Capturing the Voices of Parents: Needs, Experiences and Perspectives of Post-Diagnostic Parent Training in an ASD Assessment and Intervention Service

Submitted as per the requirements of the Doctorate in Educational and Child Psychology programme.

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Submitted to Mary Immaculate College, May 2019.

Declaration

I hereby declare that this thesis represents my own work and has not been submitted, in whole or in part, by me or any other person, for the purpose of obtaining any other qualification.

Signed: ___________________________

Date: _____________________________

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Dedication

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Abstract

Aims: This research explores the needs, experiences and perspectives of parents who attended post-diagnostic parent training, following a diagnosis of Autism Spectrum Disorder (ASD) for their child. The research sought to address a number of key areas of the parent post-diagnostic experience, namely:

- What are parents' **perspectives** of their **training needs** following a diagnosis of ASD for their child?
- What are **parents'** self-reported **experiences** of **post-diagnostic parent training in an ASD service?**
- What are parents' **perspectives on taking part in post-diagnostic parent training**?

Method: A mixed-methods, exploratory, case-study methodology was employed to examine the transition from diagnosis to post-diagnosis for parents undertaking post-diagnostic training as an intervention strategy within a disability service context in Ireland. The experiences and perceptions of parents were accessed via pre- and post-training questionnaire. Semi-structured interviews were utilised to gain a deeper insight into parents' perspectives. A total of 57 parents attended the post-diagnostic training. 39 parents agreed to participate in the research study. 25 were mothers of children with ASD, while 14 fathers participated. Of the participants' children, 24 were male and 15 were female. The mean age of child on receipt of diagnosis in this study was 8.5 years of age. The mean age of the child at the time of the training programme was 9 years. Five parents participated in the semi-structured interviews. Of these, 4 were mothers and 1 was a father. Thematic analysis was used to analyse the qualitative data, while paired sample t-tests were used to analyse the pre- and post-intervention questionnaires.

Results and Conclusions. Parents' self-rated knowledge of ASD significantly improved from pre-training to post-training. Parents stated a clear desire to receive knowledge on specific areas, mental health, and telling about the diagnosis. There was a significant increase in parents' self-reported ratings of their understanding of ASD. Parents' self-reported skills in managing their child's needs also increased significantly from pre-training to post-training. Quantitative and qualitative data both show evidence of gains in confidence in the areas of supporting the needs of the child and also, in parenting the child.

Chapter 1: Introduction

1.1 Chapter Introduction

This chapter provides an overview of the current research. Autism Spectrum Disorder (ASD) is defined. The process of receiving a diagnosis of ASD, and the evidence for parent training for ASD are outlined. A rationale for undertaking this research is proposed. The voices of parents, in the period following their child's diagnosis of autism spectrum disorder, are highlighted as the focus of this research study, with particular emphasis on parents' needs, experiences and perspectives in the context of post-diagnostic parent training. Finally, an overall outline of the structure of the thesis is delineated.

1.2 Overview of Current Study

The current research took place in an eclectic, practice-based, clinician-led post-diagnostic parent training provided by a multi-disciplinary team in an ASD diagnostic and intervention service in Ireland. Designed by clinicians in the service, the training was not based on a manualised or commercial programme, and was eclectic in nature, in that it was derived from a wide range of evidence-based interventions and strategies (Guldberg et al., 2011). The content of the programme was designed by clinicians in the ASD service in light of their own extensive experience working in the area of ASD, and was informed by evidence-based practices. The programme was delivered as group training to parents over the course of four consecutive weeks. Programme content was discipline-specific and was delivered by the services' social worker, occupational therapist, speech and language therapist, and educational and clinical psychologists. The programme was psycho-educational in nature and was designed to offer opportunities for parents to access social support through interactions with clinicians and with their peers, other parents who had received an ASD diagnosis for their child.

Aiming to explore the post-diagnostic stage, this research examines the needs, experiences and perspectives of parents engaged in post-diagnostic training. This research aimed to uncover the voices of parents, using a mixed-methods, exploratory, case-study methodology to study the transition from diagnosis to post-diagnosis for parents undertaking post-diagnostic training as an intervention strategy. The current study examined parents' self-reported priority training needs, their self-reported experiences of participating in such training and parents' perspectives before and after taking part in the training programme. The voices of parents are captured in terms of how they perceive the training in respect of its beneficence, utility, and practicality as well as the emotive and affective factors involved in taking part in such an intervention (Figure 1). This study captures the voices of parents and guardians at this stage of the ASD diagnosis journey by addressing the following research questions:

- What are parents' **perspectives** of their **training needs** following a diagnosis of ASD for their child?
- What are **parents'** self-reported **experiences** of **post-diagnostic parent training in an ASD service?**
- What are parents' **perspectives on taking part in post-diagnostic parent training**?

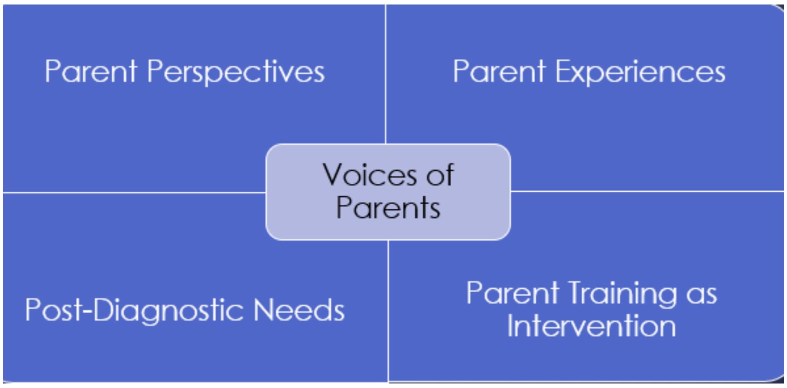


Figure 1. **Areas of Study**

1.3 Overview of Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a pervasive, neurodevelopmental condition characterised by impairments in social interaction, social communication and behavioural inflexibility (Baron-Cohen et al., 2009; Carr, 1999; Frederickson & Cline, 2009; Volkmar, Lord, Bailey, Schultz, & Klin, 2004). The Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (DSM-5) sets out the diagnostic criteria for autism spectrum disorder. In the DSM-5, characteristics of ASD include persistent deficits in social communication and social interaction across multiple contexts, as well as restricted, repetitive patterns of behaviour, interests or activities. Additionally, for a diagnosis of ASD to be made these traits and behaviours must have been present in the early developmental period, impact significantly on key areas of functioning or adaptive behaviour, and must not be better explained by the presence of an intellectual disability or a global developmental delay (American Psychiatric Association, 2013). ASD is conceived of as occurring across a spectrum (Woolfson, 2011).

1.3.1 Receiving a Diagnosis of ASD.

The process of diagnosing ASD in children and young people can be lengthy and onerous, with Connolly and Gersch (2013) reporting that parents often describe the process of receiving a diagnosis as a “journey”. Receiving a diagnosis of ASD is a significant life event, which can elicit strong emotional reactions from the parents of the diagnosed child (Banach, Iudice, Conway, & Couse, 2010). Many parents describe the receipt of the diagnosis as a life-changing experience (Fleischmann, 2004). Parents describe the role of the professional in the diagnostic process as that of a guide who would show the route, and note that for the family of a child with ASD, the journey will take a “slightly different path” (Connolly & Gersch, 2013).

1.3.2 Parent Training for ASD.

Not only can training potentially benefit parents in terms of support (Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012; Francis, 2005; Lutz, Patterson, & Klein, 2012; Pottie & Ingram, 2008; Ring, Daly, & Wall, 2018; Vernhet et al., 2018), it can also help to meet parents self-reported information needs following a diagnosis of ASD for their child (Murphy & Tierney, 2006). The process of seeking information following a diagnosis is associated with positive psychological wellbeing and adjustment (Farrugia, 2009; Pain, 1999; Salas, Rodriguez, Urbieta, & Cuadrado, 2017). Recent studies on the provision of ASD-specific services report that non-standardised, eclectic post-diagnostic training is frequently offered as indirect intervention for children with ASD through the medium of parents, as an alternative to direct contact-time with clinicians (Matson, Matson, & Mahan, 2009; Stadnick, Stahmer, & Brookman-Frazee, 2015). Clinicians train parents to enhance their knowledge of ASD and communication and behaviour management. Murphy and Tierney (2006) note that service provision for families tends to be predicated on what clinicians and professionals deem to be the needs of parents following diagnosis, a finding which is supported by Pain (1999).

1.4 Theoretical Framework

A theoretical framework is a “structure which guides research by relying on a formal theory…constructed by using an established, coherent explanation of certain phenomena and relationships" (Eisenhart, 1991, p.205). The researcher's choice of theoretical framework impacts on the research process at every level (Grant & Osanloo, 2016; Mertens, 2015). For Lysaght (2011), a researcher's choice of theoretical framework is reflective of their ontological and teleological beliefs, and exerts a significant influence on their research design and approach.

In selecting a theoretical framework for a particular research study, Lovitts (2005) asserts that the application of a theory to a research dissertation must be logical, meaningful, appropriate, well-understood, as well as making sense in the context of the research question to be addressed. There are many different theoretical frameworks which provide explanations for and structure to human experiences and development. Psychodynamic theories align the process of human development with an individual's ability to resolve challenges (Kail & Cavanaugh, 2010). Theoretical frameworks which take a behaviourist approach posit that knowledge is formed through an interaction between a stimulus and a response (Schunk, 2014). For social learning theorists, such as Bandura and his social cognition theory, learning and development occur through the observation of others (Kail & Cavanaugh, 2010). Ecological theories of development place learning and development within a socio-cultural, environmental context (Greene & Moane, 2000). Ecological approaches state that there is a continuous and reciprocal interaction between an individual and their environment (Bronfenbrenner, 1977, 1979; Moen, Elder & Luscher, 1995; Sontag, 1996).

The current research study takes an ecological approach, namely that of Bronfenbrenner (1979), as the most appropriate approach with which to address the research questions posed by this study. This study takes place at the interface between the healthcare system and the family system, and as such, an ecological systems theory was deemed to be most pertinent as a framework to situate the research within. Bronfenbrenner's ecological theory is widely used across educational and psychological research. Because of its interactional and contextual structure, it has been used in studies across the lifespan in analysing the layers of systems impacting on individuals and families, such as in the *Growing Up in Ireland* study (Greene et al. 2010), whereby the framework was used to gain an understanding of how family circumstances, the wider community and the national economy impact on child development. An additional example of how Bronfenbrenner's ecological systems framework has been used in a research study by McTernan and Godfrey (2006), which examined interagency planning for the provision of child services in Northern Ireland.

Bronfenbrenner’s theory posits that there are various nested layers within one’s ecological environment, namely, the microsystem, the mesosystem, the exosystem, the macrosystem, and a later addition, the chronosystem (1977; 1979) (see Figure 2). For Bronfenbrenner (1977), development is “the person’s evolving conception of the ecological environment, and his relation to it, as well as the person’s growing capacity to discover, sustain, or alter its properties” (p.9). This development takes place within the systemic layers of the ecological environment, and these layers are interconnected and bi-directional, hence happenings within each system, as well as the interactions between each system influence the development of the individual (Odom et al., 2004), while it is also acknowledged that the individual is “a growing dynamic entity that progressively moves into and restructures the milieu in which it resides” (Bronfenbrenner, 1979, p.21).

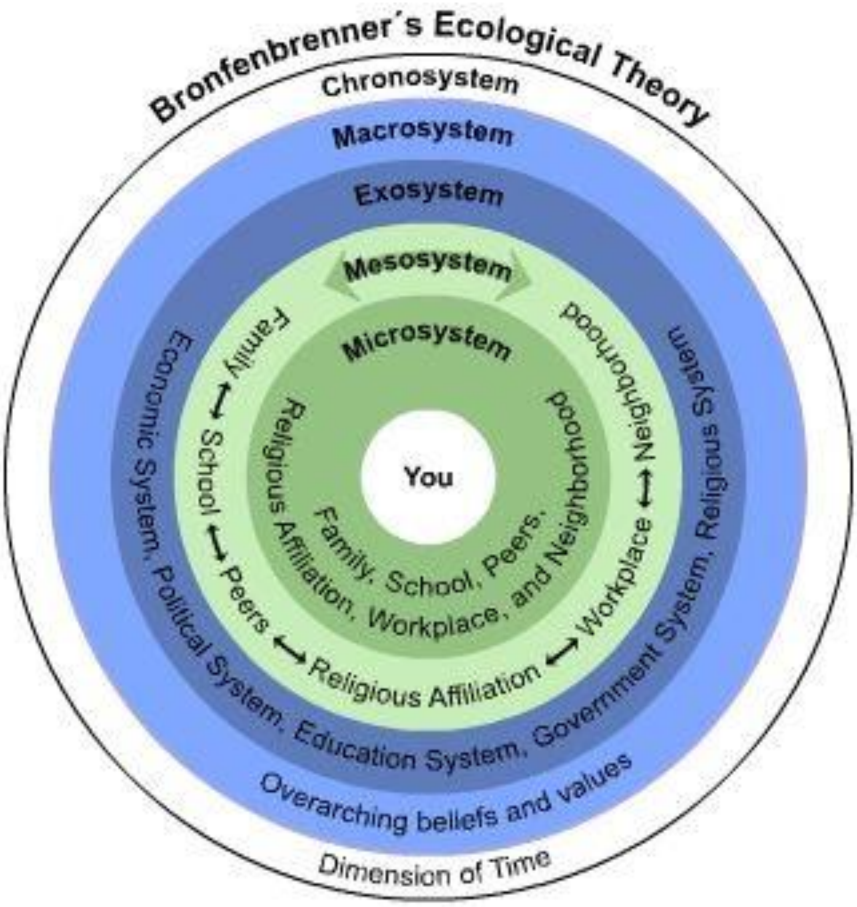


Figure 2. Bronfenbrenner’s Ecological Theory

Bronfenbrenner’s theory is often conceptualised as a series of concentric circles, with the learner placed in the centre (McGuckin & Minton, 2014). As the circles extend outward, the impact on the development is lessened, therefore the closer the circle is to the learner, the greater the impact on his/her development (Greene & Moane, 2000), The microsystem consists of an individual and their immediate context, such as their home, and includes all the reciprocal interplay, activities and interpersonal relationships that occur at this level (Bronfenbrenner, 1977; 1979). The next level in this theory is the mesosystem, which consists of a system of microsystems, or the interaction between the various settings that make up the microsystem. For Greene and Moane (2000) and McTernan and Godfrey (2006), the relationships between the microsystems or settings in which a young person interacts have a large bearing on the development of the child. For example, the relationship between the child's parents and their teachers can impact upon a child's learning (Odom et al., 2004). If the previous statement is deemed to be plausible under Bronfenbrenner's ecological framework, then it can be posited that similarly, the relationship and interactions between a child's parents and the child's clinicians in a disability setting can impact upon a child's development. It is in this context that the current research study took place, at the interface between the clinician's in a specific disability service (the health system) and the child's parents (the family system). The *exosystem* refers to the third layer of Bronfenbrenner's ecological theory, which encompasses the concrete manifestations of the macrosystem. The exosystem consists of the various social structures which may impact upon one's immediate setting, such as government, media and resource distribution.

The next system in Bronfenbrenner's ecological theory is called the *macrosystem.* The macrosystem places the individual, the microsystem and the mesosystem within the context of the cultural ideologies, attitudes and beliefs of the setting (Greene, 1994). Although the individual may appear to be at a considerable remove from the machinations of the macrosystem, they are nonetheless impacted by it (Bronfenbrenner, 1979). The macrosystem encompasses national and international changes such as the recessions, shifts in political policy, technological advances and other cultural and societal changes (McGuckin &Minton, 2014). In the context of the current research study, the macrosystem impacts on the child with ASD through the provision of healthcare and education services for ASD, as well as cultural beliefs and values around concepts of disability.

The fifth system in Bronfenbrenner's ecological theory is the *chronosystem*. The chronosystem refers to the impact of the passing of time on both the learner and the environment, acceding that the passage of time results in changes at each level of the system (Bronfenbrenner, 1994). The chronosystem can account for changes and consistencies over time, such as shifts in perspectives, changing relationships, ageing and illness (Odom et al., 2004). Given that ASD is a life-long, pervasive developmental disorder, the chronosystem allows for the contemplation of the impact of the passage of time in the context of the current research study.

1.4 Rationale for the Current Research Study

With over a decade of experience in numerous teaching roles across the Irish primary school system, I have worked with many children with ASD and their families. While teaching in a special class for children with ASD, I completed a Higher Diploma in Psychology in University College Cork. I subsequently left my teaching position in an ASD class to undertake a three-year, full-time Doctorate in Educational and Child Psychology in Mary Immaculate College. Over the course of my studies, I have had the opportunity to embark on professional placements across a range of settings and services, including an ASD diagnostic and intervention service. This placement opportunity allowed me to gain an insight into ASD from the perspectives and experiences of parents, rather than through the lens of the school system. As part of intervention for newly diagnosed children and their families, the ASD service offered post-diagnostic parent training. Having attended each session, I became interested in the experiences and perspectives of parents receiving this training.

Research has highlighted the potential benefits of group training for parents of children with ASD as an intervention following diagnosis (Brookman-Frazee, Stahmer, Baker-Ericzén, & Tsai, 2006; Ingersoll & Dvortcsak, 2006; Lundahl, Risser, & Lovejoy, 2006; Matson et al., 2009; Wyatt Kaminski, Valle, Filene, & Boyle, 2008). The current research study sought to capture the voices of parents, specifically relating to their self-reported needs, experiences and perspectives following a diagnosis of ASD for their child.

Given the nature of the setting, the eclectic training programme, and the unique characteristics of the parent group attending during the time period of the study, this research project takes a case study format, investigating a particular defined phenomenon in a bounded case setting. Case study methodology is used to investigate systems such as an individual, a group, an organisation or a community (Adelman & Kemmis; Myers, 2000), in this instance, a training programme provided by an ASD service, in order to enhance our understanding of particular, individualised and complex contexts (Hamilton & Corbett-Whittier, 2012). Case study design, in this research, was used to draw information from a number of sources in order to examine the training programme from many perspectives (Thomas, 2011). To further enhance the information gathering process, a mixed-methods approach was taken.

1.5 Thesis Outline

Chapter One provides an introduction to the research context and a rationale for undertaking the current study. Chapter Two consists of an outline of the characteristics, prevalence and diagnostic criteria of ASD. An overview of the provision of ASD services in an Irish context is provided. Literature from the field is reviewed and evaluated in this chapter. Findings of the literature review are analysed and synthesised into the themes of *Parents' Needs, Parents' Experiences* and *Parents' Perspectives*. Chapter Three documents the research methodology and a justification for the methods used. Data collection procedures are charted, and data analysis approaches are outlined. Chapter Four presents the results of the current research study, while Chapter Five provides a critical analysis, interpretation and evaluation of the results in the context of the research questions and current research in the area. Finally, Chapter Six discusses the research findings in terms of contribution to the field of research, with acknowledgements of the limitations of the study and recommendations for future research in the area. Plans for dissemination will be outlined in this chapter.

Chapter 2: Literature Review

2.1 Chapter Introduction

This chapter presents and analyses the literature in the field to contextualise the current research study. Autism Spectrum Disorder (ASD) is discussed in terms of prevalence, the diagnostic process, access to services and the current provision for ASD in Ireland. The literature review approach is outlined. The results of the literature review are presented and critically analysed in terms of parents' self- reported needs, experiences and perspectives following a diagnosis of ASD for their child.

