit their sister or brother's friends and instead of the siblings risking losing their friends, they just don't bring

them round to their house.” Regarding sibling coping mechanisms, the responses mainly showed that siblings tend to engage themselves with the child by doing homework with them, going on school trips with them and attempting to familiarize themselves with their autism as much as possible. It was also found that siblings tend to form friendships with other sibling’s also in a similar position.

4.2.2 Psychological Impact.

When the participants were asked whether or not they had witnessed any psychological distress in the family the responses were similar. Two participants said no. Two participants mentioned no also but added that stress most certainly takes its’ toll and that it was visible on the body. One participant stated “It’s pure frustration for them. Nothing serious. Sort of despondency, because there’s a lack of hope.”

4.2.3 Financial Impact.

What really stood out was a significant financial burden on families. All interviewees pointed out the need for the child to participate in private SLT sessions, whilst one participant pointed out that children on the spectrum also needed to undergo psychological testing, occupational therapy (OT) and sometimes home tuition. One participant suggested that there are not many services in the region for children with autism that might include leisure and sport, such as swimming and football. He added how this impacted financially by stating;

“It is something that every one of these children should have the right to; a special needs class with an opportunity to interact with peers. But parents have to fork out to put their kids in special camps. I mean parents of typically developing children might just let their child out on the street with a bike. Parents with children with autism-they don’t have that option.”

All 4 participants also said that if a family could not afford private SLT and OT sessions, that the child's speech may not improve, leaving the parents with a guilt around not being able to fund absolute necessities.

4.2.4 Diagnosis Impact.

When asked about whether or not the diagnosis has been accepted by the family, it was found the diagnosis is harder to accept if the child is higher functioning on the spectrum. It was suggested that this could be because the child did not display severe behaviours typical of that found on the lower end of the spectrum and because the child may only have had impairment in social interactions and communication but be developing typically in all other areas. One participant explained this thus;

“In most cases when the child is severe, yes they accept the diagnosis, but in cases where the child is higher functioning parents seem to find it harder to accept. They know there's something a little wrong but they don't fully accept it. If we advise a method for the child they don't really take it in because they think their child isn't fully autistic so you find that they wouldn't go ahead with the recommendations.”

What also came across was that parents felt that if their child was higher functioning, they almost had to prove that they needed help and support. Overall, it was found that there was a mixed response. Some parents find a feeling of relief with a diagnosis whilst others denied it and struggled to accept it. However, all of the responses stressed that there was a feeling of isolation in the aftermath of the diagnosis regardless of acceptance or denial.

4.2.5 Counselling Services.

One participant knew of two families availing of counselling. Three participants stated that as far as they were aware, counselling was not availed of by families. None of the siblings attended counselling and psychotherapy. It was found that during the process of the diagnosis, counselling was not offered to parents as a suggestion to alleviate stress and distress, however, it also emerged that financial issues may have hindered the family's decision to attend counselling. One participant stated that if counselling had been offered to parents during the process of the diagnosis, that they may have accepted the diagnosis sooner, and that it may have provided them with a great deal of relief.

4.3 The Parental Subsystem.

The second section focused specifically on the parental subsystem and explored the area of gender roles in the subsystem, coping mechanisms used by each gender, whether or not each parent accepted the diagnosis if they hadn't accepted it previously and how each parent may differ in their approach to the child and the child's behaviour. It also focused on whether or not the marital subsystem had been affected. It was found that fathers tend to be "more laid back" around seeking sufficient education for the child and how they feel about the child's behavior in public, whereas mothers tend to become embarrassed and feel that they have to explain the child's behavior if a child becomes unsettled in public. It was also found that mothers felt guilt about the diagnosis and tend to be more active and "strict" in their approach on parenting than fathers. One participant stated "I think because the mother carried the child, they feel some sort of guilt around their pregnancy, what went wrong or something you know. And they sometimes just want to do everything. I can't describe

it, it's like they are saying sorry by doing all this." There was a mixed response with regard to other areas of marital impact. Two participants suggested that marriages become stronger and more united as the parents grieved and then resolved their grief, whilst two participants suggested that raising the child together causes conflict because of differing views to parenting. One participant pointed out that "lots of couples with an autistic child have called it a day, but sure who's to say that they wouldn't have anyway-autism or not?"