2.2 Literature Review Approach

The current research study examined the experiences, perspectives and self-reported needs of parents taking part in an eclectic training programme following a diagnosis of ASD for their child. The research was conceived as an idea following the researcher's placement experiences of attending post-diagnostic parent training. This experience prompted a number of key questions in the researcher in relation to post-diagnostic parent training, and what it might feel like to be a parent undertaking this programme. Furthermore, the researcher was interested in uncovering what parents attending post-diagnostic training deemed to be their needs following their child's diagnosis. Hence, the researcher began the literature review process with the intention of finding out more about the needs, perspectives and experiences of parents attending a post-diagnostic parent training programme in an ASD service. The aim of the review was to uncover parents' needs, experiences and perspectives following a diagnosis of ASD for their child. The review was designed to specifically critically analyse current research in this area in relation to post-diagnostic parent training. A systematic approach was undertaken to structure the current review and to identify relevant literature. Systematic literature reviews involve searching for, identifying and selecting a comprehensive, peer-reviewed and unbiased body of knowledge on a particular research topic, using a consistent, defined and pre-conceived approach (Booth, Sutton, & Papaioannou, 2016).

A review of the literature was conducted to investigate the relevant, contemporary research in the area of the needs, experiences and perspectives of parents following a diagnosis of ASD for their child, as well as literature on parent training as a post-diagnostic intervention for ASD. It must be acknowledged that the term Autism Spectrum Disorder (ASD) can also be referred to Autism Spectrum Condition and

Autistic Spectrum Disorder, Autism Spectrum Difference, and Autism, therefore searches were conducted using these terms on Academic Search Complete, PsycINFO, ERIC and EBSCO. The literature review search questions and terms were carefully defined and used to guide the literature search. Table 1 outlines the search terms used in the literature review.

Table 1. Search Terms for Literature Review

Experiences of parents aut*	Parent training aut*	Aut* post-diagnostic training
Parent needs post-diagnosis aut*	Aut* diagnosis parent experience	Parent Perspective aut* training
Parents experiences ASD	Parent training ASD	ASD parent needs
ASD post-diagnostic parent training	ASD parent perspectives	ASD parent post-diagnosis

Inclusion and exclusion criteria were applied to the search results in order to access the most appropriate and relevant research (Table 2).

Table 2. Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria	Rationale
English Language Research	Languages other than English	The researcher only speaks English
Conducted from 1990-	Papers outside the timeline	This is a contemporary field of research, the current project is interested in the most up-to-date research findings, but sought to include seminal texts also.
Peer-reviewed	Non-peer reviewed	Peer-reviewed studies are considered to have reached a level of academic rigour, and have been approved by experts in the field of study, hence are considered a solid base from which to pursue

Inclusion Criteria	Exclusion Criteria	Rationale
		quality, academic research (Kelly, Sadeghieh, & Adeli, 2014)
Refers to autism/ ASD/ Autism Spectrum Disorder/ Autism Spectrum Condition/ Autism Spectrum Difference	Does not refer to autism	This study is centred on the needs, perspectives and experiences of parents of children with autism spectrum disorder, hence included articles had to be relevant to this area
Included parents	School/ service based	Included studies had to refer to parents, as opposed to schools, clinicians, or services
Parents needs/experiences /views /perspectives/ voice of parents following autism diagnosis	Views of teachers/ clinicians/ people other than parents & guardians	Included studies had to refer to parents, as opposed to schools, clinicians, or services
Refers to group intervention/ support/ training	No reference to group intervention/ support/ training	The training programme undertaken by participants in the current research study was a group intervention, hence, the review excluded interventions that did not meet this criteria

Citation chaining (Boland, Cherry, & Dickson, 2017) was employed as a strategy to identify and access key studies in the field which were cited by research which arose in the systematic review, but which had not appeared in the initial literature search. Furthermore, specific studies were selected and analysed on the basis that they most closely resembled the training provided by clinicians in this case study research and thus, were considered most appropriate for guiding the research questions arising in this study (Jesson, Matheson, & Lacey, 2011).

A thematic approach to the literature review was taken, as this was considered to be the most useful and clear way to consider the literature, as this body of research is complex, diverse, and predominantly theoretical (Boland et al., 2017; Jesson et al., 2011). Structuring the review thematically allowed for a link to be drawn between the practice-base and the literature arising from the search, highlighting the voice of parents within the literature (Rycroft-Malone & Bucknall, 2011). A thematic approach to literature review has been adopted by many researchers who addressed similar research questions in the area, including Irish research by Connolly and Gersch (2013), South African research by Mitchell and Holdt (2014) and Northern Irish research by McAleese, Lavery, and Dyer (2014), therefore this approach was deemed to be a more appropriate literature review approach than a Systematic literature review which would have a more narrow lens (Jesson et al., 2011).

A number of key themes emerged from the literature review process, which form key tenets for this literature review (Boland et al., 2017). These three themes, Needs of Parents, Experiences of Parents and Perspectives of Parents, are used to provide a framework for the discussion which follows here (Figure 3).

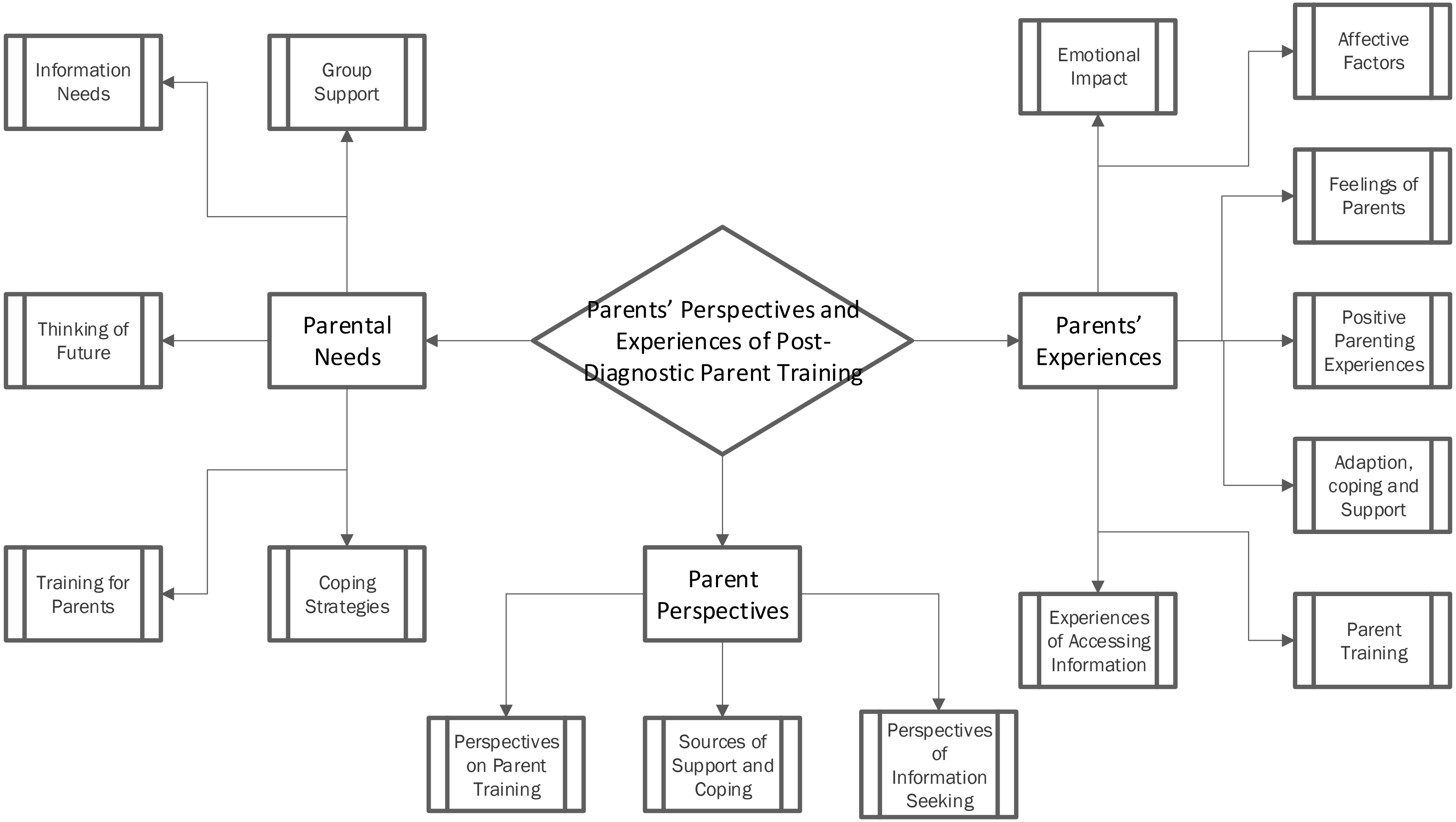


Figure 3. Systematic Literature Review Themes and Subthemes

2.3 Overview of Autism Spectrum Disorder

2.3.1 Autism Spectrum Disorder.

Autism Spectrum Disorder (ASD) is a pervasive neurodevelopmental disorder characterised by what is described as the “triad of impairments” (Frederickson & Cline, 2009; Frith, 1989; King, Nicholas, Carpenter, Jenner, & Charles, 2008; Rajendran & Mitchell, 2007; Volkmar et al., 2004), i.e. impairments in the areas of social imagination, social communication and social interaction. People with ASD experience distinct sensory sensitivities or preferences and repetitive, stereotyped movements or actions, to varying individual degrees (Chen, Rodgers, & McConachie, 2009; Frith, 1989).

The Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (DSM-5) is the standard reference tool used by health professionals to categorise and define mental disorders. This manual outlines the diagnostic criteria for autism spectrum disorder, setting parameters which define the disorder. According to the DSM-5, ASD is characterised by persistent deficits in social communication and social interaction across multiple contexts, as well as restricted, repetitive patterns of behaviour, interests or activities. Furthermore, these characteristics must be present in the early developmental period, cause a clinically significant impairment in social, occupational or other key areas of functioning, and not be better explained by the presence of an intellectual disability or a global developmental delay (American Psychiatric Association, 2013).

ASD is conceptualised as occurring along a spectrum, ranging from severe social, communication, behavioural and cognitive impairments, to average or above average IQ with impairments in socialising, communication and behaviour (Woolfson, 2011). The concept of the spectrum is key to working with people with ASD as it allows for the understanding that ASD is not a homogenous disorder and presents as a diverse range of skills and challenges, with no two people experiencing the disorder in exactly the same way (Silberman, 2015).

2.3.2 Prevalence.

Over the past decade, research has documented an increase in the prevalence of ASD. Previous research estimated that approximately 1% of the population may have an Autism Spectrum Disorder (ASD) (Baird et al., 2006; Baron-Cohen et al., 2009; Boilson, Staines, Ramirez, Posada, & Sweeney, 2016); however current research suggests that these figures may represent an underestimation of the prevalence of the condition. A 2016 Policy Advice document from the National Council of Special Education (NCSE) cited an Irish prevalence rate of 1 in 65 or 1.55%. This prevalence rate was drawn from NCSE data on students with ASD with resource teaching support or in special classes and special schools, and excluded data on children under the age of 4, on home tuition or over the age of 18. This school-based prevalence rate is in line with international prevalence findings. The US Centre for Disease Control and Prevention found the prevalence of ASD amongst children and young people to be at 1 in 68 or 1.6% (2014), while research conducted in the UK on the Millennium Cohort Study (based on data compiled on 6-8 years olds in England, Scotland, Wales and Northern Ireland) found a mean prevalence rate of 1.7%. Results from Northern Ireland alone reported the prevalence of ASD to be at 2% for children between the ages of 4 and 15. These figures are in contrast to those found in a study conducted by researchers at Dublin City University (Boilson et al., 2016). In a study of over 9,000 children residing in Ireland, the prevalence rate was reported as being at 1% (Boilson et al., 2016).

There is some discrepancy in the research on gender-based prevalence rates of ASD. The NCSE Policy Advice Document (2016) reports that boys are up to five times more likely to be affected by ASD. Of those diagnosed with ASD in the Dublin City University study, 78% were male (2016). However, a more recent systematic review and meta-analysis of 54 prevalence studies conducted by UK researchers, with 13,784,284 participants, of whom 53,712 had ASD, found that for children and young people meeting criteria for ASD, the male-to-female ratio is not 4:1 as previously thought, but instead is closer to 3:1 (Loomes, Hull, & Mandy, 2017). This meta-analysis also found what they termed to be a diagnostic gender bias, indicating that girls who meet the criteria for a diagnosis of ASD are at a significant and disproportionate risk of not receiving a clinical diagnosis (Loomes et al., 2017).

The documented changes in the prevalence of ASD over time may have multiple explanations or causations. The broadening of diagnostic criteria is posited as a possible explanation for the increased prevalence of ASD (Berument, Rutter, Lord, Pickles, & Bailey, 1999; Fombonne, 2003a, 2003b). Furthermore, changes in the methodology used to study prevalence are thought to have impacted upon prevalence statistics for ASD (Baird et al. 2006). It is also hypothesised that this increase may be linked to heightened awareness of autism spectrum disorder among parents and professionals (Wing & Potter, 2002), and improved systems of monitoring in childhood (Eyal, 2010; Grinker & Leventhal, 2009).

2.3.3 The Diagnostic Process.

There are not yet any agreed-upon biological or genetic markers for ASD, therefore assessment is conducted through reporting and observation (Baron-Cohen et al., 2009; Carr, 1999; Wing & Potter, 2002). The National Institute for Health and Care Excellence (NICE) guidelines, which outline evidence-based international best practice, suggest that ASD diagnostic assessment for children and young people should be conducted by a multidisciplinary team consisting of, at minimum, either a clinical or educational psychologist, a speech and language therapist and an occupational therapist (2011). Furthermore, the NICE guidelines suggest that every ASD assessment should include a detailed interview with the parent/carer and when appropriate, the child or young person themselves. This is in order to gather a developmental history, family background and relevant medical information and to gather details of their experiences of home, school and social living. The child should be assessed, both through interaction and observation, in terms of their social, communication and play skills. ASD-specific tools can be used to capture this information, such as the Autism Diagnostic Observation Schedule (ADOS), The Diagnostic Interview for Social and Communication Disorders (DISCO), or The Autism Diagnostic Interview-Revised (ADI-R), as these are consistent with ICD-10 or DSM-V criteria. Clinicians must also consider the possibility of a differential diagnosis and the co-existence of other co-morbid conditions associated with ASD ((NICE), 2011). The aim of ASD assessment is to evaluate the difficulties of the person with the aim of using this information to develop an appropriate intervention plan, hence the outcome of the assessment is not a diagnostic label alone, but also a profile of strengths and needs which is used to support intervention planning (Psychological Society of Ireland, 2010). The median age for a diagnosis of ASD is 55 months, or the beginning of school attendance (Brett, Warnell, McConachie, & Parr, 2016; Crane, Chester, Goddard, Henry, & Hill, 2016).

2.3.4 The Irish Context.

In terms of the process of assessment of ASD in Ireland, assessments can arise from assessments of need, with onward referrals to ASD-specific diagnostic teams. An Irish study on a wait-list intervention for families of children awaiting an assessment of ASD by Connolly and Gersch (2013) found that parents felt the length of time waiting for an assessment, and the dearth of early intervention for ASD in this time to be a huge source of frustration and worry. Some parents described it as the most stressful part of the process. Current media reports cite large delays and lengthy waiting lists for disability assessments in Ireland, with over 700 children awaiting assessment, and a waiting time of over two years in some parts of the country (Baker, 2018; Humphreys, 2015; O'Regan, 2018). A review by the HSE (Health Service Executive, 2013) found that a “significant number” (p.9) of service users were on the waiting list to meet with a psychologist, but were not currently receiving any intervention, therapy or input from psychological services. A recent debate in Dáil Eireann highlighted the difficulties facing the assessment system for children and young people, with approximately 800 children awaiting an assessment for ASD in the Cork region (Topical Issue Debates Disability Assessments, 2018). Against the backdrop of such extensive waiting lists and the continued demand on services, legal challenges have been taken by some parents demanding access to assessments and intervention supports for their children with additional needs (Healy, 2017; O'Loughlin, 2018).

The Irish government has made efforts to address the crisis of waiting lists and access to supports in disability services, whereby the HSE has identified a requirement to develop a Standard Operating Procedure (SOP) (2013). This SOP aims to replace current assessment guiding procedures, which are currently over 50 pages in length, in order to define the assessment process, to standardise approaches across the state and to ensure balanced and equitable access to assessments despite geographical location (*Topical Issue Debates Disability Assessments*, 2018). Part of the proposed SOP suggests an initial assessment, known as a Preliminary Team Assessment (PTA), which it is stipulated must be concluded within a maximum of 90 minutes, regardless of the child’s needs. The representative body for psychologists in Ireland, The Psychological Society of Ireland (PSI), published a document in response to concerns raised by their members in relation to the operationalisation of the SOP in practice (2018). The PSI has called for implementation of the SOP to be postponed in order to allow for consultation with their members and other relevant allied health professionals. Furthermore, the PSI has cautioned their members against complying with the SOP procedure, as to do so may prove to be a breach of ethical practice. Among the issues raised by the PSI is that the PTA is too brief to allow for thorough, person-centred assessment, while also impacting on the clinical autonomy of the assessors. Additionally, they raise concerns that financial considerations may be at the heart of the SOP proposal, rather than the spirit of human rights, fairness and equality. The PSI argue that implementation of the SOP may inadvertently lead to children being misdiagnosed, placed on inappropriate waiting lists and thus, the exacerbation of the delays and waiting lists already felt by children requiring an assessment.

In 2012, the HSE published a National Review of Autism Services. The review identified that service provision is very varied, depending on geographical location, ranging from “robust, comprehensive and integrative to isolated, patchy and ineffective” (National Review of Autism Services, Health Service Executive p.2). The review also notes that models of service and approaches to service provision differed vastly across regions. It is acknowledged that ASD is a heterogeneous disorder with significant variations across individuals’ profiles and, indeed, across the lifespan, hence service delivery must account for differing and changing needs across the group and the lifespan (HSE, 2012). The review makes a significant recommendations, such as the provision of a key worker to work with an individual and their family across their ASD journey, maintaining person-centred principles and highlighting equity of access to quality services which are “integrated, co-ordinated and seamless” (p.3). Five years on, a national review of ASD services was due to be published in September 2017. Submissions from various groups highlighted that most of the recommendations made in the 2012 review have not yet been implemented (Irish Autism Action, 2017). The findings from this review are yet to be published, and will undoubtedly be followed with close interest by the individuals with ASD, their parents, and the clinicians and service providers involved in working with people with ASD.

2.3.5 Access to Services.

Following a diagnosis of ASD, many parents seek to access the relevant local or regional services (Grant, Rodger, & Hoffmann, 2015; Murphy & Tierney, 2006). However, accessing appropriate services can be difficult, with sparse availability of interventions or therapies (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003; Divan et al., 2012; Murphy & Tierney, 2006; Ring et al., 2018; Siklos & Kerns, 2006). A study on parents’ experiences of an ASD diagnosis in the United Kingdom found that following a diagnosis of ASD, 85% of parents receive a written report on their child’s diagnosis. However, only 56% of parents receive a follow-up appointment, with only 21% of parents being directly offered help or assistance following diagnosis. 38% of parents reported being directed towards sources of advice or help, while 35% reported that they received no offers of assistance following their child’s diagnosis (Crane et al., 2016). According to Dillenburger, McKerr, and Jordan (2014), governmental responses to diagnoses of ASD are vital, given that research suggests that 20-40% of children who receive targeted and appropriate early intervention therapies can achieve optimal outcomes (Fein et al., 2013; Orinstein et al., 2014). Furthermore, a study in the UK by Järbrink and Knapp (2001) estimated that appropriate levels of early intervention for children with ASD has the potential to save 65% of the cost of adult service provision. Therefore, governmental policies not only impact qualitatively on the lives of individuals with ASD and their families, but also financially, in terms of cost to the state.

2.3.6 Teacher Knowledge of ASD.

A study conducted in Northern Ireland by Fennell and Dillenburger (2018) investigated teachers knowledge of ASD, with particular emphasis on applied behaviour analysis as a school-based intervention. Teachers (N=165) were surveyed about their self-reported knowledge and skills in working with students with ASD. Results of this research showed that teachers' self-reported knowledge was greater than their actual knowledge (Fennell & Dillenburger, 2018). A study conducted in Irish post-primary schools found that, in specific relation to Asperger's Syndrome, teachers did not possess an adequate level of knowledge or understanding, and that continued professional development had a minimal effect (Young, Mannix McNamara, & Coughlan, 2017). It was found that teachers who completed continued professional development courses scored only marginally better than those who had not (2.85%). A study on initial teacher education conducted in Scotland highlighted a number of issues with teacher education in relation to ASD (Ravet, 2018). Key findings of the study included that while students and teachers had some basic ASD awareness, they had little or no knowledge or understanding of teaching techniques for children with ASD. Additionally, it was noted that there was not enough input on ASD in the training programme, a factor which was linked to insufficient tutor expertise, curriculum overload, prioritisation of other issues and concerns about medical labelling (Ravet, 2018).

2.4 Parent Training as an Intervention for Children with ASD.

Following a diagnosis of ASD, the roles of clinicians is to provide evidence-based information about ASD, supports and risk factors, to be open to the parents' emotional responses, to show understanding of parental reactions and to acknowledge challenges while also fostering positivity in relation to interventions and strategies that may help their child (Sullivan, 1997; Mansell & Morris, 2004). In the UK and Ireland, the eclectic approach is widely implemented, whereby clinicians and educators adopt a wide range of interventions and strategies to meet individuals' needs (Guldberg et al., 2011). In a review of international evidence-based best practice, Guldberg et al. (2011) note that parent training should be made available to educators and parents of children with ASD, both to provide knowledge on ASD and its characteristics and to provide information about the range of evidence-based interventions which are available. Parent training, as a term, has been used to describe a wide range of interventions including psychoeducation, social and/or behavioural strategies, language, care or maladaptive behaviours (Bearss, Burrell, Stewart, & Scahill, 2015).

Given that following a diagnosis many parents seek out information (Banach et al., 2010; Crane et al., 2016; Grant et al., 2015; Mansell & Morris, 2004), parent training programmes can be pivotal in providing quality, evidence-based information. Effective programmes can support parents in adjusting to the diagnosis and to manage their own assumptions and expectations about ASD and the prognosis for their own child (Bearss et al., 2015). Programmes tend to be structured over a short term, generally 6 to 12 weeks, and occur in groups or with individuals. Group interventions provide the added benefit of promoting social support for parents of children with ASD (Farmer & Reupert, 2013). Research has highlighted the need to evaluate parent training programmes in order to gain a measure of their impact on practice and on outcomes for individuals with ASD (Guldberg et al., 2011). A further recommendation from this study is that persons with ASD must be offered opportunities to develop their own knowledge about the spectrum and to be active consultees in relation to addressing their own identified needs (Guldberg et al., 2011).

There has been some ambiguity regarding what constitutes parent training in the field of ASD intervention, with varying labels and definitions being offered to describe a variety of treatments, ranging from language skills, social skills, psychoeducation and challenging behaviours (Bearrs, Burrell, Stewart & Scahill, 2015). Across the field of ASD studies, researchers have referred to “parent training” (Aman et al., 2009; Bearss et al., 2013; Coolican et al., 2010), “parent education” (Schultz et al., 2011; Steiner et al. 2012; Symon, 2001), “parent-implemented” (McConachie &Diggle, 2007), “parent-mediated” (Oono et al. 2013), and “caregiver-mediated” (Kasari et al., 2010). Hence, there is a lack of consensus on the issues of definition and content in relation to parent training programs, which has both academic and clinical implications. A research paper by Bearrs et al. (2015) endeavoured to offer a taxonomy of parent training programs for children with ASD, differentiating between two broad categories of intervention: parent support programs and parent-mediated interventions. These can be further divided into categories: care coordination and psychoeducation under parent support programs, and interventions for symptoms and/or behaviours under parent-mediated interventions.

In spite of the taxonomic issues around the concept of parent training as an intervention for children with ASD, there has been significant research conducted on a variety of manualised parent training programs, such as COMPASS for Hope, Early Bird & Early Bird Plus, Cygnet Parenting Support Program, Project ImPACT and Stepping Stones Triple P, as well as practice-based parent programs and systematic reviews and metanalyses of existing research in the field. COMPASS for Hope (C-HOPE) (Kuravackel, Ruble, Reese, Ables, Rodgers & Toland, 2017) is a US-based parent behaviour training and support program delivered through face-to-face or telehealth modalities. It was developed from a pre-existing framework known as the Collaborative Model for Promoting Competence and Success (Ruble, Dalyrymple & McGrew, 2012), an ASD-specific, school-based consultation intervention for children aged 3-8 years with a diagnosis of ASD. C-HOPE was developed as a group and individual therapy intervention for parents and guardians of children with ASD, with the aim of promoting positive parent and child outcomes, such as reduced challenging behaviour, reduced parental stress and increased parental competency (Kuravackel et al., 2017). A pre- and post-test control group design was implemented to explore the effects of C-HOPE on child behaviour, parental stress and parental competency, in the contexts of face-to-face and telehealth interventions. Participants (N= 33) were parents of children aged 3-12 years with a diagnosis of ASD. The study took place over an 18-month period across four locations, two rural and two university settings. Participants were randomly assigned to a treatment condition: face-to-face, telehealth or waitlist control group (Kuravackel et al., 2017). Participants received four group intervention sessions and four individual sessions, either in person or via video link. Results of this study indicated that both face-to-face and telehealth interventions reduced problem behaviours, increased parent competency and reduced parent stress, however the effects were smaller for telehealth participants. Researchers found there was no effect of modality of delivery on the parental satisfaction with the intervention received.

A further parent training intervention for parents of children with ASD was developed by the National Autistic Society in the UK. EarlyBird (for children under 5 years) and EarlyBird Plus (for children aged 4 to 9 years) are support programs for parents developed by the National Autistic Society (NAS) to offer advice, guidance and training to parents on strategies and approaches for young children with a diagnosis of ASD. Both EarlyBird and EarlyBird Plus build parents' understanding and knowledge of ASD and aim to foster parental confidence in interaction, communication and behaviour management (NAS, 2019). EarlyBird and EarlyBird Plus are 12-week parent education programmes, which aim to support parents following an ASD diagnosis, to empower parent and develop a positive understanding of ASD and to help parents implement evidence-based practice. In the EarlyBird Plus programme, parents were encouraged to invite along a professional who works closely with the child to participate. Intervention was delivered through group sessions and home visits. Each group session lasts 2.5 hours and follows a structured protocol from the training manual. EarlyBird and EarlyBird Plus programmes are widely implemented in the United Kingdom across the National Health Service as a first-line, post-diagnostic intervention for ASD (Dawson-Squibb, Davids & DeVries, 2019). The EarlyBird programmes have been associated with increased parental knowledge of ASD (Morris, 2002; Engwall & McPherson, 2003; Stevens & Shields, 2013). Research studies have also found that parents who engaged in EarlyBird training reported increased confidence in their parenting of their child with ASD (Halpin, Pitt & Dodd, 2011), as well as a reduction in parent stress (Shields & Simpson, 2004; Anderson, 2006). Furthermore, children of parents who participated in EarlyBird training were noted to have improved communication and behaviour (Hardy, 1999; Morris, 2002; Peters and Scott-Roberts, 2014).

A recent study by Dawson-Squibb, Davids and DeVries (2019) sought to investigate the evidence supporting EarlyBird and EarlyBird Plus, carrying out a systematic scoping review of the available literature on the widely implemented NAS programs. Researchers conducted a search and screened titles and abstracts for inclusion in the study, following this process 18 articles were identified for inclusion in the scoping review. 16 of these were from the UK, while the remaining two studies originated in New Zealand. The researchers reviewed the included studies in terms of context, participants, research design, population demographics, outcome measures, focus of study (parental perception; parental or child changes) and feasibility of the EarlyBird programmes. Of the included studies, 13 involved research on the EarlyBird programme, 2 studies used the EarlyBird Plus programme and 3 studies used both EarlyBird and EarlyBird Plus. Four of the studies were quantitative, 5 were qualitative, 6 were mixed methods studies, and 3 were factual descriptions of the programme, with no quantitative or qualitative data. The results of the scoping review found that the majority of studies on the EarlyBird programmes were descriptive or non-randomised control trials. The authors' note that no randomised control trials of either EarlyBird programme has been identified. The majority of the studies included in this scoping review examine acceptability to parent and/or performed limited efficacy testing. A limited number of studies explored aspects of the feasibility of the programme, such as implementation, demand and expansion. Dawson-Squibb, Davids and DeVries (2019) note that the current level of evidence for EarlyBird and EarlyBird Plus is “lower-level” but that there is “consensus support for the efficacy of the programmes” (p. 553). The authors call for randomised control trials to be carried out to improve the level of evidence for the efficacy of the programmes, while also acknowledging that the standardised nature of the programmes are typically most implementable in well-resourced settings, and are more difficult, if ever, employed in lower and middle resourced health service settings.

In the face of service restrictions, such as limited clinician time, scarcity of resources and increased waiting lists, psychologists in the United Kingdom borough of City and Hackney developed a practice-based research project to provide psychoeducation and meet an ongoing demand for parental support for their client base (Roughan, Parker & Mercer, 2019). The researcher-practitioners used a quality improvement methodology to develop a drop-in, regular group programme of psychoeducation for parents, developed in conjunction with occupational therapists, speech and language therapists and educational psychologist. The researchers tracked the monthly attendance and designed a questionnaire to gather parental feedback on their confidence in managing their child with ASD and their satisfaction with the intervention. The feedback from questionnaires and attendance information was used to develop the intervention and to monitor new developments such as letter reminders, a parental focus group, an email information and reminder system and a parent co-facilitator. The results of the study were that the parental attendance at the monthly groups increased and remained stable, parental satisfaction with the groups was high, and participants reported increases in their own confidence in managing their child with ASD. Researchers noted that the practice based, quality improvement system allowed them to develop efficient and cost-effective ways to intervene with a large clinical population in a resource-challenged environment (Roughan, Parker & Mercer, 2019).

Matson, Mahan & Matson (2009) conducted an investigation into parent training programmes and the evidence surrounding them. The researchers note that on the whole, there is an acknowledgement that interventions for ASD certainly benefit from parental involvement, but that there are specific pragmatic issues which impact upon parental capacity to intervene. Time pressures, fidelity of implementation, ages and demands of children with ASD, parenting stress and co-morbid conditions can impact upon parental involvement in training programmes (Mudford et al., 2001; Matson, Mahan & Matson, 2009). The ability of parents to develop skills particularly in the area of applied behavioural analysis can result in more effective treatment for the child with ASD (Matson et al., 2009). The researchers also comment on the advantages of involving parents in interventions for their child, highlighting greater opportunities for the generalisations of acquired skills, less expense, less clinician time and greater potential for the maintenance of intervention gains while simultaneously improving parents' knowledge and understanding of ASD. Matson et al. state that parent training programmes need to account for age of child, severity of ASD and any co-morbid conditions and also should address issues across the lifespan, suggesting a lifelong treatment model of parent training as well as booster sessions to maintain existing skills.

While there is a vast array of parent training programmes available, both with manuals and without, the most effective parent training programmes have key features in common. Following a meta-analysis of parent training programmes, a number of key components of effective programmes have been identified (Wyatt Kaminski et al., 2008). Firstly, in line with other research on parent training (Lundahl et al., 2006; Maughan, Christiansen, Jenson, Olympia, & Clark, 2005; Reyno & McGrath, 2006), there was an overall positive impact of parent training, supporting the implementation of parent training for a range of challenging behaviours (Wyatt Kaminski et al., 2008). Programmes that included training in fostering *positive parent-child interactions* and which allowed the parent to *practice their skills with their own child* during sessions yielded significant positive results, while programmes with lesser levels of parent activity or active involvement (for example, homework, role playing) were not predictive of positive programme outcomes (Wyatt Kaminski et al., 2008). Secondly, programmes teaching *skills of emotional communication* and *disciplinary consistency* were also likely to produce significant positive results. Interestingly, the use of a standardised or manualised programme did not appear to impact on the outcomes of parent training. Westen, Novotny, and Thompson-Brenner (2004) hypothesise that the manualisation of a programme is less important than ensuring the programme achieves positive outcomes. Regardless of whether a programme is manualised or not, programmes containing the four elements of *working with one's own child, skills relating to emotional communication, teaching positive interactions with children and disciplinary consistency* have greater impact and positive outcomes that parent training programmes which do not (Wyatt Kaminski et al., 2008).

Interventions which employ a parent as a therapist or co-therapist have had positive results, suggesting that parents are a key factor in promoting changes in a child's behaviour and development (Panerai, Ferrante, & Zingale, 2002b). Best practice suggests that following a diagnosis of ASD, parents should be offered training and information both in the theory and phenomenology of ASD, and also how ASD may impact upon their child (McConachie, Randle, Hammal, & Le Couteur, 2005). In terms of clinician time and resourcing, parent training is a cost-effective way to provide information about ASD to groups of parents as opposed to providing individual intervention (Bearss et al., 2015; Connolly & Gersch, 2013; McAleese et al., 2014). Haine-Schlagel and Walsh (2015) argue that parent involvement is crucial in effective practice in delivering psychosocial interventions for children, while insufficient or ineffectual parental engagement is reported as a major barrier to the delivery of evidence-based interventions (Langley, Nadeem, Kataoka, Stein, & Jaycox, 2010). Parental participation in treatment is known to improve outcomes for children and young people (Dowell & Ogles, 2010; Ingoldsby, 2010; Karver, Handelsman, Fields, & Bickman, 2006; Sanders & Kirby, 2011; Wyatt Kaminski et al., 2008). This finding may be of particular relevance to parents of children with ASD, as parent involvement has been shown to enhance the intensity of the intervention by extending and generalising the child's acquired skills across contexts (Brookman-Frazee et al., 2006; Francis, 2005; Ingersoll & Dvortcsak, 2006; Warren et al., 2011; Wong et al., 2015). Parent training interventions have also been found to increase parental knowledge and confidence (McConachie et al., 2005), while training in a group setting has been reported to promote social support and peer support by creating an opportunity for parents of children with ASD to interact with each other (Drew et al., 2002; McAleese et al., 2014).

Common outcomes for psychoeducational parent training programmes for parents of children with ASD include increased knowledge, competence in advocacy skills, along with reduced stress levels and decreased sense of isolation (Bearss et al., 2015). Given the limited timeframe in which most parent training programmes occur, behaviour management techniques and strategies for language or social skills acquisition may be referred to, thus increasing knowledge and awareness of these strategies also (Bearss et al., 2015; Farmer & Reupert, 2013). That said, there is mixed evidence to support the use of parent education programmes. A systematic review of interventions for children with ASD examining specifically the outcomes for families found moderate strength evidence for parent education and coaching programmes improving efficacy and confidence, while evidence of stress reduction and improved family coping skills are mixed, finding either reduced stress or no change at all (Kuhaneck, Madonna, Novak, & Pearson, 2015).

Additionally, participants reported feeling empowered by their knowledge and appreciative of the social support the accessed as a result of engaging in the group. Parents who attended training in this Northern Irish research rated the training sessions quite positively and reported having a deeper understanding of how their child with ASD experiences and makes sense of the world (McAleese et al., 2014). A study by Rivard et al. (2016) focused on the impact of a group parent training course aimed specifically at ASD, combined with individual weekly sessions, prior to their child accessing behavioural interventions, with participants reporting positive reactions to the input. The participants felt that their own psychological wellbeing and that of their family improved following participation in the parent training.

Eclectic training is an approach which uses the combined skills of different clinicians, drawing upon a variety of educational and therapeutic techniques (Dillenburger, 2011; Dillenburger et al., 2014; Parsons et al., 2009). The rationale behind the use of an eclectic approach is that given the heterogeneous presentations of people with ASD, no particular methodology is suitable for all, hence clinicians can choose from a variety of evidence-based methods, systems or approaches (McMahon & Cullinan, 2016). The training discussed in the current research study is offered as an eclectic, indirect intervention for children with ASD through the medium of parents as an alternative to direct contact-time with clinicians (Bearss et al., 2015; Matson et al., 2009; Postorino et al., 2017; Stadnick et al., 2015).

The training discussed in the current research study was devised from a combination of evidence-based practice and practice-based evidence. Evidence-based practice in psychology is a long-established tradition, enshrined in the training and education programmes in third-level education around the world (Barkham, Hardy, & Mellor-Clark, 2010; Goodheart et al., 2006). Evidence-based practice is described as the integration of best research evidence with clinical expertise and patient values (Sackett, Rosenberg, Gray, Haynes & Richardson, 1996). Evidence-based practice supports public health and enhances psychological practice through the application of empirically sound, evidence-based practices of psychological assessment, case formulation, therapeutic alliances and appropriate interventions (Goodheart et al., 2006). According to Fineout-Overholt, Melnyk, and Schultz (2005), evidence-based practice comprises a problem-solving approach to practice, which systematically seeks out and evaluates the most relevant evidence to answer a question which arises from clinical practice. For Goodheart et al. (2006), psychologists who have been trained in the skills and practices of evidence-based clinical work have a vital role to play in the continuing development of the paradigm, becoming producers, evaluators and consumers of research and allowing research to inform their practice, and practice to inform their research, with the benefit of the client or patient at the centre of the practice.

Practice-based evidence focuses primarily on what works in a real-world context, taking the emphasis away from randomised-control trials and theoretically orientated constructs of what works, and moving towards clinicians' accounts of what is effective in practice (Barkham et al., 2010; Barkham & Mellor-Clark, 2013). This approach supports a move beyond experimental designs, towards field settings and the implementation of interventions in naturalistic settings (Barkham & Mellor-Clark, 2013). Practice-based evidence fits well within a pragmatic case-study methodology (Barkham, Hardy, & Mellor-Clark, 2010). This builds a significant and robust evidence base of effective professional practice in psychology (Barkham et al., 2010; Barkham & Mellor-Clark, 2013; Margison et al., 2000).

2.5 Parental Needs

The literature review identified a number of key areas of information needs reported by parents whose children have been diagnosed with ASD. These areas have been categorised as: *thinking of the future, information needs, coping strategies, group support, training for parents, mental health information* and *telling the child about the diagnosis.*

2.5.1 Thinking of the Future.

Following a diagnosis of ASD for their child, many parents begin to think about the future and the implications of an ASD diagnosis for their child as they grow and develop. Murphy and Tierney (2006) conducted six focus groups with 27 mothers and 11 fathers in an Irish context over the course of two months in order to investigate the information needs of parents, noting that when parents receive an ASD diagnosis, they begin to think about the long-term impact. Given that ASD is a lifelong condition, which pervades across the lifespan; parents consider the diagnosis of ASD and the implications for their child's future (Murphy & Tierney, 2006). For many parents their knowledge of ASD was limited to the film Rainman (1988) (Mitchell & Holdt, 2014; Silberman, 2015). This limited knowledge of ASD meant that some participants reported having difficulty in envisaging what the future may hold for their child (Murphy & Tierney, 2006). This uncertainty is compounded by limited supports and direction from professionals (Murphy & Tierney, 2006), a finding which is supported by the research of Howlin and Moore (1997) and Mansell and Morris (2004). Thus, the post-diagnostic period can often be a time of information-seeking, searching for supports and swinging between hope and disappointment while adapting to the diagnosis (Mansell & Morris, 2004).

2.5.2 Information Needs.

Families identified the need for follow-up supports in terms of information and services following a diagnosis of ASD as a means of addressing their feelings of uncertainty and the inadequacy of support (Banach, Iudice, Conway and Couse, 2010). Case study research found that parents identified a need for support and information in terms of self-advocacy to schools and other services (Drake, Couse, DiNapoli, & Banach, 2008).