4.4 Service Provision.

The third section focused on service provision, whether or not the alleged lack of services impacted on the family, and how the alleged long process of receiving a diagnosis was perceived by the family. The research found parents feel angry at what they feel is a lack of support and acknowledgement for their child. They also feel that if more support for their child's education were available, that the population would become more educated about autism, which in turn would impact positively on how society perceives autism. It was also found that parents felt despair and a lack of hope due to the alleged lack of education and the long waiting lists for suitable education. One participant stated that children with autism need one-to-one education which entails "huge" waiting lists and added "There are not enough day placements and it's a growing strain for parents. Where do they go when they hit 18? There are only residential services and the parents don't want that." What came across strongly was a growing strain of worry as the child becomes older due to the concern around services for the child when they reach adulthood, and the lack of support around after care for their child. One participant stated; "Any parent needs support, but a parent with a child who has special needs needs even more."

4.5 Symptomatology.

The fourth section focused on symptomatology and attempted to explore if it was the traits of autism that had a negative effect on the family and if so, if that meant that lower functioning children with aggressive or destructive symptomatology caused more stress in the family. What was found was that the symptoms impacted on the quality of life. One child wanted all of the family to sit in the front garden from 7pm until 8pm, and the family felt that if they refused to do so, the child's behaviour would become unmanageable and so obliged this request on a daily basis. One participant showed how behaviours like this affects the family as a whole by stating; "It affects how a family functions. Everything centers around the child, holidays, and you know there would have to be allowances made and those allowances extend on to the siblings too." One participant mentioned that the worse the symptomatology, the greater the fear for the child's future. However, what was found in the responses of all participants was the greater the symptomatology, the greater the family impact around daily schedule, public outings and relationships with extended family. A child on the lower end of the spectrum was found to cause greater stress on a family than those with a higher functioning child. It was also found that the traits of autism take different forms with the onset of puberty causing a greater deal of angst for parents and a greater deal of embarrassment for siblings. There was also the added pressure for families with adolescents around trying to restrain violent behavior due to the fact that the autistic adolescent had more physical strength than that of an autistic child. With regards to children under the age of 12 years, the research showed that it was difficult for children to vocally and verbally express their needs and wants causing frustration and sadness for the family, whilst families of adolescents between the ages

of 12-18 years tend to be able to communicate a little more. Three participants suggested that the stage of having a child with autism would be more difficult than the stage of having an adolescent with autism, whilst one participant suggested it is harder with an adolescent due to the inability to restrain, and the heavy burden of attempting to locate day services and respite adult services.

4.6 Coping Strategies.

What came across strongly was the need to keep oneself busy in order to cope. Mothers tend to terminate their employment to become homemakers and then become quite active in fundraising, housework and raising awareness for autism. Fathers tend to keep busy at work, often working late hours, and weekends when the child is very young. However, fathers then tend to spend more time at home when the child becomes older. Rationalization and intellectualisation were found to be defences that mothers used. Parents tend to form friendships with other parents of autistic children and thus felt more understood. Other parents may become spiritually or religiously oriented. One participant cited a parent as saying “Whatever God gives me, I must take”. All parents attempt to use the support of their own parents, although it would appear that parents do not enlist the help of neighbours. If the child attends school parents request home help from the child’s special needs teacher which extends as far as babysitting and household help. Overall, it was found that help is only sought when the burden is absolutely overwhelming. This was found to be due to the very nature of autism. The traits and symptoms which sometimes manifests themselves into what could be perceived as inappropriate behaviour leave parents reluctant to seek outside relief for fear of the child acting out. Therefore, parents feel that it is their own responsibility to take care of their child most of the time. This was explained by one participant thus; “For some people there’s a sense of guilt about having a child with

autism because there's a lot self-blame and for some people there's a sense of shame and embarrassment and they are reluctant to ask for help." It was also found that parents felt it would not be fair to the child to leave him or her with anyone but mother or father for any length of time, due to their resistance to change and their need for regular and consistent schedules. Siblings were not enlisted for help with household chores or babysitting services, but nonetheless parents do find a great deal of support from their other children.

4.7 Conclusion.

Four participants were interviewed, all of whom worked closely with families raising a child on the autism spectrum. The impact of this on the family and the subsets within the family were disclosed, which included methods of coping, levels of stress with regard to symptomatology, awareness of the opportunity to receive counselling and the maternal and paternal roles in relation to the child. The following chapter will explore these findings in detail.