Whether a parent experiences shock, sadness, anger, relief or surprise at their child’s diagnosis, parents tend to seek information on how ASD could impact on their and their child’s lives (Barnett et al., 2003; Da Paz, Siegel, Coccia, & Epel, 2018; Divan et al., 2012). In the period following a diagnosis of ASD, information seeking on the disorder is a key activity undertaken by parents (Grant et al., 2015; Murphy & Tierney, 2006; Pain, 1999; Reichow et al., 2012). A survey of parents’ information needs reported a perceived lack of support from professionals and clinicians, with the responsibility to seek information falling primarily on the parents (Murphy & Tierney, 2006). It is hypothesised that information seeking serves as a coping mechanism following a life-changing diagnosis, while also building connections with local, national and international communities of support (Barnett et al., 2003; Divan et al., 2012; Lutz et al., 2012; Murphy & Tierney, 2006; Pain, 1999; Siegel, 1997; Stoner & Angell, 2006; Vernhet et al., 2018).

Research suggests that information seeking behaviour is associated with positive psychological well-being, with reasons attributed to information seeking, such as coming to terms with a diagnosis, adjusting to the disability, behaviour management and accepting the impact upon the wider family (Farrugia, 2009; Pain, 1999; Salas et al., 2017). While research undertaken in the Irish context supported the international research, it did, however, identify additional purposes to information seeking, namely, to find answers to specific and immediate questions, to gather information on services and entitlements, to aid decision-making in relation to treatment and intervention, to help to plan for the future and to generally gain a greater sense of control of outcomes for the child and their family (Murphy & Tierney, 2006). Connolly and Gersch (2013), in their wait-list intervention research, found that parents reported fear and anxiety resulting from inaccurate or insufficient information. Parents in this study reported that having information empowered them in supporting their child with ASD.

Key areas of need emerged from the data: information relating to diagnosis, services, intervention/practical strategies, educational issues, concerns, informing the child and others, resources and future concerns (Murphy & Tierney, 2006). Further findings include the timeframe in which parents search for information; prior to and following diagnosis were the times when parents searched most urgently for information, including attendance at conferences, trainings and seminars. Following this timeframe, searching became less of a focus with parents reporting seeking information at critical junctures in development or transition (Murphy & Tierney, 2006). A study on the intervention decision-making process and information preferences of parents of children with ASD by Grant et al. (2015) found that parents report seeking information on ASD interventions from a number of sources, and applying a trial and error approach to choosing and evaluating these interventions. Furthermore, a recent review of parents information-seeking and treatment selection by J. Matson and Williams (2015), found that interventions and treatments which make claims of efficacy without empirical evidence are widely available, leaving parents confused about what might be best for their child. Murphy and Tierney (2006) also found that over time parents sought less information as they became more familiar with their child's profile of strengths and needs within ASD. However, further to this point, Gibson, Kaplan, and Vardell (2017) note that the availability of information sources for parents decreases as their children get older, with fewer resources available for adolescents and adults with ASD.

The process of seeking information following a diagnosis is a vital step in gaining an understanding of the practicalities and realities of the disability (Pain, 1999). This research finding was supported in more recent years by that of Salas et al. (2017). Research by both Pain and Salas et al. (2017) highlighted that information seeking behaviours facilitated parental adjustment to the diagnosis. When trying to plan for how to best support their child and meet his/her needs following a diagnosis of ASD, parents can be overwhelmed by the sheer volume of information available outside of clinical sources, in terms of new treatments, diets, medications, behavioural strategies and educational interventions (Murphy & Tierney, 2006). More recent studies focused on the difficulties faced by parents when deciphering for the validity and reliability of available information (Gibson et al., 2017; Grant et al., 2015; Matson & Williams, 2015; Stephenson, Carter, & Kemp, 2012). Schopler (1995) discussed how merely searching through the barrage of information can be daunting, with some parents expressing feelings of hopelessness when faced with trying to keep up with each latest advancement, a finding which was later supported by Connolly and Gersch (2013). For Mackintosh, Myers and Goin-Kochel (2005), parents desire knowledge and information, but can feel overcome with the process of finding information which is of good quality and relevant to their own situation. Despite parents' reported desire for information, findings from Pain's research (1999) state that information seeking can be of mixed benefit for the parents of children with disabilities, in that it can provide strategies, knowledge and can aid in emotional adjustment and behaviour management, but can also be disheartening and can increase anxiety, especially if the information outlines a grim outlook for the future or focuses on services which are not available in the region. Matson and Williams (2015) and Connolly and Gersch (2013) noted that parents were overwhelmed in the face of pessimistic information, and also, when faced with a lack of information. Gibson et al. (2017) highlight the changing and different information needs of people with ASD and their families in terms of medical, educational and social supports across the lifespan.

2.5.3 Coping Strategies.

Coping strategies identified which were predictive of daily positive mood were Problem-Focused, Social Support, Positive Reframing, Emotional Regulation and Compromise. A study examining the daily stresses, coping strategies and overall well-being of parents of children with ASD by Pottie and Ingram (2008) highlighted approaches which had positive and negative impacts on the daily stress levels of parents. Lowered daily positive mood was identified as being associated with the coping strategies of Escape, Blame, Withdrawal and Helplessness (Pottie & Ingram, 2008). Low daily mood was predicted by the coping strategies of Distraction and Emotional Regulation, while higher levels of daily negative mood was associated with the increased reliance on the coping strategies Problem-Focused, Blaming, Worrying and Withdrawal. Pottie and Ingram (2008) note that for parents of children with ASD, using a Problem Focused coping strategy may not necessarily be of benefit when responding to daily stresses. The authors note that due to the nature of the challenges which some parents of children with ASD may face, such as rigidity, repetitive behaviours, a more flexible approach adopting a variety of coping responses may be more effective.

In contrast, a study by Vernhet et al. (2018) found that increasing the use of problem-focused strategies lowered overall stress levels, while increasing the use of emotionally focused strategies increased their stress levels. It was reported that coping strategies which were problem-focused in nature served as protective factors for parental quality of life, while the use of emotion focused coping increased the risk of conflict and altercation. The use of emotional coping strategies such as avoidance, escapism or distancing were correlated with more depressive symptoms, feeling more socially isolated and more fractious relationships with their children. On the other hand, parents who sought social support or used a problem-focused approach were at a reduced risk of experiencing negative outcomes and negative impact on overall quality of life (Vernhet et al., 2018).

2.5.4 Group Support.

Given that parents of children with ASD are at risk of social isolation and lack of understanding from others (Woodgate, Ateah, & Secco, 2008), group support can offer an opportunity for parents to meet other parents of children with ASD and to gain knowledge, understanding and acceptance (Banach et al., 2010). One of the greatest needs for families of children with ASD is thought to be acceptance and support from other people (Banach et al., 2010; Woodgate et al., 2008). Parents taking part in a support group for parents of children with general disabilities reported an increased sense of belonging, with an enhanced sense of empowerment in their ability to come together to advocate for and support their children at a broader community and societal level Law, King, & Stewart, 2001). Additionally, participants reported an increased sense of knowledge and competence in managing behavioural issues and other daily concerns (Law et al., 2001). Mansell and Morris (2004) report that a post-diagnostic parent support group was ranked as the most useful of all post-diagnostic information, while a study by Bitsika and Sharpley (1999) highlights the reported increase in self-concept and decrease in stress levels following participation in a parent support group for parents of children with ASD.

2.5.5 Telling About the Diagnosis.

Smith, Edelstein, Cox, and White (2018) undertook a systematic review of the available research on parental disclosure of an ASD diagnosis to their child, including five qualitative studies. Their results found that parents reported concerns about the time taken to process the emotional impact of the diagnosis, delays between the receipt of the diagnosis from clinicians and disclosing the diagnosis to the child, worries about the stigmatisation associated with a label of ASD and, more positively, a sense that knowing about their diagnosis would help the child to make sense of their own behaviours and symptoms (Smith et al., 2018). Smith et al. called for the development of best-practice guidelines to support parents in disclosing the diagnosis of ASD to their child, and for further research in the area.

2.6 Parents’ Experiences

This section of the literature review critically analyses parents’ experiences following a diagnosis of ASD for their child.

2.6.1 Post-Diagnosis Feelings of Parents.

Following a diagnosis of ASD, the experiences of parents can include difficulties with adaptation, affective impacts, struggles to access and navigate services, resources and supports, as well as a desire for further information (Barnett et al., 2003; Da Paz et al., 2018; Fleischmann, 2004; Lutz et al., 2012; Mansell & Morris, 2004). As well as reportedly experiencing a flurry of emotions (Murphy & Tierney, 2006), researchers have noted that parents' experiences can have a significant and long-lasting impact on parents' psychological well-being. Baird, McConachie and Scrutton (2000) found that the level of satisfaction experienced by parents in relation to how the diagnosis is delivered may be linked to the manner in which the information is conveyed, the structure of the disclosure and the quality of information offered to parents at this time. Woolley, Stein, Forrest, and Baum (1989) found that a positive diagnostic experience is correlated with higher levels of diagnosis acceptance, more effective coping strategies and lower levels of stress. The support offered to parents and families following a diagnosis of ASD is very limited, with most support and benefit being derived from educational provision (Crane et al., 2016). Research has found that up to 53% of parents report dissatisfaction with the help they receive post-diagnosis (Howlin & Moore, 1997; Siklos & Kerns, 2006). This perceived lack of support can impact upon parental coping ability (Clifford & Minnes, 2013; Pepperell, Paynter, & Gilmore, 2018).

2.6.2 Emotional Impact for Parents.

The emotional impact of an ASD diagnosis for parents cannot be underestimated. Many parents report a feeling of relief on receipt of a diagnosis (Midence & O'Neill, 1999; Sullivan, 1997). It is thought that this sense of relief is linked to the corroboration of their worries and suspicions (Midence & O'Neill, 1999; Sullivan, 1997), as well as providing an explanation of the child's presentation, both for themselves and for others (Mansell & Morris, 2004). Parents can also express relief at the receipt of a "label", in that having a definitive diagnostic label for their child's behaviour and difficulties can enable their access to support and services (Mansell & Morris, 2004; Murphy & Tierney, 2006).

For other parents, receiving a diagnosis of ASD can be a shock, and some parents may express disbelief and not accept the diagnosis (Da Paz et al., 2018; Siegel, 1997). Diagnosis of ASD can be very upsetting for many families, and the process of acclimatising to the diagnosis has been compared to a process of grieving for the "hoped-for child" (Mansell & Morris, 2004). Feelings of anger, sadness, disbelief and disagreement are common, and are linked to various points in the grieving process after receipt of an ASD diagnosis (Barnett et al., 2003). Trigonaki (2002) reported that following an ASD diagnosis, parents' worlds as they know them fall apart; they had imagined raising healthy children who were full of life, and instead, this image is replaced by words such as disabled, challenging, unmanageable and autistic. Studies have shown that following the diagnosis of ASD for their child, parents can experience increased levels of stress, anxiety, depression, financial problems and difficulties in relationships, while their levels of self-competence and self-confidence may decrease (Fitzgerald, Matthews, Birkherk, O'Connor, Eastern Health Board, 1997; Symon, 2001).

There are many implications of being a parent to a child with ASD. Hennel et al. (2016) report that parents of children with ASD are impacted across several domains in their daily lives, including medical, financial, emotional, psychological, social and time. Research has shown that parents of children with ASD report higher levels of distress and depressive symptoms when compared with parents of children with typical development or with parents of children with other forms of developmental disorder (Eisenhower, Baker, & Blacher, 2005). Furthermore, parents of children with ASD report increased levels of stress and adjustment difficulties than parents of children without an ASD (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005).

There are a number of hypotheses which seek to explain the affective impacts of parenting a child with ASD. Firstly, it is well documented that children with ASD experience a significantly greater levels of challenging emotional and behavioural traits than typically developing children and children with other disabilities (Brereton, Tonge, & Einfeld, 2006). Secondly, given that ASD presents along a vast spectrum of needs, abilities and challenges, parenting can be very stressful due to the complexity of the condition, which can be further compounded by the child's ability to communicate effectively, possible learning differences and difficulties as well as inappropriate and sometime aggressive or violent behaviours (Davis & Carter, 2008; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Myers, Mackintosh, & Goin-Kochel, 2009). Furthermore, additional sources of stress for parents of children with ASD can include emotional distress from receiving a diagnosis of ASD for their child, the strain of additional parenting demands, the pressure to seek information and to deliver interventions to their child, lost time from work, as well as the greater financial costs of caring for a child with ASD (Cidav, Marcus, & Mandell, 2012). Finally, these stresses can be compounded by the challenges of considering the potential for their child's ongoing dependency, planning for the child's future in the face of uncertainty, as well as acting as advocate for their child in the educational, disability, social and medical settings (Altiere & von Kluge, 2009; Myers et al., 2009).

2.6.3 Experiences of Parents in Accessing Information Post-Diagnosis.

Parents of children with ASD seek information from a wide variety of sources, but other parents of children with ASD are reported to be a significant information resource (Crane et al., 2016; Grant et al., 2015; Law et al., 2001; Mackintosh, Myers, & Goin-Kochel, 2005; Murphy & Tierney, 2006; Pain, 1999). A large, web-based survey of 498 parents found that parents reported getting information on ASD from nearly 7 different sources, including personal relationships, professionals, web-based sources, books, journals and other print media, along with group gatherings such as conferences, workshops and ASD group meetings (Mackintosh et al., 2005). By far the largest source of information for this cohort was other parents of children with ASD (72%), a figure which is strikingly larger than the number of parents who mention receiving information from professionals, including physicians (48%), educators (49%) and other ASD professionals (57%) (Mackintosh et al., 2005). The findings of Mackintosh et al. are supported by those of Murphy and Tierney (2006), where parents reported that other parents of children with ASD were their greatest source of information, expressing appreciation for the knowledge and advice of those who may have experienced similar challenges to them. Additionally, the parents in this research reported particularly valuing the information given to them from other parents in relation to behavioural issues and management strategies. However, key issues that emerged for the parents in the study were related to the fact that this information would not have been appraised by a clinician and also that these informational relationships were happened upon by chance, in a piecemeal and ad-hoc manner, where luck and access to other parents of children with ASD played a large role (Matson & Williams, 2015; Matson, Adams, Williams, & Rieske, 2013; Murphy & Tierney, 2006).

Mackintosh, Myers and Goin-Kochel (2005) also report that parents draw on written materials as a source of information, a finding which is reflected across the literature in this area (Gibson et al., 2017; Grant et al., 2015; Murphy & Tierney, 2006). Written sources of information include books, journal articles, magazine articles, research studies, government papers and ASD newsletters. For Mackintosh, Myers and Goin-Kochel, books were the most referenced written sources of information mentioned by parents (88%), followed by email lists (86%), ASD newsletters (69%) and scientific journals (44%). Scientific journals can be difficult to access, given that many are not openly accessible and are mainly available in a university or research context. Furthermore, the information and findings contained within can be complex and challenging for a layperson to understand, hence making them a less preferred source of information for parents. Books, media articles and other forms of print media may be a valuable source of information, but there are so many sources, many of whom operate from subjective perspectives, that it can be difficult to decipher for the quality and reliability of the information (Schopler, 1995). An additional point highlighted by Matson and Williams (2015) is the difference between empirical data gathered and the information collated by national and international ASD associations. Stephenson et al. (2012) compared data on information on psychological interventions, finding that information geared towards parents can often favour diplomacy above presenting the most accurate empirical information.

Attendance at workshops and conferences was also a means of gaining information reported by parents (Gibson et al., 2017; Mackintosh et al., 2005; Murphy & Tierney, 2006). However, as Mackintosh, Myers and Goin-Kochel (2005) note, the cost of attending face-to-face conferences and workshops can be prohibitive, limiting their accessibility and information to those who can afford to attend.

With the advent of increased accessibility to technology, the internet has become a significant source of information for parents, with increasing numbers citing the web as a valuable information source (Hall, Culler, & Frank-Webb, 2016; Mackintosh et al., 2005). Online resources and information for parents of children with disabilities have risen exponentially in recent years (Jones et al., 2013; Pagliari et al., 2005). Grant et al. (2015) report a dramatic rise in sources, with searches for information on ASD going from 104,950 sites in 1999 to 17.4 million in 2005. Use of the internet as an information source has numerous benefits: it is cost-effective, publicly available, accessible to all and may be particularly useful where access to professionals and clinicians is limited (Hall et al., 2016). That said, there are some reservations around the use of the internet in this manner. The quality of information on the internet is known to be variable, inconsistent and at times, misleading (Grant et al., 2015). A study by Reichow et al. (2012) found that web searches using the same key words did not always produce the same results when repeated, with consistency decreasing over time. The quality of information available on the internet can also be inconsistent and questionable (Gagliardi & Jadad, 2002; Grant et al., 2015). Areas of intervention and health information conveyed in particularly concerning manner online included treatment risks, what happens if no treatment is pursued, benefits, how the intervention or treatment works and the impact, if any, on overall quality of life to be expected from treatment or intervention (Grant et al., 2015). Such information is important for the decision-making process when selecting interventions or treatments for children with ASD, and indeed, all health-related decisions, and disparity in the provision and quality in relation to these factors can impact upon the ability of parents to make informed decisions (Grant, Rodger & Hoffman, 2015).

2.6.4 Positive experiences of parenting a child with ASD.

Despite the documented challenges experienced by parents of children and young people with ASD, research has found more positive perspectives and viewpoints. A metasynthesis of qualitative research conducted by DePape and Lindsay (2015) reported themes which described the benefits of parenting a child with ASD. These included ‘feelings of normalcy’ and ‘benefits’. For parents, there was a sense of adaptation and finding a new normal for their family unit (DeGrace, 2004; Koydemir-Ozden & Tosun, 2010; Luong, Yoder, & Canham, 2009; Midence & O’Neill, 1999). Furthermore, feelings of normality occurred when parents accepted that their child had ASD and no longer tried to fix their child (Koydemir-Ozden & Tosun, 2010; Luong et al., 2009). Parents outlined the benefits of parenting their child with ASD, naming close relationships with their child (Midence & O’Neill, 1999) and close relationships with their partner-parent (Hock, Timm, & Ramisch, 2012) as key benefits. Additionally, parents reported personal changes such as increased patience and tolerance (Altiere & von Kluge, 2009) and greater coping ability (Altiere & von Kluge, 2009; Markoulakis, Fletcher, & Bryden, 2012). Luong et al. (2009) report that parents felt that caring for a child with ASD has changed their worldview and their feelings of spirituality.

2.6.5 Experiences of Coping and Support.

Following a diagnosis of ASD, attention often shifts towards a process of coping and support (Barnett et al., 2003; Divan et al., 2012; Lutz et al., 2012; Pottie & Ingram, 2008; Vernhet et al., 2018). As previously discussed, research has indicated that parents of children with ASD experience higher levels of stress than parents of typically developing children (Brereton et al., 2006; Davis & Carter, 2008; Hoffman et al., 2009). The study of Vernhet et al. (2018), following a systematic review of available literature, noted that parental stress is influenced by a child's behaviour and difficulties in socialisation and communication, while also being impacted by parental traits such as age, gender and personality. Once a child is diagnosed with ASD, the challenges and stresses of adapting to meeting the needs of the child and the family as a whole increase (Blackledge & Hayes, 2006; Sivberg, 2002). Mitchell and Holdt (2014) and Scheeren and Stauder (2008) note a further factor which may complicate parents' experiences of their child's diagnosis; namely, the possible presence of autistic traits or ASD phenotype within the parents themselves. The presence of autistic traits in parents is thought to impact upon parental stress and depression (Ingersoll & Hambrick 2011). Furthermore, the presence of an ASD phenotype in parents affects parental ability to elicit social supports, sustain friendships and cope with their child's condition, along with any future difficulties that parenting a child with ASD may bring (Ingersoll & Hambrick, 2011).