CHAPTER 5 DISCUSSION

5.1 Introduction.

This chapter discusses and analyses the research, separately and in light of global research. How the family system as a whole is impacted by autism will be discussed followed by analysis and discussion of how the parental subsystem differs by gender in approach to coping. Service provision is then discussed with the findings analysed in conjunction with previous research. Symptomatology, coping strategies and the use of counselling are then examined followed by a discussion of overall impact and recommendations for further research. Four service providers to families raising a child with autism were interviewed and participants communicated that the family system is more negatively than positively impacted by autism, through the process of diagnosis, the traits of autism, the lifestyle that needed to be adapted to and in relation to services they felt they needed to be able to provide to their child.

5.2 How the family system is impacted.

Much of the literature focusing on acceptance of diagnosis has been on an international level. The researcher bore in mind that different countries have different policies and therefore internationally the process of a diagnosis may not take as long as is anticipated in the Republic of Ireland. In this respect, it may be worth noting that the long process in Ireland could mean that the way in which the diagnosis is accepted here could differ from how diagnoses are accepted by parents who are resident in different countries. Whilst this is presently a matter of speculation, what the current research found was that the diagnosis is more difficult to accept if the child is high functioning. Similar findings could not be found in early and recently reviewed

literature; however the current study does support that of Gray (2003) who cited shock and impact on emotional well-being following a diagnosis. There was a prominent theme of isolation in the current study, particularly in the immediate aftermath of the diagnosis and this concurs with findings by Heiman and Berger (2008).

It was found that whilst siblings are often embarrassed by the child's behaviour, and at times resented the child, they nonetheless are quite supportive of both their parents and of the child. This supports research by Roeyers and Mycke (1995), who reported that was no correlation between less attention to siblings and sibling jealousy. However, when participants in this study were questioned about sibling impact and noted that siblings tend to repress their own needs, they did not elaborate on their view that siblings repress their own needs. There was a theme of siblings having to be prematurely independent and mature in the current research, for example, it was consistently cited that the siblings were remarkably grown up for their ages, and this was not thought of in a negative way, but to be a very positive aspect of their being. The researcher has considered the possibility of the defence of splitting in relation to sibling coping styles or defences, however this has not been mentioned in the reviewed literature. It is noted however, that the researcher was not aware of the sizes of families in this study, and also notes that a larger sized family may help bring about possible feelings of isolation and exclusion as proposed by Kaminsky and Dewey (2002).

Whilst the current study did not report any psychological distress on families, the researcher notes that participants may have felt under obligation to disclose such information as it is deeply personal to families. Bromley et al (2004) reported that 50% of mothers suffered from some form of psychological distress. Abbeduto *et al*

(2004) also reported that mothers of children with autism reported lower levels of psychological well-being. However, literature has not been widely researched into the potentially devastating impact that isolation and marginalisation can have on single mothers or fathers living with a child with autism or indeed how it can impact on the family system. Palermo (2003), states that a rise in filicide, the act of killing one's own child, has included several cases of children with autism concluding a need for the review of risk factors. Financially, it would appear that parents struggle with regard to the need for extracurricular activities, SLT and OT and psychological assessments. What also emerged from the findings of the current study was the theme of guilt. If parents could not afford these services, they felt that they were letting their child down. This struggle concurs with that found by Sharpe and Baker (2007)

5.3 Ways in which the parental subsystem is affected and coping styles.

Mesibov and Schopler (1984), suggest that marital discord could be avoided if parents could take time together away from the house at least once a week. However, the current research found that parents are reluctant to enlist the babysitting services of others unless absolutely necessary. A theme of responsibility arose with regard to the reluctance to call in support, coinciding with a study by Gray (2003), which found that mothers report changes in their lives with regard to responsibility. In addition, in this current study, mothers were found to cite embarrassment and worry around the possibility of the child engaging in destructive behaviour whilst with a child minder, and were therefore inclined not to seek child minding services at all. Mothers were also reported to feel more burden than fathers and also were more likely to be vocal about their feelings, whilst fathers were reported to spend more time at their place of employment than would have been usual before the diagnosis. Gray (2003), found

that there was a difference between genders in the parental system in their approach to dealing with daily struggles, namely that the mothers' stress was acknowledged by the fathers', but yet impacted on the marriage in a negative sense.