A study by Salas et al. (2017) found that the age of the child with ASD is associated with a lower level of life satisfaction in their parents, with life satisfaction of parents declining with age. Self-efficacy arose as a major factor which affected life satisfaction in mothers. Problem solving was posited as a factor which explained life satisfaction reports of fathers. In terms of coping strategies and stress management, Salas et al. (2017) found significant differences between genders, with mothers reportedly using more emotional expression and social support strategies than fathers in this study. The systematic review by Vernhet et al. (2018) highlighted interesting findings in that parents of children with ASD tend to use more social avoidance strategies than parents of typically developing children. Avoidance techniques tend to be used to support coping with a stressful situation. While Salas et al. (2017) reported that mothers tend to use social support more than fathers, generally speaking parents of children with ASD reported using less social support seeking strategies than parents of typically developing children (Vernhet et al., 2018). Furthermore, for some parents the ASD diagnostic process can be quite stressful, causing a strain on relationships with friends and family members, consequently restricting their opportunities to access social support (Vernhet et al., 2018). In contrast, research suggests that parents of children with ASD seek social support and interaction with other parents of children with ASD, citing shared experiences, sense of belonging and receipt of advice as advantages of such social exchanges (Divan et al., 2012; McAleese et al., 2014; Murphy & Tierney, 2006; Siklos & Kerns, 2006).

2.6.6 Experiences of Parent Training.

A study by McAleese et al. (2014) found that parents of children with ASD who attended a psychoeducational, therapeutic group experienced a significant increase in their knowledge of the manifestations of ASD, and also in their knowledge of appropriate behavioural interventions for supporting their child. Oono, Honey, and McConachie (2013) conducted a systematic review of the literature to examine parent-mediated interventions for young children with ASD. The review concluded that, while on the one hand, there was some evidence for the effectiveness of parent-mediated interventions in ASD, on the other hand, Oono et al. noted that the evidence to support the hypothesis regarding parent training reducing parental stress levels is not sufficiently robust. The authors recommend further high quality studies to add to the body of work on parent training for ASD (Oono et al., 2013). A systematic review and meta-analysis by Postorino et al. (2017) found evidence to support the use of parent training in reducing disruptive behaviours in children with ASD. The authors also highlight the necessity for cost-effective and replicable interventions for children with ASD, noting that parent training is suitable for implementation across a wide range of settings such as clinics and schools (Postorino et al., 2017).

2.7 Parents' Perspectives

This section of the literature review examines parents' perspectives, i.e. what parents thought about parent training following a diagnosis of ASD for their child.

2.7.1 Parents' Perspectives on Information Seeking.

Researchers agree that information seeking, and the fulfilment of the information needs of parents has been linked with emotional resilience, coping and better child and family well-being outcomes (Pain, 1999; Salas et al., 2017; Tong, Morton, Howard, & Craig, 2009). Bearing this in mind, the quality of the information received by parents as well as the preferred sources of information for parents must be carefully considered in light of the importance of information seeking. Participants in Murphy and Tierney's study (2006) reported that access to information came about mainly through luck, perseverance and their own advocacy skills. Furthermore, they reported dissatisfaction with the quantity and quality of information available to them, with the information available deemed as “unhelpful, vague, or worse still, too much, too little and too late” (Murphy & Tierney, 2006, p.26). Grant et al. (2015) found that information on interventions is difficult to access and often incomprehensible, particularly in relation to information on intervention efficacy. This is congruent with research which found that not only is information not always accessible to parents, evidence-bases are not always considered by parents when making decisions around interventions for ASD (Bowker, D’Angelo, Hicks, & Wells, 2011; Carlon, Carter, & Stephenson, 2013; Green et al., 2006). Furthermore, despite the multiplicity of information sources, there exists within these sources a wide discrepancy in expertise, evidence, training, subjective experiences, epistemological stances and personal viewpoints about what works and what does not (Matson & Williams, 2015).

Qualitative reports from the study conducted by Murphy and Tierney (2006) show that although parents have access of huge quantities information online, many felt that this was, in fact, unhelpful in their search for appropriate information for their own child and family, leaving them feeling overwhelmed and exhausted. Some parents reported spending money on expensive treatments and interventions which purported to cure ASD, but which did not work and lacked any evidence base (Matson & Williams, 2015; Matson et al., 2013). Additionally, some parents felt that due to a lack of services available to them for support and information, they had no option but to navigate through the internet for solutions. However, use of the internet as an information source can lead to fear and anxiety, with parents noting that online information was often either too much to assimilate or else described worst case scenarios (Connolly & Gersch, 2013; Gibson et al., 2017; Grant et al., 2015; Reichow et al., 2012; Stephenson et al., 2012).

2.7.2 Perspectives on Sources of Support and Coping.

A frequent finding arising from the literature on coping and support for parents of children with ASD is that parents reported that other parents of children with ASD were their greatest source of information and support (Mansell & Morris, 2004; Murphy & Tierney, 2006). Mackintosh et al. (2005) refer to this form of social support as the “walking in our shoes factor” (p.50), with parents in this study reporting other parents of children with ASD as a support, above any other form of social support. That said, the number of supports cited by parents differed according to parent income, with lower income parents accessing fewer supports than those with middle or upper income levels (Mackintosh et al., 2005). Grant et al. (2015) research found that mothers used the internet to access support; this included providing support to other mothers and receiving support from other parents online. In this study, some mothers reported that online was the only place they could access support and interact with other mothers of children with ASD.

2.8 Conclusion

The process of receiving a diagnosis of ASD is a journey, both for the individual receiving the diagnosis and for the parents and family members (Connolly & Gersch, 2013). Parents of children with ASD have a unique perspective and insight into what it is to care for and raise a child with ASD, hence their voices must be taken account of in all parts of the journey. Following a diagnosis of ASD, parents experience a range of emotions and seek knowledge, skills, support and information to help to acclimatise to the diagnosis (McAleese et al., 2014; Murphy & Tierney, 2006). Many ASD services struggle to provide services and intervention due to current high levels of demand for assessment (Divan et al., 2012; Mansell & Morris, 2004). Parent training offers a cost-effective, evidence-based means for ASD services and professionals to meet parents' needs for information, support and training following diagnosis. An additional benefit of parent training is the social support reportedly received by participants of parent training (Wyatt Kaminski et al., 2008).

It is clear following a review of the literature that following a diagnosis of ASD for their child, parents desire to receive information from an evidence-based, reputable and reliable source (Banach et al., 2010; Fennell & Dillenburger, 2018; Hennel et al., 2016; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010; Ring et al., 2018). However, this is not always available. Furthermore, parents would like to receive support from peers and from services. Parents would like to learn about coping strategies and would like to understand what ASD is, and how it affects their child. Post-diagnostic parent training is an appropriate way to try to meet these parental needs (Bearss et al., 2015; Ingersoll & Dvortcsak, 2006; Lundahl et al., 2006; Matson et al., 2009; McConachie et al., 2005; Oono et al., 2013; Rivard et al., 2017; Wyatt Kaminski et al., 2008). The researcher found that the training she attended during a doctoral placement would provide an opportunity to uncover the voices of parents in the post-diagnostic process, with an emphasis on parental needs, experiences and perspectives.

This research seeks to capture the voices of parents participating in parent training following their child's diagnosis of ASD. The focus of the research is to gain an insight into the experiences of the parents taking part and their perceptions of participating in the parent training programme.

This project proposes the following research questions:

- What are parents' **perspectives** of their **training needs** following a diagnosis of ASD for their child?
- What are **parents'** self-reported **experiences** of **post-diagnostic parent training in an ASD service?**
- What are parents' **perspectives on taking part in post-diagnostic parent training**?

This research has implications for educational psychology practice, as it will establish a practice informed evidence-base for the experiences and perspectives of parents on post-diagnostic training in an ASD service. This practice-led action research case study will inform future practice in post-diagnostic intervention, enabling clinicians to support parents in a meaningful way, allowing psychologists to "give their psychology away" (Birch, Frederickson, & Miller, 2015; Miller, 1969) and to maximise the use of their time through group training (Banach et al., 2010; McAleese et al., 2014; Wright & Williams, 2007). The evidence will be used to enhance experience quality for parents who attend training of this type in the future. Following a review of the literature, it was decided that a case study methodology was suitable to answer the research questions, as this approach suits the unique and bounded nature of the research setting and more importantly, the research questions.

Chapter 3: Methodology

3.1 Chapter Introduction

This chapter provides the background and rationale for the research methodology, in light of the epistemological stance of the researcher. This chapter presents the study design, providing a rationale for the chosen approach. Case study methodology is discussed. The data collection methods include questionnaires and semi-structured interviews. Participants and sampling are outlined, before the ethical underpinnings and considerations for the research are elaborated upon. Data analysis strategies are defined, including both quantitative and qualitative approaches, in relation to how the research questions were addressed. Approaches to best practice for conducting high quality research are discussed in terms of reflexivity and dependability.

3.2 The Aims of the Study

The aim of this research was to capture the voices of parents of children recently diagnosed with ASD who participated in a parent training programme. This research aimed to identify the needs, experiences and perspectives of the parents taking part in this post-diagnostic parent training, in terms of the benefits, utility, practicality and emotive impact of participation. This research was designed to give a voice to parents at this stage of their ASD journey and to hear from them about their self-reported experiences, as they perceived them, on this training programme.

3.2.1 Research Questions.

Following a systematic review of the literature, the following research questions arose:

- What are parents’ **perspectives** of their **training needs** following a diagnosis of ASD for their child?
- What are **parents’** self-reported **experiences** of **post-diagnostic parent training in an ASD service?**
- What are parents’ **perspectives on taking part in post-diagnostic parent training**?

3.3 Epistemology

Research is informed by one’s worldview or perspective; this is referred to as a paradigm (Reason, 1998). A paradigm is a way of looking at the world (Mertens, 2004, 2011). Paradigms, or worldviews, can be described as a general philosophical understanding of the world, the nature of knowledge and the nature of reality (Creswell, 2014; Reason, 1998). By stating the research paradigm they subscribe to, a researcher acknowledges their own ontological and epistemological stance, and the impact this may have on their research approaches (Creswell, 2014; Merriam, 2009). Ontological assumptions give rise to assumptions about the nature of knowledge, which, in turn, influence research design and methodological decisions. These subsequently impact upon data collection and implementation (Cohen, Manion, & Morrison, 2007; Creswell, 2014; Hitchcock & Hughes, 2002). Four major paradigms are discussed in research literature; these are post-positivism, constructivism, transformative, and pragmatism (Creswell, 2014; Mertens, 2015).

Post-positivism aims to discover laws about the world using quantitative methods and emphasises positive facts based in empirical evidence (Bowling, 2009). Methodologies associated with post-positivist research tend to be quantitative in nature. The quantitative paradigm utilises a formal, objective and systematic process to capture information, which is quantifiable, can be presented in numerical format and statistically analysed (Parahoo, 2014). Research which subscribes to the transformative paradigm, which is sometimes known as critical research, (Mertens, 2015), is often concerned with issues of marginalisation, power, social justice, discrimination and oppression (Creswell, 2014; Merriam, 2009). Research conducted from a transformative worldview perspective seeks to change, emancipate and empower disenfranchised members of society (Cohen et al., 2007; Merriam, 2009). Research in this paradigm tends to be action-research, and often examines issues of feminism, queer theory, Neo-Marxism, race theory and critical ethnography (Merriam, 2009; Mertens, 2015). A pragmatic worldview arises from a preoccupation of what works in terms of actions, situations and consequences, rather than investigating antecedents as seen in post-positivist research (Creswell, 2014). The pragmatic paradigm posits that there is one reality, however every individual will have their own unique experience and interpretation of that reality (Mertens, 2015). Pragmatism is concerned with solutions to issues and with the application of successful strategies (Patton, 1990). Pragmatic research often takes a mixed method approach, drawing upon both quantitative and qualitative methods as the need arises (Mertens, 2015). A fourth research paradigm is that of social constructivism. Researchers who adopt constructivist approach generate new patterns of meaning from the information they encounter over the course of the research (Creswell, 2013). The constructivist approach acknowledges that research is a by-product of the values of the researcher and cannot be separated from them (Mertens, 2015); this can be considered both a strength and a weakness of the paradigm, depending on perspective. The constructivist approach assumes that historical and social perspectives inform world views, and that the basic generation of meaning is always social, occurring in and arising from human interaction (Creswell, 2013). Qualitative data collection methods tend to be used by researchers in the social constructivist paradigm (Merriam, 2009; Mertens, 2015). The assumptions of each research paradigm are outlined in Appendix A.

The current research study subscribes to the pragmatic paradigm. A pragmatic approach is best suited to answering the questions posed by the current research project, as it is a worldview which allows for researcher's freedom of choice in the best approach to answer a given question, acknowledges that research occurs in social, historical and political contexts, and places a value upon the differing perspectives, approaches, worldviews and assumptions in social research which create meaning in a post-modern world (Creswell, 2014; Merriam, 2009).Adopting a pragmatic approach to this research captures the voices of parents in a post-diagnostic training programme setting through a variety of methods , while also creating meaning from their reported experiences and perspectives, rather than a position of disproving a hypothesis or theory as in post-positivist research (Braun & Clarke, 2013; Creswell, 2014).Additionally, a pragmatic paradigm allows the researcher to address the research questions directly to the research methods posed (Creswell, 2003), taking a "what works" approach (Darlington & Scott, 2002). Armitage (2007) suggests that a pragmatic approach is suitable for research in social contexts, as it is in line with a mixed qualitative and quantitative approach that is often taken within practitioner-based research. Given that the current research took place in a real-world, practice-based setting, a pragmatic paradigm was seen as the most suitable approach with which to undertake problem-centred, real-world, practice-oriented research (Creswell, 2014). Furthermore, pragmatic research acknowledges that intersubjectivity is a key aspect of social life (Mertens, 2015), which is of paramount importance in the current research study which examines parent training as an intervention for parents of children with ASD. Given that this research is informed by Bronfenbrenner's ecological theory (1977; 1979), a pragmatic approach which emphasises the importance of human psychological experiences (intersubjectivity) is well-suited to this research context.

3.4 Research Design

Research designs are outlined procedures which guide the collection, analysis, interpretation and reporting of data in research studies (Creswell & Plano Clark, 2011; Mertens, 2015). A case study approach was selected as best suited to answering the given research questions as this approach allows information to be gathered from a multiplicity of sources, using a variety of data collection tools and methods (Thomas, 2011). The current research study gathers information through both qualitative and quantitative procedures and from parents and clinicians and researcher observations in order to create a rich, thick description of this post-diagnostic parent training (Merriam, 2009).

3.4.1 Case Study.

Case study research is a method which seeks to examine a specific, bounded phenomenon in great detail, with the potential to illustrate a more general principle (Cohen et al., 2007; Nisbet & Watt, 1984). Case studies examine bounded systems, such as an individual, a group, an organisation or a community (Adelman & Kemmis; M. Myers, 2000), enhancing our understanding of these contexts and their specific, individualised complexities (Hamilton & Corbett-Whittier, 2012). A case study design allows for information to be drawn from a multiplicity of sources, with the capacity to examine the situation from many angles and perspectives (Thomas, 2011). This creates what philosopher Michel Foucault (1981) refers to as a ‘polyhedron of intelligibility’. Furthermore, as case studies seek to provide a holistic understanding of unique phenomena (Yin, 2013), and acknowledge the importance of real life situations (Nisbet & Watt, 1984). Case study research is concerned with “the uniqueness of the thing and the thing in its completeness” (Thomas, 2011, 3). Case study research is grounded in real-life circumstances and offers a rich, holistic, “thick description” of a bounded phenomenon (Merriam, 2009, 51).

Limitations of a case study approach include questions of subjectivity, generalisability and observer bias (Nisbet & Watt, 1984; Stake, 1995; Thomas, 2011; Yin, 2013). Concerns have been raised about the rigour applied to case study research, whereby the researcher has not followed systematic procedures or has allowed subjectivity to influence the research findings (Yin, 2013). Given that the researcher is deemed to be a primary tool of data collection and analysis in case study research, questions of sensitivity, integrity and skill arise (Merriam, 2009). Furthermore, case study methodology has been criticised for its lack of generalisability, yet as Merriam (2009) and Yin (2013) argue generalisability is not the aim of case study research. Despite these limitations, however, it must be noted that the case study research can be easily understood by a wide audience and provides participants with a voice by building realistic representations of participants' perspectives and experiences (Thomas, 2011). Case studies can capture nuanced details and information which may go unnoticed in larger-scale studies and can provide insights in other, similar situations and cases, thereby supporting the interpretation of other cases (Cohen et al., 2007; Nisbet & Watt, 1984; Stake, 1995; Thomas, 2011). Furthermore, case study research can be conducted by a single researcher and can cope with, and even embrace, unexpected events and outcomes in the research process (Cohen et al., 2007; Hamilton & Corbett-Whittier, 2012).

Case study methodology was employed in the current research project as it allowed for the examination of a bounded, one-off phenomenon i.e. the post-diagnostic parent training provided by a specific ASD service in an Irish setting, where the training was clinician-designed, practice-led and non-manualised. Additionally, case study methodology allowed for the investigation of specific training with information from a multiplicity of sources, without the restrictions of replicability or generalisability (Hamilton & Corbett-Whittier, 2012; Stake, 1995; Thomas, 2011). By gathering data from many sources and in a variety of formats, a thick, rich description of the case can be built up (Hamilton & Corbett-Whittier, 2012; Merriam, 2009). This thick description allows one to get close to reality, with small questions leading to big answers (Flyvbjerg, 2001; Thomas, 2011).

3.4.1.1 Case Study Design.

In the current research study an exploratory, mixed-methods, case study methodology was applied. This approach has been selected as appropriate to explore what Yin deems "a contemporary phenomenon within its real-life context" (2003, p.23). This methodology allows for an extensive, in-depth description of social phenomena and experiences (Robson & McCartan, 2016; Yin, 2013). This approach was chosen as the most appropriate for this research, as the research context in this study is a bounded situation: an eclectic, psychoeducational ASD post-diagnostic parent training programme. The case study in this research is informed by information from a variety of sources, gathered together and analysed to generate a polyhedron of intelligibility, or a rich, dynamic and tangible description of the situation, with a view to answering the research questions (Figure 4) (Foucault et al., 1981; Stake, 1995).

Figure 4. Data Contributing to Case Study

3.5 Research Setting

This research took place in a government-funded diagnostic and intervention service for children with ASD aged between six and eighteen years of age. The service is a multi-disciplinary agency, which is operated by a voluntary body in Ireland. Clinicians in this service provide a non-standardised, psychoeducational, eclectic post-diagnostic training to parents following receipt of a diagnosis of ASD for their child.

3.6 Training Description

The clinicians who designed and delivered the training were employed in the ASD assessment and diagnostic service, as part of multi-disciplinary teams. The clinicians were from a variety of backgrounds. Two social workers co-ordinated and organised the logistics of the training, a speech and language therapist provided training on the communicative aspects of ASD, two educational psychologists and one clinical psychologist provided psychoeducational input on ASD and an occupational therapists trained parents in supporting functional, sensory and movement needs frequently associated with ASD. Each discipline provided a night of training. The training took place across four sessions, once a week for four weeks. Each session lasted approximately three hours, with a social break for refreshments for 20 minutes at the mid-point. The training was conducted in a community centre rather than in the service building itself; this was in order to accommodate large numbers of attendees. All parents of children within the service catchment area who were diagnosed with ASD in the previous six months were invited to attend parent training from the service provider. Information from clinicians, and researcher observations were used to devise an outline of the training programme. Documentary data and observation data were used to build a picture of the training experienced by parents attending post-diagnostic parent training. A comprehensive description (Appendix B) and a summary of the material covered in the training are provided in Appendix C. Each evening included a tea break of approximately 25-30 minutes to facilitate parents talking to each other and to the clinicians in a less structured manner. Figures 5 to 8 provide a visual summary of the structure of the training programme.