The current study received a mixed response with regard to marital impact, with 50% of participants suggesting that marriages sustain the stress and become more united, and another 50% suggesting that conflict in differing views to parenting caused the marriage to become difficult to negotiate. This supports Mesibov and Schopler's (1984) finding that marriages can either become stronger or can result in conflict. The researcher acknowledges that both the current study and the reviewed literature did not have information on the history of the marriages prior to both pregnancy and diagnosis, and therefore cannot conclude whether or not it was precisely the burden of autism that caused a marriage to run into difficulty.

5.4 Services provided to autistic children and their families.

There was a prominent theme of frustration and anger in this particular area of the research. These feelings were brought on by the perceived lack of regard for autism by the Irish Government, and how this impacted on societal views of autism.

Participants felt that if the general population were more informed and educated on autism, they would be less allegedly judgmental of destructive behaviours displayed by children whilst in public places. Indeed, literature suggests that there has been no actual consensus on how to educate children with autism, along with a lack of funding for services. This current study found that parents tend to take on much responsibility for seeking funding, although it was also found that this served as a coping mechanism for parents in order to feel useful to their child and to keep busy. The maintaining worry around respite and day services for their child in the future was a factor in the stress around service provision in this study. However, it was

acknowledged by the participants that there has been significant improvement in the promotion of autism awareness and that this brought a theme of hope to the research findings.

5.5 How symptomatology impacts on family lifestyle and dynamic.

This research found that the greater the level of symptoms of autism that manifested in behaviour, the greater the amount of stress on the family system and dynamic. The dynamic of the family was found to be compromised by the child's ritualistic behaviours and resistance to change. Families tended to cope by complying to extraordinary demands from the child in order to avoid unmanageable behaviors. There appeared to be a theme of isolation around attempting to deal with symptomatology, particularly in cases where one parent worked and the other is at home alone with a child who either did not want to leave the house, or refused to let outsiders in. The findings in the current study are consistent with those of Sharpley *et al* (1997) who cite a considerably high 81.9% of parents who struggled on a daily basis to cope with the traits of autism. Dunn *et al* (2001) also found that isolation is prominent in families with a child on the spectrum. This finding by Dunn *et al* (2001), also links in with an above finding in this study (5.3) that mothers are reluctant to seek child-minding services because of the behaviours of their child. There was also a theme of worry around the symptoms becoming more difficult to manage as the child became older and more difficult to have to explain to strangers.

5.6 The Coping Strategies employed by the family.

There was a theme of avoidance that arose in coping strategies. Mothers tended to keep themselves busy whilst fathers tended to spend more time at their place of employment. There was also a theme of rejection in that neighbours did not offer help nor was their help sought by parents. A theme of guilt was also evident. Parents felt self-blame and embarrassment and so avoided enlisting the help of others. This coincides with findings by Luther *et al* (2008) which identify the urge to seek social support but also identified denial, which in turn prevented parents from seeking help. However, the current study found that help was sought when there was a feeling of becoming overwhelmed by burdens, resonating with Gray's (2003) finding that social support is the most widely used coping mechanisms. No widely used way of coping was identified in the research. This may be because no two individuals with autism are the same. Therefore, different coping strategies may be employed by different families which apply specifically to their own child. Luong *et al* (2009) cite acceptance, spiritual enlightenment and engaging in peer relationships as coping strategies used, and the current study coincides with this finding.

5.7 The Use of Counselling by Families.

This study found that most families did not engage in any forms of counselling. There is a limitation to the amount of research undertaken in this particular area, which highlights a lack of professional recognition of counselling for the families. It was also found that financial burdens may have prevented families from seeking counselling as a means of support, which shows a need for families to be informed of the availability of low cost counselling during the diagnosis process and in the following months and years. With consideration to findings by Bromley *et al* (1999),

that 50% of mothers were found to be suffering from distress, it would appear imperative that counselling and psychotherapy services be more widely available to families. It is noted however, that the fact that some parents are offered directive counselling on how to manage their child's behaviour, may assist with alleviating stress. When this directive therapy comes in the form of support groups, it could provide an even wider source of support due to contact with other families who can empathise with family stress. Nonetheless, the therapeutic relationship along with a space to be listened to and accepted unconditionally in the environment of individual counselling could provide much relief for mothers, fathers and siblings.

5.8 Conclusions.

The results of the study indicate a great deal of stress on families. This stress has been found to arise from financial burden, isolation, marital disharmony, symptomatology and a lack of support from family members, neighbors and professionals. Autism is a life-long disorder that affects the family throughout their life-cycle and this study finds that the permanency of it can often pronounce negative impact on the family.

CHAPTER 6 CONCLUSION

6.1 Overview

The research has demonstrated a heavy burden and great deal of stress for families of autistic children. Living with and raising a child with autism can be distressing by the onset of the disorder, the diagnosis, family isolation and symptomatology. The lack of emphasis by professionals on the importance of counselling is heavily evident in this research. There also appears to be paucity on research carried out to explore the benefits and experiences of counselling and psychotherapy for families who care for the child. Strikingly, only one of the interviewees knew of parents availing of counselling. Following the research, the researcher became aware that parents were not aware that they could avail of low cost counselling. There appeared to be an assumption that counselling may be financially draining, and this was a factor in the reluctance to engage in counselling. In this respect, it may be of considerable importance for professionals to make families aware of low cost counselling services in their area.

6.2 Recommendations

This study has findings supported by that of which has been researched on a global level. It may be of use to carry out further research in a number of years when there may be more adequate service provision to evaluate whether or not that particular aspect could alleviate stress and impact. This study found that there is a greater impact to be found on the family when their child has been diagnosed as higher functioning. This finding does not concur with that of the reviewed literature. It may be of benefit to carry out research on this particular aspect. Counselling and Psychotherapy were not services availed of by the families that appeared in this

research and it also appeared that counselling was not offered to them by various professionals that they had met in their journey to the diagnosis, and in the time that followed. Due to the isolation felt by families and the heavy burden that has been reported, it may be of use to carry out research related to the benefits of counselling for families of autistic children.

Reference List

- Abbeduto L., Mailick, M., Seltzer, P. S., Wyngaarden Krauss, M., Orsmond, G.,
Murphy, M. M., Floyd, F. (2004). Psychological Well-Being and Coping in
Mothers of Youths with Autism, Down Syndrome, or Fragile X Syndrome.
American Journal on Mental Retardation; 109, 237-254.
- Akkok, F. (1994). An overview of parent training and counselling with the parents of
children with mental disabilities and autism in Turkey. *International Journal
for the Advancement of Counselling*; 17(2), 129-138.
- Bågenholm, A., Gillberg, C. (1991). Psychosocial effects on siblings of children with
autism and mental retardation. *Journal of Mental Deficiency Research*; 35,
291-307.
- Bee, H., Boyd, D. (2007). *The Developing Child*, Eleventh Edition, Library of
Congress Cataloguing-in-Publication Data. USA.
- Bitsika, V. (1999). An exploratory examination of the effects of support groups and
the well-being of parents of children with autism: General Counselling.
Journal of Applied Health Behaviour; 1(2), 16.
- Boushey, A. (2004). *Parent to Parent, Information and Inspiration for Parents
Dealing with Autism or Asperger's Syndrome*. Jessica Kingsley Publishers.
London.

- Brobst, J. B., Clopton, J.K., Hendrick, S. S. (2009). Parenting Children with Autism Spectrum Disorders; The Couple's Relationship. *Focus on Autism and Other Developmental Disabilities*; 24(1), 38-49.
- Bromley, J., Hare, J. D., Davison, K., Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders. Social support, mental health status and satisfaction with services. *Autism*; 8(4). 409-423.
- Bryman, A. (2010). *Social Research Methods*. Oxford University Press. UK.
- Coplan, J. (1999). Counselling Parents Regarding Prognosis in Autistic Spectrum Disorder. *Official Journal of the American Academy of Pediatrics*; 105(5), 65.
- Crbich, C. (2007). *Qualitative Data Analysis*. Sage Publications. London.
- Dey, I. (1993). *Qualitative Data Analysis: A User Friendly Guide for Social Scientist*. Routledge. London.
- Dunn, H. E., Burbine, T., Clint., B. A, Tantleff-Dunn, S. (2001). Moderators of Stress in Parents of Children with Autism. *Community Mental Health Journal*; 37(1). 39-52.
- Gardner, N. (2007). *A Friend Like Henry*. Hodder & Stoughton, UK.