Figure 5. Overview of Training

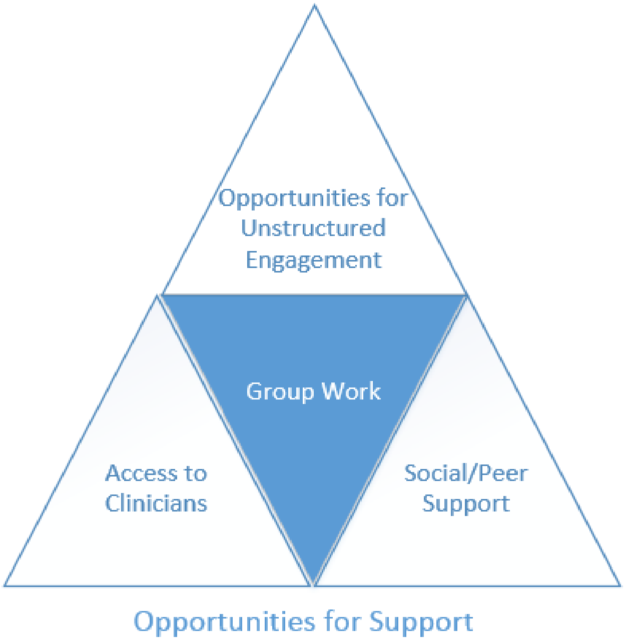


Figure 6. Opportunities for Support during Post-Diagnostic Parent Training

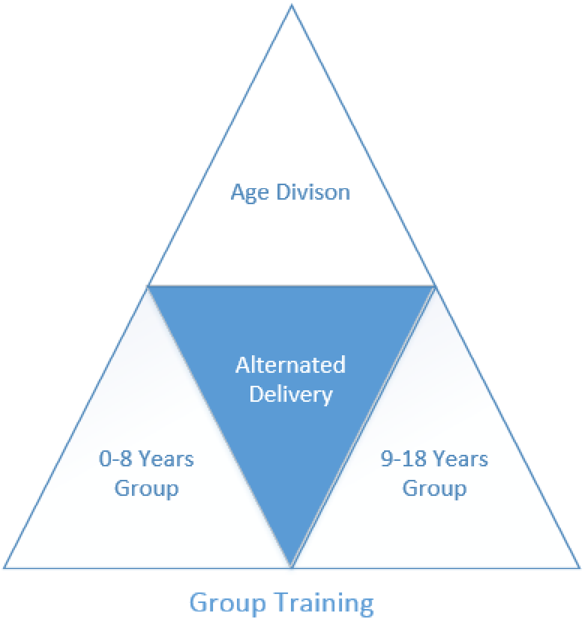


Figure 7. Structure of Group Training

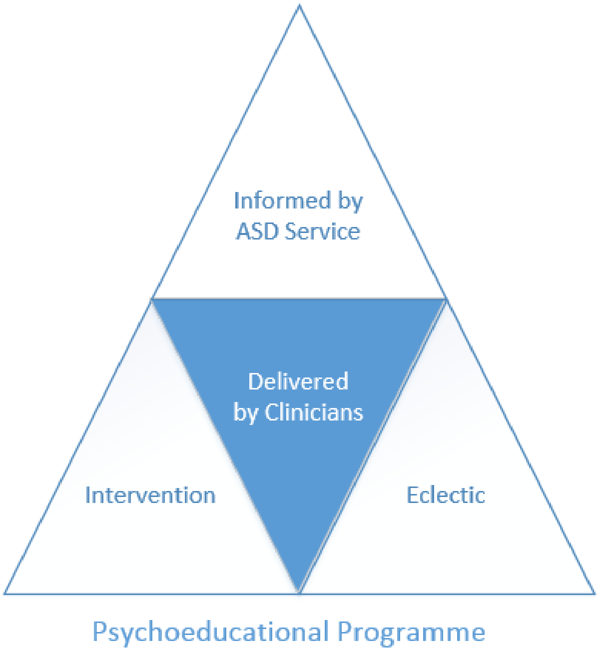


Figure 8. Components of the Psychoeducational Parent Training Programme in Current Study.

On the first week of training, all parents received the same input. For the subsequent weeks, parents were divided into two separate groups on the basis of their child's age in order to receive input with parents of similar-age children. Training was provided by clinicians within the service from the disciplines of Social Work, Speech and Language Therapy, Occupational Therapy and Psychology. An overview of the topics covered by each discipline is provided in Figure 9 below. An outline of the training programme is provided in Appendices B and C.

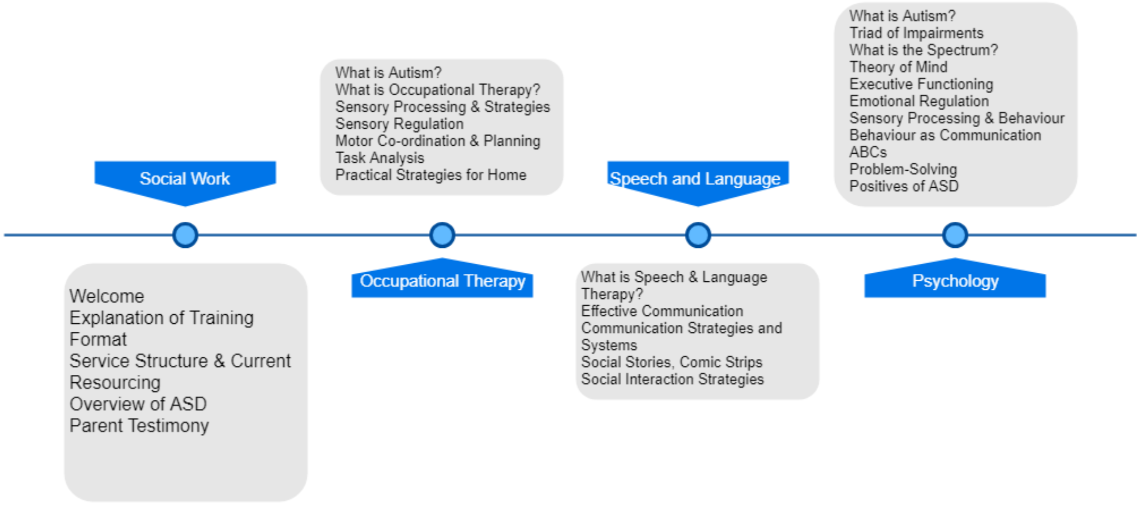


Figure 9. Overview of Parent Training Topics Covered by Each Discipline

3.6.1 Clinicians' Descriptions.

Clinicians were asked to provide information detailing the intervention provided to parents. As each discipline planned and delivered their training on separate nights, the information was provided separately and was later compiled into a descriptive template to provide an outline of the training programme experienced by attending parents (Appendix B). This information was used to account for the material covered in the programme, in lieu of a manual. The descriptions provided by the clinicians were synthesised by the researcher to provide the information depicted in Figure 9 above.

3.7 Participants

The participants in this research study are parents of children recently diagnosed with ASD. A total of 57 parents attended the post-diagnostic training. 39 parents agreed to participate in the research study. 25 were mothers of children with ASD, while 14 fathers participated. Of the participants' children, 24 were male and 15 were female. Participants were asked to disclose the age at which their child was diagnosed with ASD, and also, the child's current age. The mean age of receipt of diagnosis in this study was 8.5 years of age. The mean age of the child at the time of the training programme was 9 years.

For the semi-structured interview stage of the research, 27 parents volunteered to take part in semi-structured interviews. All of these were contacted by telephone within the fortnight following the end of the post-diagnostic training. From 27 parents, 7 agreed to take part in the semi-structured interviews, however, 2 parents did not attend for scheduled interviews. Therefore, five parents participated in the semi-structured interviews.

Some demographic information was gathered about the participants, such as their role (mother/father/guardian), sex of child, age of child at time of diagnosis and age of child at the time of accessing the post-diagnostic parent training. Information on the source of diagnosis (public/private, unidisciplinary/multidisciplinary), other family members with ASD, co-morbidity with other conditions, previous interventions tried, or presence or absence of intellectual disability was not sought. This was for a number of reasons, most significantly restrictions imposed by the service's Ethics Committee surrounding the gathering and holding of only strictly necessary data. Additionally, given the sensitive nature of the subject of the parent training, and the recency of the diagnosis of ASD for most families, it was felt that in order to garner as many participants as possible, the amount of personal data harvested from the questionnaires should be kept to a minimum to maximise parent participation while also bearing in mind the restrictions imposed by the Ethics Committee of the service.

3.8 Sampling

Sampling in case study research involves decisions that the researchers make regarding sampling strategies, the number of case studies, and the definition of the unit of analysis ("Encyclopedia of Case Study Research," 2010). It is central to theory-building and -testing through case study research. In qualitative research, research studies typically use a small sample of people, studied in depth in their particular context (Braun & Clarke, 2013; Merriam, 2009; Miles, Huberman, & Saldana, 2014; Patton, 1990). The current research study used convenience sampling. Convenience sampling occurs when the participants in the study were chosen due to their overall availability, rather than for purposes of generalisability (Cohen et al., 2007; Mertens, 2015). This can be seen as a limitation, but given that generalisability is not an aim of case study or qualitative research generally speaking, this was not considered to be a significant issue in this research (Merriam, 2009; Mertens, 2015).

This type of sampling was selected on the basis that the participants were drawn from a specific population, i.e. parents in a specific region, whose children were recently diagnosed with ASD by this particular ASD Assessment and Intervention Service, who have been invited to and have agreed to attend post-diagnostic parent training. The ASD Service organised the training and were responsible for inviting attendees, therefore purposive sampling was not possible in this study.

3.9 Mixed Methods Approach

Mixed methods research is a methodological approach which includes both qualitative and quantitative features in the research design, data collection and data analysis (Teddlie & Tashakkori, 2009). Mixed methods research is an approach, which allows the researcher to use the most appropriate techniques and methods to gather data to best answer their question (Mertens, 2011; Teddlie & Tashakkori, 2009). In mixed methods research, neither qualitative nor quantitative methods are favoured above the other, instead the research uses the methods sequentially at various stages of the study, with each stage informing the subsequent one (Creswell, 2013; Creswell & Plano Clark, 2011). Mixed methods research can be used to combine positivist objective measurement with subjective, descriptive experiences (Timmins, 2015). A key advantage of a mixed methods approach is that using both qualitative and quantitative approaches in conjunction supports a more comprehensive understanding of research problems than either approach alone (Creswell & Plano Clark, 2011; Mertens, 2011).

Qualitative research has been defined as the study of processes or behaviours in their natural settings, through which the researcher attempts to understand and make sense of phenomena and the meanings that people attribute to them in their lives (Shank, 2006). Qualitative research provides a methodology through which to explore the experiences of individuals and to develop an understanding of social phenomena (Tong et al., 2009). It can be used to gain a rich understanding of phenomena which cannot be measured in numbers or figures easily, while also giving a voice to participants, allowing them to be experts in their own life stories (O'Day & Killeen, 2002). For Morse (1992), qualitative research can be used to develop theory, to assess the conceptual bases of theoretical propositions and to develop a richer understanding of the theory.

Quantitative research places an emphasis upon precise measurement of phenomena in order to identify causal relationships between variables and to develop predictive models, while also attempting to isolate individual variables as explanatory factors (Jones & Forshaw, 2012). An emphasis on quantifying information using mathematical and statistical measures is a key aspect of quantitative research (Mertens, 2015; Polit & Beck, 2010; Teddlie & Tashakkori, 2009). Quantitative research is rooted in the post-positivist paradigm, which seeks to confirm or disconfirm hypotheses about the world (Mertens, 2015). Quantitative research can follow experimental or quasi-experimental designs (Creswell, 2014).

While there are advantages to using a mixed methods research design, issues persist in relation to the approach. A lack of agreement on the terms to be used in specific mixed methods research, along with questions of how to integrate quantitative and qualitative research findings, as well as dissonance between paradigms, are some issues which arise in discussions on mixed methods (Creswell & Garrett, 2008). For Chen (2006), merging of data sets can be challenging, especially if the results for the quantitative and qualitative sections are not convergent. Additionally, mixed methods research has, on occasion, been accused of lacking the depth of expertise and insight provided by quantitative or qualitative research alone (Creswell & Garrett, 2008; Creswell & Plano Clark, 2011; Onwuegbuzie & Collins, 2007).

There are a number of different types of mixed methods designs which can be used in conducting research, namely, the triangulation design, the embedded design, the explanatory design and the exploratory design (Creswell & Plano Clark, 2011; Klingner & Boardman, 2011). Following consideration of the most appropriate approach for the current research study, an embedded mixed methods design was selected, where quantitative methods are embedded in the overall qualitative research design, providing a supportive, supplementary role within the research (Creswell & Plano Clark, 2011; Odom et al., 2005).

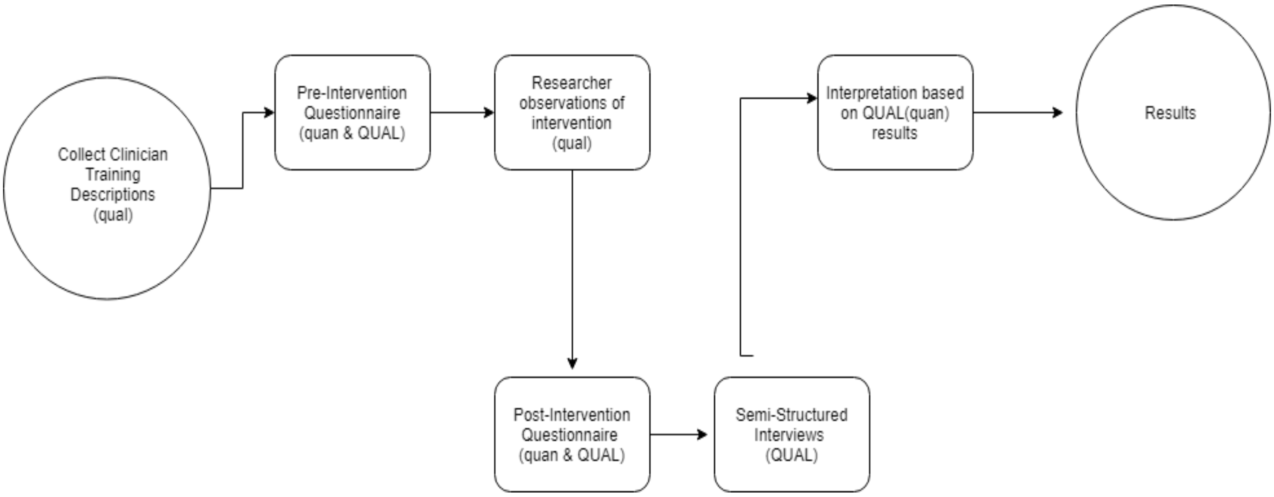


Figure 10. Embedded Mixed Methods Research Design (Creswell & Plano Clark, 2011).

3.9.1 Data Collection Procedures.

In the current research study, participants were asked to complete a questionnaire pre- and post- parent training intervention (Appendices D & E). These questionnaires contain a mixture of scaled (quantitative) and open-ended (qualitative) questions. Following completion of the parent training, parents were asked to participate in a semi-structured interview (Appendix F) with the researcher. This information was qualitative in nature and was analysed in a qualitative manner. Furthermore, observations of the parent training were recorded by the researcher; this information was also qualitative in nature (Appendix G). A visual representation of the mixed methods research design is visible in Figure 11.

Data was collected in numerous ways in order to capture the needs, experiences and perspectives of parents. The data collection procedures are summarised in Table 3 below.

Table 3. Overview and Purpose of Data Collection Procedures

Data Collection Procedure	Purpose
Gathering training materials and clinician descriptions	To compile information about the training programme i.e. what it specifically addressed, and did not address in light of the eclectic, non-manualised approach adopted by the service. The aim of this step was to be able to understand and outline the intervention; this research was not concerned with evaluating the programme or the intervention.
Pre-training Questionnaire	To gather baseline data in relation to parents' self-rated confidence, knowledge, skills and understanding, in relation to ASD, prior to the training programme commencing. To gather information on parents' expectations and hopes for the training programme. To decipher parents' top three learning priorities for the training programme.
Post-training Questionnaire	To gather post-intervention data in relation to parents' confidence, knowledge, skills and understanding of ASD, following participation in the post-diagnostic training programme. To use this data to compare with data gathered prior to the intervention, to determine the impact of participating in the parent training programme.
Researcher Observation	For the researcher to gain an understanding of the training programme, and to observe the delivery of the training. Again, the function of this was not to evaluate the training programme or the clinicians delivering it. To be present in order for parents to become familiar and comfortable with my presence in order to facilitate parents who wished to volunteer for participation in semi-structured interviews. To allow for participants to ask questions about the research at any stage throughout the programme.

Semi-Structured Interviews	To gain a deeper understanding of the participants' self-reported needs, experiences and perspectives of post-diagnostic parent training, to a level which would not be possible in questionnaires. To capture the voices of parents in the post-diagnostic journey.

Approaches to data collection included gathering clinician descriptions of the parent training to build the context of the training programme (Appendix H), administering pre- and post- training questionnaires (Appendices D & E) to participants, researcher observation of the training (Appendix G) and semi-structured interviews (Appendix F) with parents following completion of the parent training programme.

Figure 21. Data collection procedure

3.9.2 Questionnaires.

Questionnaires are frequently used in research and are a useful instrument for gathering survey information, and providing structured, often numerical data, on a topic, while also being relatively straightforward to analyse (Cohen et al., 2007). Surveys can be used to gather the views and opinions of large groups of people (Timmons, 2015). Moule and Goodman (2014) state that questionnaires are used to measure knowledge and should contribute to answering the research question. When developing a questionnaire, one must consider the target population for the tool. Furthermore, the tool must be validated or piloted to ensure that it measures what it intends to measure (Pink, Pink, & Elwyn, 2009).

The questionnaires used in this research study have been designed by the researcher (see Appendices D & E). The researcher drew upon a number of existing parenting questionnaires and ASD-specific questionnaires in designing the questionnaires for the current research study. The Autism Parent Questionnaire (APQ) (Anderson, Birkin, Seymour & Moore, 2005), developed as part of a research study on the efficacy of EarlyBird programme was used, as well as the Parenting Stress Index 4th Edition (PSI-4) (Abidin) and the ASD Parent Groups Evaluation Form designed by Roughan, Parker and Mercer (2019). Aspects of each of these questionnaires were included in the design of the questionnaire in the current study. Given the eclectic nature of the parent training programme, and the particularistic setting and format of the programme delivery, no one particular questionnaire was deemed appropriate to capture the views and experiences of parents; hence it was decided to self-design questionnaires. This research uses pre- and post- intervention questionnaires, which were administered prior to the parent training beginning and directly following the final parent training session. Given the relatively small number of research participants (n=39), the questionnaires in this research study are a mixture of structured and semi-structured questions, operating on the hypothesis that the smaller the size of the sample, the less structured, more open and word-based the questionnaire can be (Cohen et al., 2007). Furthermore, this research was bounded to a site-specific case study, therefore a more qualitative and open-ended style of questionnaire was preferred, in order to capture the nuances and specificities of the responses (Cohen et al., 2007)

The closed questions in the questionnaires use five-point Likert scales, which were rated by participants. A Likert scale is a scale used in research to represent people's attitudes to a topic (Brooke, 1996; Matell & Jacoby, 1971). Five-point Likert scales were chosen above the use of a seven-point scale as research has found that the use of a five-point scale increases response rate and response quality, while reducing respondent frustrations (Babakus & Mangold, 1992). Furthermore, five-point Likert scales have been found to be more easily comprehensible than scales with greater points

(Revilla, Saris & Krosnick, 2013). The questionnaires also contain open-ended questions to allow for broader information to be provided by participants (Cohen et al., 2007; Creswell, 2014; Mertens, 2015). These open-ended questions were analysed using thematic analysis (Braun & Clarke, 2013).

3.9.2.1 Piloting of Questionnaires.

Piloting of questionnaires is recommended in order to check for issues of clarity, usability, validity, operationalisation of the constructs, readability and usefulness of questions asked (Cohen et al., 2007; Oppenheim, 1992; Rattray & Jones, 2007). The piloting of questionnaires in this research study was of particular importance, given that they were researcher-designed and not standardised or normed.

To enhance the credibility and validity of the questionnaires, three psychologists with experience in ASD assessed the questionnaires and provided critiques. Additionally, the questionnaires were piloted with a group of parents (N=5) of children with ASD, as well as by consultants (N=2) from ASD advocacy organisation, AsIAm. Questionnaires were revised to reflect the considerations arising from the piloting process. Consideration was given to the use of person first language in the questionnaires. Additionally, one question referred to “controlling” the behaviour of the child with ASD; this was revised to be read as “manage”.

The reliability of the questionnaires was tested using a measure of reliability known as Cronbach’s Alpha. For Julie Pallant (2010), values above .7 in this measure are considered acceptable. The Cronbach Alpha Co-efficient for the Pre- Intervention Questionnaire was .732. The Cronbach Alpha Co-efficient for the Post-Intervention Questionnaire was .716. The pre-post- intervention design and analysis provides an indication of parents’ progress, and also a measure of the programme’s effectiveness in this particular case study. Factor Analysis was not deployed in the development of this questionnaire due to the small number of items and the small sample size (Pallant, 2010; Tabachnik & Fidell, 2007). This is a limitation of the current research study.

3.9.3 Researcher Observations.

An observational case study is one in which the majority of data gathered arises from participant observation (Creswell, 2014; Hamilton & Corbett-Whittier, 2012; Merriam, 2009). While the current research study cannot be categorised as an observational case study, there are aspects of the observational case study which this research employs. This research entailed observation of each training session; the researcher attended each training session and conducted narrative observations and note-taking to document the training programme. Furthermore, it was crucial to attend and observe the training in order to inform later semi-structured interviews with participants, and for the later analysis of data. An example of researcher observations can be seen in Appendix G.

3.9.4 Semi-Structured Interviews.

Using interviews as a form of data collection allows for very rich data and a deeper level of understanding than other forms of data collection (Hamilton & Corbett-Whittier, 2012). Semi-structured interviews allow for a more in-depth discussion with a small number of participants (Braun & Clarke, 2013; Hamilton & Corbett-Whittier, 2012). Semi-structured interviews were selected as a time-efficient means of gathering rich qualitative data from a small group of people who undertook a shared training opportunity. Semi-structured interviews create opportunities for a narrative to unfold, while including questions informed by theory and by information garnered in the questionnaires (Galletta, 2013). This method offers insight into individual experiences and perceptions and is designed to yield a more complete story than quantitative means alone (Galletta, 2013). Furthermore, a semi-structured interview method allows participants to express their views (Bryman, 2015; Mertens, 2005). Interview questions can be identified in advance, along with general topics for discussion (Bryman, 2015; Gill et al., 2008). This approach also allows for additional questions and probes to be used throughout the interview in a flexible manner (Bryman, 2015; Gill et al., 2008; Howitt, 2013). By incorporating qualitative measures, in this instance a semi-structured interview process, it allows for a sample population of participants to express their views in a less restricted manner than in quantitative research alone (Bryman, 2015; Gill, Stewart, Treasure, & Chadwick, 2008; Howitt, 2013; Kitzinger, 2005; Krueger & Casey, 2014).

Participants were asked to indicate their interest in taking part in a semi-structured interview on the Participant Consent Form (see Appendix I). Following the conclusion of the post-diagnostic parent training programme, I contacted the consenting participants. Seven parents agreed to be interviewed, however two of these withdrew from the study at a later stage, and thus, five participants agreed to be interviewed for the final stage of the study.

3.10 Data Analysis

Data analysis in mixed methods research studies involves analysing quantitative data using quantitative means, and qualitative data using qualitative means in order to discover useful information, address research questions, inform conclusions and support decision-making (Creswell & Plano Clark, 2011). The process of data analysis allows sense to be made of the raw data gleaned from data collection methods (Jones & Forshaw, 2012).

3.10.1 Quantitative analysis.

Quantitative approaches to data analysis emphasise the measurement and quantification of human behaviour (Jones & Forshaw, 2012). Quantitative approaches rely on mathematical and statistical procedures to understand a phenomenon (Mertens, 2015). In the current research study, the quantitative data obtained via the questionnaires was analysed using the Statistical Package for the Social Sciences (SPSS v25: IBM) to identify statistically significant differences in the participant group from Time 1 (pre-training) and Time 2 (post-training). The data were analysed to compare the participants' views of their knowledge, understanding, skills and confidence pre- and post- intervention, to identify any changes in their views that had occurred in this time period. Quantitative data from the questionnaires was analysed via a paired samples t-test in order to compare pre- and post- training ratings.

3.10.2 Qualitative data analysis.

Qualitative data analysis is a process which is ongoing and emergent; it is an activity which occurs throughout the data collection process (Merriam, 2009; Mertens, 2015). The process is recursive and dynamic, and tends to become more intensive as the study proceeds (Braun & Clarke, 2006; Braun & Clarke, 2013; Merriam, 2009).

Qualitative data from the questionnaires and semi-structured interviews were coded and analysed thematically. Thematic analysis is an analytic strategy which seeks to systematically identify patterns within and across data and to interrogate and interpret the patterns identified (Braun & Clarke, 2013). Braun and Clarke (2006) offer a six-step approach to qualitative analysis; the researcher can move back and forth between the various stages many times, particularly if the data is complex. The approach is not bound to a particular theoretical framework or epistemological stance (Braun & Clarke, 2006).

Thematic analysis allows for the data to speak for itself and to build upon a rich and thick description of what is happening in a specific situation (Braun & Clarke, 2013; Merriam, 2009; Mertens, 2015). Following data collection and transcription, including open-ended questions and interviews, the raw data were analysed using thematic analysis (Braun & Clarke, 2006; Braun & Clarke, 2013). A data-driven approach was taken. Emergent themes developed from within the data and, following close readings, patterns emerged from across the data set. This approach was selected as it is a flexible form of analysis that fits within a mixed method design (Braun & Clarke, 2006). Six key phases of data analysis were followed (Braun & Clarke, 2006) as presented in (Appendix I). An excerpt of coded transcript is included in Appendix J. Coding was conducted under the supervision of the research supervisor.

The first step in the analysis of the qualitative data was to read and re-read the transcripts of the interviews and become familiar with the data. Early impressions and comments were noted at this point. In the second phase of thematic analysis, data was grouped and organised in a way that made sense to the researcher i.e. meaning began to accrue and was assigned a code in order to reduce the large amount into smaller, more comprehensible parts. The data was analysed while bearing the research questions in mind. For the third phase of the thematic analysis, the codes were examined and some clearly fitted into a theme. The themes selected were largely descriptive, in the sense that they seemed to describe something specific about the data and seemed to respond to the research questions in some way. The themes were categorised under the categories of Needs, Experiences and Perspectives, in an inductive manner in line with the literature review. In Phase 4 the themes were reviewed in light of the data. The themes were scrutinised to ensure that they made sense in the context of the research questions and also, whether or not they were true to and borne out by the data. For the fifth stage of thematic analysis the themes were refined into their final iteration to reflect “the essence of what each theme is about” (Braun & Clarke, 2006, p.92). The final stage, step 6, involved the writing up and reporting of the thematic analysis.

3.10.3 Merging of the Data Sets

In mixed methods research studies, researchers deliberately integrate or combine sets of qualitative and quantitative data as a means of maximising the strengths of the approaches and minimising the weakness inherent in each (Creswell & Plano Clark, 2011). The current research project connects the data gathered by initially analysing the quantitative data, then using the information garnered by this to inform the next stage of the data collection process, i.e. the semi-structured interviews. Hence, the integration of the quantitative and qualitative data takes place by connecting the initial data analysis to the subsequent stage of the research. The quantitative data is embedded in the larger research design, with the emphasis in this study on collecting qualitative data on parent's needs, perspectives and experiences of taking part in post-diagnostic parent training. In this research study, the quantitative data (pre- and post-questionnaires) and qualitative data (open-ended questions, semi-structured interviews & researcher observations) were merged in the form of combining the qualitative data in the form of text with the quantitative data taking numeric form. The results are reported together in Chapter 4: Results. The quantitative data are reported first, in the form of statistics, while the qualitative results are reported next using quotations and observations to support the quantitative findings.

3.11 Ethical Considerations

Ethics refers to the relationship with participants, the wider research community and the world at large, in psychological studies, ethicality is judged on the basis of the process and how research is conducted rather than on outcomes alone (Braun & Clarke, 2013). This research received ethical approval from Mary Immaculate College Ethics Committee and from the Service Ethics Committee (see Appendix L). Issues such as informed consent were considered, along with consideration of the potential for a power imbalance, whereby parents may believe that participation in the research was necessary in order to partake in the training programme. Written information sheets, consent forms as well as an oral description of the research and what it entailed for participants were provided (see Appendix M). Issues of anonymity and confidentiality were addressed, and appropriate measures were put in place for the storage of data to comply with MIC Data Retention Schedule.

3.12 Dependability

Dependability refers to whether the process of the study is consistent, reasonably stable over time and across methods (Merriam, 2009; Miles et al., 2014). Triangulation is a key strategy used in this research to enhance the internal validity of a study (Merriam, 2009). There are four types of triangulation: the use of multiple methods, the use of multiple data sources, the use of multiple investigators and the use of multiple theories to confirm emerging findings (Braun & Clarke, 2013; Denzin, 2017; Merriam, 2009). Dependability and consistency in this study are enhanced by the use of triangulation of data sources, namely, questionnaires, interviews, training documentation and observations. This will lend itself to the corroboration and validity of the research findings and will also aim to widen the audience to whom this research is relevant.

3.13 Reflexivity

Reflexivity is a concept which refers to the researcher's position in the research study and the practice of critically reflecting on oneself as an instrument of research (Merriam, 2009). By a process of identifying one's own worldview, and what one seeks to address in the research openly and clearly, one increases reflexivity in the research process (Cohen et al., 2007; Miles et al., 2014). The practice of reflective journaling and documenting the research process throughout (see Appendix N), as well as asserting a clear position on my own research paradigm have supported the process of reflexivity in this research study (Braun & Clarke, 2013; Miles et al., 2014).

3.14 Conclusion

The current research study used a case-study, mixed-methods approach to uncover the voices of parents in relation to their experiences and perspectives of participating in a post-diagnostic parent training programme following a diagnosis of ASD for their child. Measures were taken to ensure that data was collected and analysed following best practice procedures. Results of the study are presented in Chapter Four.

Chapter 4: Results

4.1 Introduction

The current research study aimed to explore the experiences and perspectives of parents taking part in post-diagnostic training following a diagnosis of ASD for their child. This study examined needs, experiences and perspectives using a case study, mixed methods approach. The study aimed to capture the voices of parents in a post-diagnostic intervention setting. Pre- and post-training questionnaires were used to gather quantitative information while semi-structured interviews built a rich, qualitative picture.

The results of the current research study are presented in this chapter. The quantitative results are presented first, followed by the results of the qualitative analysis of the open-ended survey questions and the semi-structured interviews. Results are presented in terms of responses pre- and post- parent training programme. A thematic presentation of the findings will follow.

4.2 Quantitative Data Results

Pre- and post- intervention quantitative data were gathered from 39 parents attending parent training following a diagnosis of ASD for their child. All participants completed the questionnaires at Time 1 (the start of the intervention); however 8 participants did not complete the post-training questionnaire at Time 2 (the end of the intervention, four weeks later). In instances where a full pre- and post- data set was not available, cases with missing values were excluded from analysis.

The analysis below examined scores for each measure, before and after the training. The overall changes to scores across the training period are presented. The data was tested for violation of normalcy ($p < .05$). The data did not violate assumptions of normalcy ($p < .063$). Hence, parametric analysis was considered to be most appropriate. The reliability of the questionnaires was tested using a measure of reliability known as Cronbach's Alpha. For Julie Pallant (2010), values above .7 in this measure are considered acceptable. The Cronbach Alpha Co-efficient for the Pre- Intervention Questionnaire was .732. The Cronbach Alpha Co-efficient for the Post-Intervention Questionnaire was .716. The pre-post- intervention design and analysis provides an indication of parents' progress, and also a measure of the programme's effectiveness in this particular case study. A paired samples t-test was conducted to explore the impact of post-diagnostic parent training on parents' self-reported scores on a number of measures. The results of the paired samples t-test were as follows:

Table 4. Results of Paired Samples t-Test.

Item	**Pre-Mean**	**Post- Mean**	**Eta Squared (effect size)**	**p. value**
Knowledge of ASD	3.16	4.16	0.41 (large)	.000
Understanding of ASD	3.29	4.16	0.37 (large)	.000
Skills in Managing Child's Needs	3.16	3.70	0.15 (large)	.024
Confidence in supporting Child with ASD	3.06	3.80	0.2 (large)	.010
Frequency of Communication with Other Parents	1.83	1.74	0.003 (small)	.751
Difficulty Managing Child's Behaviour	2.83	2.87	0.000 (small)	.909
Confidence in Understanding Child's Behaviour	3.16	3.32	0.008 (small)	.616
Confidence in Parenting your Child with ASD	2.87	3.74	0.22 (large)	.006
Difficulty in Communication with your Child with ASD	2.32	2.29	0.00 (small)	.917
Confidence in Meeting Intervention Needs for Your Child with ASD	2.58	2.87	0.02 (small)	.354

There was a significant increase in scores on "*Knowledge of ASD*" from Time 1(M = 3.16, SD = 1.18) to Time 2 (M = 4.16, SD = .68), t (31) = 4.597, p < .001 (two-tailed). The mean increase in scores was 1.00, with a 95% confidence interval ranging from -1.44 to -.55. The eta squared statistic (.41) indicated a large effect size.

There was a significant increase in scores on "*Understanding of ASD*" from Time 1 (M = 3.29, SD = 1.24) to Time 2 (M = 4.16, SD = .68), t (31) = 4.227, p < .001

(two-tailed). The mean increase in scores was .87, with a 95% confidence interval ranging from -1.29 to -.45. The eta squared statistic (.37) indicated a large effect size.

There was a significant increase in scores on "*Skills in Managing Child's Needs*" from Time 1 (*M* = 3.16, *SD* =.96) To Time 2 (*M* = 3.70, *SD* = .86), t (31) = 2.373, p < .001 (two-tailed). The mean increase in scores was .548, with a 95% confidence interval ranging from -1.02 to -.07. The eta squared statistic (.15) indicated a large effect size.

There was a significant increase in scores on "*Confidence in supporting Your Child with ASD*" from Time 1 (*M* = 3.06, *SD* = 1.23) to Time 2 (*M* = 3.80, *SD* = 1.04), t (31) = 2.745, p < .001 (two-tailed). The mean increase in scores was .74, with a 95% confidence interval ranging from -1.29 to -.189. The eta squared statistic (.2) indicated a large effect size.

There was a significant increase in scores on "*Confidence in Parenting Your Child with ASD*" from Time 1 (*M* = 2.87, *SD* = 1.17) to Time 2 (*M* = 3.74, *SD* = 1.26), t (31) = 2.942, p < .001 (two-tailed). The mean increase in scores was .87, with a 95% confidence interval ranging from -1.47 to -.26. The eta squared statistic (.22) indicated a large effect size.

Items *"Frequency of Communication with Other Parents", "Difficulty Managing Childs' Behaviour", "Confidence in Understanding Your Childs' Behaviour", "Difficulty in Communication with Your Child with ASD"* and *"Confidence in Meeting Interventions Needs for Your Child with ASD"* were also analysed. There were no significant differences between Time 1 and Time 2, pre- and post- training.

4.3 Qualitative Results

Results of qualitative data analysis are presented in this section. The data from the questionnaires did not contain identifying information and therefore, qualitative data from the questionnaires are identified in the upcoming results sections using the signifiers *Pre Q* or *Post Q* to indicate whether the responses were given pre- or post-intervention. Pseudonyms are used for the data from the semi-structured interviews. The interviews and the open-ended questions in the pre- and post- questionnaires provided the qualitative data. The results are presented and discussed thematically in Table 5.

Table 5. Qualitative Results: Categories, Themes:

Category	**Theme**
Needs	*Thinking of the Future*
	"There can never be enough information to help us navigate ASD".
	"We need support from every angle!"
	Please can we have some more (training)?
Experiences	*Feelings of Taking Part: Fear, Guilt, Relief, Frustration*
	Coming Face to Face with The Service
	Your Family is Different, but You are Not Alone
Perspectives	*Realising the impact of other people's perceptions of ASD: Positives and Negatives*
	Practicalities of Attending Post-Diagnostic Parent Training

4.3.1 Needs.

Parents discussed their needs following their child's diagnosis of ASD. Their needs were further conceptualised into themes which give a clear picture of participants' responses. These themes include: Thinking of the Future, *"There can never be enough information to help us navigate ASD", "We Need Support from Every Angle"* and *"Please can we have some more (training)?*

4.3.1.1 Thinking of the Future.

Findings from the current study indicate that for many parents, the time following diagnosis is one of uncertainty; on attaining an ASD diagnosis, the next steps are less certain. Prior to the commencement of the parent training programme, parents expressed feelings of uncertainty regarding appropriate next steps. One parent commented that:

> *"Right now, I have my diagnosis, where do I go? I just wonder where do I go now. And I just feel like now I have the diagnosis, what do I do?"* (Pre Q).

Despite participation in the post-diagnostic training programme, it appears that these feelings of uncertainty and lack of direction persist. One parent stated:

> *"I have my diagnosis now and I understand more about the condition now, but what next? Where do I go or what do I do?"* (Patricia).

Parents reported further concerns about the medium- and longer-term future, in terms of education and adulthood. All parents identified a pre-training desire to gain an understanding of what challenges they may face in the future, in generic terms such as, *"what to expect down the line" (Q),* but also, more specifically, in terms of how to support their child in post-primary education, and further along, into adulthood. Following attendance at the post-diagnostic parent training, parents' uncertainty around the future was not assuaged, with parents reporting a persistent need to *"Address the older child; preparation for adulthood"(Q).*

While it must be acknowledged that worrying about the future of one's child is not an experience which is unique to parents of children with ASD, the participants in this study report having to worry about things that other parents may take for granted, such as whether or not their child will attain independence, or how to navigate the teen years for a child whose behaviours may visibly mark them out as different from their peers. For the participants in this study, the worry about the future was very much linked to a search for acceptance and a future where their child can be accepted and supported and allowed to express themselves to their fullest potential. Participants were pragmatic and aware of the lifelong nature of ASD; therefore, they were already looking to next stage in their children's lives and seeing that their needs might not necessarily be met by the current disability support system. This, of course, fosters a huge sense of trepidation and uncertainty about the future.

4.3.1.2 "There can never be enough information to help us navigate ASD".

Participants in this research described having a child with ASD as a "journey in an unknown land" *Post Q*, where there can never be enough information to guide them or to provide them with a map with which to navigate the complexities of the disorder.

Hence, parents reported information and knowledge as a primary need for them. However, the type of information they report needing ranges from the general to the more specific. This approach of needing all types of information, on every facet of ASD, ranging from the generic to the specific appears to be symptomatic of an overall feeling of helplessness, uncertainty and not feeling confident in their existing knowledge and skills. Parents in this study reported "*Looking for a Roadmap for ASD*", as well as specific information on "*Mental Health and Well Being Concerns for Children with ASD*" and "*How to tell my child about their diagnosis".*

Looking for a Roadmap for ASD:

At the beginning of the training programme, parents reported a need to understand ASD as a condition, and as a spectrum, in order to better manage in their everyday lives. Prior to the training programme, one parent stated that she wished to "*Gain deeper understanding of the ASD spectrum"(Pre Q)*, while another parent sought a "*better understanding of theories"* in order to be "*able to apply knowledge to day to day living"(Pre Q*). Parents were interested in learning about the ASD service, and in the role that they might play in helping their child, with a pervasive sense of feeling directionless and at sea in this phase of adapting to a diagnosis. Participants reported seeking knowledge and understanding as a means to gain some control over their lives, recapture a semblance of normality and to find well-trod pathways of support for their child (pathways that have been shown to work for other families like their own).