Gray, D. (2003). Gender and coping: the parents of children with high-functioning autism. *Social Science and Medicine*; 56, 631-642.

Gray, D. E. (2002). Everybody just freezes. Everybody is just embarrassed; felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health and Illness*; 24(6), 734-749.

Hartley, S. L., Barker, E. T., Seltzer, M. M., Floyd, F., Greenberg, J. Orsmond, G., Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*; 24(4), 449-457.

Hastings, R.P., Johnson, E, (2001), Stress in UK Families, Conducting Intensive Home-Based Behavioural Intervention for Their Young Child with Autism, 31, (3), 327-336.

Heiman, T., Berger, O, (2008). Parents of children with Asperger syndrome or with learning disabilities: Family environment and social support. *Research in Developmental Disabilities*, 29 (4), 289-300.

Heller, T., Miller, A.B., Hsieh, K. (1999). Impact of a Consumer-Directed Family Support Program on Adults with Developmental Disabilities and Their Family Caregivers. *National Council on Family Relations*, 48, (4), 419-427.

- Holmes, N., Carr., J. (1991). The pattern of care in families of adults with a mental handicap: A comparison between families of autistic adults and Down syndrome adults. *Journal of Autism and Developmental Disorders*; 21(2), 159-176.
- Ireland, Department of Education and Science. (2008). The National Council for Special Education, Annual Report 2008. Dublin.
- Ireland, Department of Education and Science. (2001). Educational Provision and Support for Persons with Autistic Spectrum Disorders: the Report of the Task Force on Autism. Dublin.
- Jarbrink, K., Fombonne, E., Knapp, M. R. J. (2003). Measuring the parental, service and cost impacts of children with autistic spectrum disorder: a pilot study. *Journal of autism and developmental disorders*; 33(4), 395-402.
- Kaminsky, L., Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism, *Journal of Child Psychology and Psychiatry*; 43(2), 225-232
- Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M. Dyck, P. C. (2008). A National Profile of the Health Care Experiences and Family Impact of Autism Spectrum Disorder Among Children in the United States, 2005-2006. *Pediatrics*; 122(6), 1149-1158.

- Kring, A. M., Johnson, S. L., Davison, G. C., Neale, J. M. (2010), *Abnormal Psychology, Eleventh Edition*. John Wiley and Sons. UK.
- Kubler-Ross, E, Kessler, D. (2005) *On Grief and Grieving*, Simon & Schuster Inc., Great Britain.
- Lord, C., McGee, J.P. (2001). *Educating Children with Autism*, Library of Congress Cataloguing-in-Publication Data. National Academy Press. Washington.
- Luther, E. H., Canham, D. L., Cureton, V. Y. (2005). Coping and Social Support for Parents of Children with Autism. *The Journal of School Nursing; 21(1)*, 40-47.
- Luong, J., Yoder, M. K., Canham, D. (2009). Southeast Asian Parents Raising a Child With Autism: A Qualitative Investigation of Coping Styles. *The Journal of School Nursing; 25(3)*, 222-229.
- Messenger, K. (2009). *Somewhere Between Here...And Autism: Laughing with Angels, Dancing With Butterflies*. Author House. Bloomington.
- Oppenheim, D, Goldsmith, D.F. (2007). *Attachment Theory in Clinical Work with Children*. The Guildford Press, New York.

- Palermo, M. T. (2003). Preventing Filicide in Families with Autistic Children. *International Journal of Offender Therapy and Comparative Criminology*; 47(1), 47-57.
- Peralta, S. (2002). *All About My Brother; An Eight Year-Olds Introduction to Her Brother Who Has Autism*. Autism Asperger Publishing Co. Kansas, USA.
- Sanchez, R., Rose, D. (2010 May 25). Dr Andrew Wakefield Struck off Medical Register, The Sunday Times.
- Ritchie, J., Lewis, J. (2003). *Qualitative Research Practice*. Sage Practice. London.
- Roeyers, H., Mycke, K. (1995). Siblings of a child with autism, with a mental retardation and with a normal development. *Child: Care, Health and Development*; 21, 305-319.
- Rowe, D. (2007). *My Dearest Enemy, My Dangerous Friend*. Routledge. UK.
- Ryce-Menuhin, J. (1988). *The Self In Early Childhood*. Free Association Books, London.
- Schopler, E., Mesibov, G.B. (1984). *The Effects of Autism On The Family*. Plenum Press, New York.

Sharpe, D.L., Baker, D.L. (2007). Financial Issues Associated with Having a Child with Autism. *Journal of Family and Economic Issues*; 28, 247-264

Stern, D.N. (1998). *The Interpersonal World of The Infant., A View from Psychoanalysis and Developmental Psycholog.*, Basic Books. New York

The Belmont Report. (1979) National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research. Washington DC.

Whitaker, P. (2002). Supporting Families of Preschool Children with Autism. What Parents Want and what Helps. *Autism*; 6(4), 411-426.

Wing, L. (1985). *Autistic Children, A Guide for Parents and Professionals.* Constable Publishers. London.

APPENDIX 1 INTERVIEW QUESTIONS

The Family Overall:

1. You have been working at ‘The School’ for over a year with point to point contact with families. What is your understanding of how the marriages or partnerships of those you have encountered have been affected by living with a child who has been diagnosed with autism?

(b) Do you know of couples available of relationship counselling?

2. How do you think siblings have been affected?

(b) Do any of the siblings attend counselling?

3. Have you any experience of parents and siblings suffering from psychological distress, or needing to attend counselling, psychotherapy or a psychiatrist?

4. Do you think having a child with autism impacts financially, and if so, how?

5. The alleged long and frustrating process of diagnosis may be labouring on a family. What can you say about your experience of observing the aftermath of a diagnosis?

(b) Were parents offered counselling services after the diagnosis?

Parental Subsystem:

7. Do you feel that there is a difference between genders (i.e. mothers and fathers) in how autism impacts on the family?

8. Which, if any, coping mechanisms have you witnessed in parents?

9. Have the parents in the family changed in how they feel about the diagnosis?

Service Provision:

9. The media has, of late, has been widespread in their coverage about the lack of services for autistic children. How do you think this alleged lack of services has impacted on the family?

10. The long and frustrating process of diagnosis may be laboring on a family. What can you say about your experience of observing the aftermath of a diagnosis?

11. What is your understanding of the current position on services for children with autism and the impact of this on parents?

(b) What is your understanding of counselling services offered to families?

Symptomatology:

12. Would you say that it is the typical traits (such as acting out, hair pulling, shouting, screaming, ritualistic behaviour etc) of autism that impacts so much, or the very fact that the child has a diagnosis of autism?

13. Are there any differences in your opinion, between the stressors of having an adolescent and the stressors of having a child with ASD?

Coping:

14. Which support systems are accessed by parents and siblings?

15. Can you discuss or identify coping strategies employed by parents and coping strategies employed by siblings?

16. Do you have any knowledge of parents availing of any types of counselling services?

APPENDIX 2 LETTER OF INVITATION TO PARTICIPATE

Kate Brennan,
Highfield Park,
Kilcock,
Co. Kildare.

25/02/2011

00353 (0)86 3299378

To Whom It May Concern:

I am currently a 4th year student studying a BA (Hons) Counselling and Psychotherapy at Dublin Business School, conducting research under the supervision of Siobain O' Donnell. The aim of this research is to attempt to understand the experiences of families who have a child on the Autism Spectrum Disorder (ASD).

This research involves interviews with service providers, and will assist in gaining an authentic perspective into the lives of families with a child with ASD. The interview will be recorded and will last a maximum of one hour. All information will be in the strictest of confidence with the researcher alone having access to it. Although the content of the interview may be included in the research findings, your identity will not be disclosed.

If you are interested in taking part in this research, please contact me at the above address or phone number to arrange an interview that will work best around your schedule. I hope to hear from you soon,

Yours Faithfully,

Kate Brennan

APPENDIX 3

LETTER OF INFORMED CONSENT

I understand that I am participating in a recorded interview as part of a research project examining the impact of autism on the family system, the interviewer and author of the paper being Kate Brennan.

I understand that there are limitations to confidentiality, namely that the content of this interview will be published. I understand that my anonymity is assured and guaranteed.

I understand that even though I have signed this letter of consent I nevertheless have the right to withdraw from participation at any given time should I wish to do so.

Name _____

Signed _____

Witness (researcher) _____

Date _____