Many parents reported needing practical strategies and tips to use in supporting their child with ASD. Value was placed on practicable, relevant and realistic skills in terms of type of knowledge parents reported needing, with one parent seeking to gain *"knowledge on how to calm my son when he has a meltdown, I just hope I can pick up some practical tips"(Pre Q)* and another stating a need for the *"sharing of ideas and strategies to cope"(Pre Q).*

Following post-diagnostic parent training, some parents reported satisfaction with the information that they received. A parent reported that following post-diagnostic training that she has gained *" strategies for dealing with behaviour, communication and our child's sensory issues" (Post Q).* Parents reported wanting to hear about "things that will actually help us in real life" (*Pre Q)* and expressed some disappointment that some of the information could be found in a simple internet search. After taking part in post-diagnostic training parents referred to the specific needs of their own child, seeking information and strategies on supporting their specific child, rather than generic information. One parent reported disappointment that the topics covered fell short of her expectations, stating a preference for more in-depth information that would be directly applicable to her child:

> *"I would have liked in more depth something on emotional regulation, because Colin's biggest issue is emotional regulation" (Katie).*

This sense of disappointment with the general nature of the information on offer, and the lack of opportunity for in-depth, child specific discussion may have led to a sense of disappointment for some parents with the realisation that the idealised roadmap for their child does not necessarily exist and that there is no quick fix in the ASD journey.

Telling about the Diagnosis

For parents, it can be difficult to talk to their child about ASD, with different families adopting different approaches (Matson & Williams, 2015). Nonetheless, prior to post-diagnostic training beginning, parents reported needing information from clinicians on how to *"learn ways to tell her (child) she has the diagnosis" (Pre Q),* and further how to support them in adapting to the diagnosis. Parents reported needing information on how to support their child in accepting the ASD diagnosis and ensure the child "*not think of it as a negative" (Pre Q).*

Following participation in the training programme some parents had spoken to their child about ASD and about having a diagnosis of ASD and saw it as an important and impactful need for their child. One parent remarked:

> *"She was telling me there was something wrong with her before we knew there was something up with her, she knows about her diagnosis now and she's excited now" (Ann).*

Some parents reported that their children responded well to knowledge of the diagnosis, expressing relief and pride, with the diagnosis "*like a weight lifted off her shoulders" (Mary).*

Parents reported that knowledge of a diagnosis was important for their child as "*there's reasons for this and explanations" (Mary)*, and also to acknowledge the supportive feeling of not being the only one with a diagnosis and removing the uncertainty about why they might feel different to other children. One parent stated:

> *"it's important for Colin to know because like the parents, he knows that then he's not alone, that there are other people like him and also that there's a reason for why he thinks the way he does and why he is the way he is" (Katie).*

Some parents expressed surprise at the fact that the topic of informing your child of the diagnosis hadn't arisen in the parent training programme:

> *"They didn't really (speak about talking to your child about autism) which might have been beneficial for maybe the younger group, but the older people are newly diagnosed as well, so maybe it would have been beneficial for them too" (Mary).*

However, some parents did express reluctance to share the diagnosis of ASD with their child or with other people, and acknowledged that telling about the diagnosis is a *"very personal thing"* which can be influenced by child factors, as well as other external or family factors.

Mental Health and Well Being Concerns for Children with ASD:

Many parents spoke about the anxiety experienced by their child with ASD, and how this can impact upon their lives. Prior to the parent training programme, some parents reported that they would like input and knowledge *"to deal with my child's anxieties-social and school phobia" (Pre Q).* After training had finished, some parents expressed surprised that anxiety and mental health had not been covered as a topic in the training programme, given that it was a topic parents were seeking to understand and discuss; it was not covered by the training programme:

> *"One thing that I noticed from talking to other parents was that anxiety came up a lot. I was a bit surprised that that wasn't covered more in the sessions" (Ann)*

Parents expressed that mental health, and anxiety more specifically, is a gap in their knowledge that they would like to have had input on, as they are seeing these as needs for their child:

> *"I would know nothing about the mental health aspects of autism so it would be great to find out a bit more; and it's not something that's spoken about in general… The more subtle things like mental health and anxiety if those were talked about more then maybe we would have seen more of it in her" (Mary).*

For many of the participants, their children had come to receive an ASD diagnosis having previously attended with the Child and Adolescent Mental Health Service with suicidal ideation, self-harm and anxiety, and then being referred onwards by those clinicians to the ASD service for an ASD assessment. Parents reported anxiety, mental health and self-harming behaviours as aspects of their everyday lives with their children with ASD, so the absence of any input in relation to these topics was disappointing. Given the co-morbidity of ASD and mental health disorders, parents felt engaging with either the ASD challenges or the mental health challenges in isolation was not useful and was a failing in the health service at large.

4.3.1.3 We need support from every angle!

Receiving a diagnosis for one's child is a challenging event. Parents in the current study reported that following the diagnosis they felt alone, at sea and vulnerable. Hence, coping and support needs were cited by many parents as priority needs prior to the commencement of the parent training programme. The need for support from other parents of children with ASD, and from clinicians was mentioned by parents. However, the type of support sought from other parents was different to the information sought from clinicians. Parents report a need for a sense of solidarity with others experiencing the same thing, while from clinicians' professional guidance and simply access to the service was reported. Parents reported needing to learn about available supports from public and private professionals, both in terms of the service providing the training and the wider supports available, "*what public and private supports are out there" (Pre Q).* Parents cited a perceived prior lack of support from the ASD services and framed the need to gain their support as *"a battle" (Pre Q)*. Despite prior negative experiences, parents were hopeful that the training would provide them with support from the service and clinicians. The sense of solidarity and support from other parents placed parents at one side of the "battle" and clinicians and the health service at the other side. Parents spoke about other parents and clinicians in terms of an "us" and "them". The need for support from other parents with similar or shared experiences was reported by many parents. Prior to the beginning of the training programme parents outlined the need to *"meet parents in a similar position"(Pre Q)* and to *"meet and share advice with other parents on the course"(Pre Q).* Furthermore, parents anticipated the perceived benefits that meeting other parents of children with ASD could provide to them in terms of adapting and adjusting to a diagnosis of ASD and the emotional impact, with parents hoping to *"gain a sense of being ok" (Pre Q)* and to *"be more confident and assure ourselves that we as parents are doing a good job" (Pre Q).* One parent reported a need for support in terms of the emotional impact following a diagnosis of ASD for their child, stating a need for "*some guidance- I feel lost and as if the weight of the world is on my shoulders"(Pre Q).* This statement captured how alone parents can feel in the face of an ASD diagnosis, and hence, the need for support from all angles: other parents, family, friends and the health service. This finding is reflective of the

Bronfenbrenner's Ecological Systems framework which underlies this project, in that this need for support in coping with a diagnosis of ASD can be seen in the microsystem, the mesosystem, the exosystem and the macrosystem, and also across the chronosystem.

4.3.1.4 Please can we have some more (training)?

For many parents, having completed the post-diagnostic parent training, the need for more training was to the forefront. Despite having completed over ten hours of parent training in a short four-week period, parents felt that training remained a priority need for them following their child's diagnosis. Some parents commented that they would appreciate *"more in-depth training"* and also the need for "*more access to intervention"(Post Q).* It is likely that this need is linked to the desire for continued support, but also is symptomatic of a fear of the unknown and uncertainty about the future. There was a palpable sense of urgency from parents in relation to attending the training, as they were aware that access to services is very limited and that this might be the only training they were going to receive.

Additionally, having experienced the post-diagnostic training themselves, some parents felt that the schools and teachers of their children with ASD would benefit from exposure to similar training from the ASD service. Parents remarked that they had personally benefitted from participating and noted that their children would also should this type of training be made available to their teachers as "*they (teachers) would just understand so much better where he's coming from" (Post Q).* Parents stated that *"training for teachers would be fantastic for our kids"(Post Q).* One parent, when commenting on her child's experiences of attending a mainstream school, felt that teacher training would make a big difference to her child's school experience. She expressed frustration with what she perceived as a lack of knowledge and awareness of behalf of school staff, which she believed could be improved upon by participation in the service's training programme:

> *"If they had the time to have a team like that go out to school and do things like this training with teachers… like how can you have teachers teaching that are not actually aware of autism?" (Katie).*

Furthermore, this parent remarked on the impact that a child's experiences of school can have on their home life. It was felt that teacher training in ASD from the ASD service would improve school staff's understanding of ASD and have a positive impact on the child's school day:

> *"If there was something done linking the team to the school because its half the child's day and whatever happens at school has a huge impact at home and he can get so upset" (Katie)* and *"It should be mandatory for teachers to have to do autism training… so imagine how much understanding that the teachers could bring away from that" (Post Q).*

For parents attending the post diagnostic training, the training highlighted a series of unmet needs both for themselves and for the systems in which they and their child exist. Parents were calling for training in terms of the interface between the clinicians and the school environment as a means of intervention for the child, supporting the interactions between the child, the microsystem, the mesosystem, the exosystem and the macrosystem. Parents' awareness of what it felt like to gain this new knowledge was heightened, hence the urgency to imbue others in the child's life with this new knowledge came to the fore.

4.3.2 Experiences.

This category explores the experiences of parents who participated in post-diagnostic training following a diagnosis of ASD for their child. Parents' references to their experiences were categorised into the following subthemes: *Feelings of Taking Part: Fear, Guilt, Relief, Frustration,* Information, Coping and Support, and Training.

4.3.2.1 Feelings of Taking Part: Understanding, Fear, Guilt, Relief, Frustration.

Prior to parent training commencing, parents reported that they desired an understanding into ASD, and further, into how ASD might shape how their children see the world. Following completion of the training programme, parents reported feeling that they had gained insight and understanding into ASD as a condition and also, into the perspectives of their own child:

> *"The training introduced topics underpinning ASD; it has provided me with a foundation to enable me to delve deeper and improve my understanding which should help my daughter when she encounters difficulties"* (Post Q)

Furthermore, one parent reported that she felt that she could now understand her son's feelings, and that there may be more to his presentation than she would have initially thought, acknowledging that "*he has feelings and that there might be an underlying issue" (Post Q).* This growth in understanding led to feelings of relief in the parents, as well as a newfound sense of competency in terms of being able to support and empathise with their child. One parent remarked that participation in the training had removed some mystery from ASD, and that she felt less scared by ASD, allowing for her to begin to understand her child: *"this training just took some of the scariness away from autism and things have started clicking with us" (Ann)*. Raising a child with ASD can be associated with increased levels of stress and uncertainty, parents reported that participating in the intervention allayed some of the fear, albeit temporarily. The emotionality of gaining insight into the world of their child with ASD resulted in some parents feeling guilt at not understanding previously. One mother reported the emotional impact of newfound understanding of her son's experiences and worldview, with the session from the occupational therapist as the catalyst:

> *"At the OT session, I don't know why, I just kept nearly crying…because of some of the things she was saying, because a lot of the things I didn't know, where I just hadn't put two and two together" (Katie).*

Following attendance at post-diagnostic training, parents' awareness of the service's restricted resources was apparent. This impacted upon parents' experiences of participating in the training in terms of interacting during the sessions, in that they did not have enough time to ask questions "*you could feel like it was a little bit rushed" (Mary).* This led to an element of urgency and almost panic, when parents realised that the training programme was the only intervention they are likely to receive from the service:

> *"Knowing that this is going to be the only contacts that you're going to have with the speech and language therapist, OT or psychologist for SERVICE… oh my god is this it? It's my only chance, we are never going to talk to them 1 on 1, we are never going to get to ask our questions". (Mary)*

While parents were understanding of the resource constraints, the frustration of parents was palpable. Participants in this study reported having to wait a long time for an assessment for ASD and had hoped that once they were in the service they would finally receive significant intervention for their child; the realisation that this training will likely be the only intervention provided by the service was extremely disheartening, anti-climactic and frustrating.

4.3.2.2 Coming Face to Face with The Service.

Having spent significant time waiting for an assessment and intervention, parents were apprehensive about finally coming "*face to face with the service we have heard so much about" (Pre Q)*. First impressions of the service were negative. Parents were invited to attend post-diagnostic parent training via a posted letter. Some parents reported experiencing receiving information and invitations to the training as an off-putting and negative experience, as the training was pre-empted with information about what interventions would not be made available to the family. Parents reported feeling negatively about attending the training, stating *"that's very off-putting as you can imagine… you're coming into this training with your shoulders over your ears before you even start".* Furthermore, prior to the training, parents reported not knowing what they were actually coming to attend and what they could expect to be offered by the clinicians at the training, given the negative first impression garnered from the invitation letter. One father reported:

> "*When we got the letter initially we weren't quite sure what we were coming to…but they just said you won't be getting any of the following and there is a big list… it sets a negative tone straight away… some of the things on the list of stuff we weren't getting, I wasn't even aware of, I wouldn't have been disappointed not to have gotten them, but now that I do know of these things of course I want them for my daughter!" (Noel).*

Despite some initial negative impressions, when parents spoke about their experiences after training had finished, they reported positive experiences of interacting with the clinicians providing the training, despite service restrictions. Parents said that the clinicians were "*exceptional"* and *"brilliant",* stating that *"they tried to give you as much as they possibly could in such a short space of time" (Katie).* Additionally, this mother reported becoming emotional one evening after training had ended, when two clinicians stayed with her and advised her on her situation with her child. She remarked on the kindness of these clinicians stating, *"they gave me their time and they listened, and they were very conscious that this is some of the only intervention that I'm going to get for a long time" (Katie).*

4.3.2.3 Your Family is Different, but You are Not Alone.

Parents reported experiences of spending time with other parents of children with ASD as supportive and positive in terms of their own family identity. Many parents cited that meeting other families with children with ASD reduced their feelings of isolation and aloneness. One parent remarked that *"your family experience is different to a lot of people's family experiences but you're still not alone out there" (Mary).* For parents, the realisation that one is not alone, and that there are other people experiencing similar experiences is an affirmative and reassuring experience, leading parents to reassess their conceptions of normality. One parent remarked upon the experience of meeting other parents as *"realising that this is a different normal"(Post*

Q), while other parents were reassured by the number of other parents who shared similar experiences.

> *"I suppose knowing that there is more parents out there that are doing the same thing and experiencing the same things is kind of selfishly refreshing and I suppose to know that you're not the only one struggling or the only one with 101 questions, waiting to be diagnosed, the frustration with the service" (Mary)*

One parent commented on the difference between receiving information from parents and from clinicians, noting that

> *"the parent's information is coming from a different side. When you are hearing it from a professional you can kind of glaze over " (Mary)* and
>
> *"I feel I got more from meeting other parents and listening to parents than I did from the professionals… where else would you have the experience of meeting so many other parents with the same experience from the same region? That was really powerful" (Mary).*

That "powerful" feeling that came from experiencing meeting other parents of children with ASD was reflected as being positive and supportive for parents attending this training programme. The importance of gains in understanding that arose following post-diagnostic training was highlighted by one mother, who remarked on the role of parents in the life of a child with ASD:

> *"its parents who need to have the understanding of what is going on for their children. We are going to be her biggest fans and her biggest advocates throughout her whole life, so we need to understand her whole world" (Ann).*

The concept of parents as advocates for their child with ASD was reiterated by participants; it is a notion which brings significant responsibility, but also considerable alliances with other parents in the same position.

4.3.3 Parents' Perspectives.

This category relates to parents' perspectives on parent training and on their participation in the training programme. Parents expressed opinions and perspectives on the themes *Realising the impact of other people's perceptions of ASD: Positives and Negatives* and *Practicalities of Attending Post-Diagnostic Training.*

4.3.3.1 Realising the impact of other people's perceptions of ASD: Positives and Negatives .

Over the course of participation in the post-diagnostic training, participants had the opportunity to engage with other parents, be exposed to people with experience of

ASD, and to hear about and reflect upon other peoples' perceptions of ASD. Participants remarked upon this as an opportunity to reflect on their experiences of support and coping within their social networks, their extended families and the education system. One mother remarked that one of the best aspects of attending post-diagnostic parent training was listening to parents with similar experiences:

> *"I think that that was one of the best things, not necessarily getting knowledge but like you spend too much time thinking like… you know you are not the only one because there's so much of it out there but like people don't understand kind of…but sitting there, listening to so many parents having the exact same issues is actually really nice in a way" (Katie).*

Some parents expressed interest in hearing other parents' stories about their journey to an ASD diagnosis for their child, noting both similarities and differences with their own experiences. One participant noted that they had not realised how alone and bereft of alliances they felt until they found themselves surrounded by parents with similar experiences: *"my friends don't get it, they act all awkward about my son's ASD, they don't want to know… it's different here, we are all in the same boat, and that feels good" (Post Q).*

While other parents were reported as a source of support for the participants, some expressed concern and disappointment with their experiences of support from their extended families. Prior to training, some parents expressed a desire for support in teaching family members about how to manage their child's ASD. One parent sought information *"To teach his siblings (of child with autism) how to detach themselves when he is getting awkward and not to take it so personally"(Pre Q).* Following the parent training programme, some parents noted an awareness of the differing perceptions and knowledge of ASD a family member may display and the emotional impact that may have:

> *"…and it's kind of upsetting when you hear someone so close saying that, so I think hearing it from the other grandparents was helpful and you feel less dismissed by her saying something like that" (Mary).*

Some parents reported less upset in relation to this gulf in understanding, instead, expressing frustration at the perceived denial of ASD. One parent described two instances of this from her immediate family.

> *"I think my mum's generation don't understand autism, they are like, where was this before? Like if it's so common where are they in my age group? I have this argument with her often and my auntie was here the other day and she was like, 'she doesn't really have it, not like other people have it" (Ann).*

Participants felt that their concerns were being minimised and "*gaslighted" (Post Q)* when family members dismissed their concerns about their child, although they acknowledged that the intentions of these people were good. This feeling of not being listened to and not being heard and supported was common, highlighting the need of the current research study in providing parents of children with ASD with a voice.

Another system of support for the child with ASD which parents perceived as lacking was the school system. Parents reported a general lack of empathy and understanding from schools. Parents reported frustration at this lack of understanding, noting that it often makes difficult circumstances more difficult.

> *"I don't know, it's the lack of understanding really like, there was three of them and he was having a meltdown…I don't think they really get it but it's so difficult" (Katie).*

Additionally, one parent mentioned the school's use of terminology in relation to ASD and the impact that this can have:

> *"Colin has a problem with the word "special", he's got a big problem with it, like he just hates it… he went up and it said special room outside the classroom… he was like look I ran away from my special teacher mum, it says special class outside the door and I just ran away…it's just things like this that they never try to ask him what he thought…maybe there's a bigger issue here with the school, maybe it's not just me and Colin, maybe it's an issue with the system" (Katie).*

The impact of school staff's perceptions of ASD cannot be underestimated, as parents report significant emotional consequences at home following issues that arise at school. This finding links with parents' call for school staff to receive training from disability service clinicians in order to breach what they perceive as a major gap in understanding and empathy.

4.3.3.3 Practicalities of Attending Post-Diagnostic Parent Training.

Following attendance at the post-diagnostic training programme, parents' experiences of the training, both in terms of practicalities and in terms of the impact of the training, are discussed. After completing the training many parents reported that the training sessions were long, with intimidatingly large groups, too wide of an age span of children within the groupings and an over-reliance on group work. Some parents reported disliking working in small groups, noting instead a preference for the clinicians to use hypothetical examples.

On speaking about the division of the groups into under 9 years and over 9 years, one father remarked that *"there is a huge difference between the challenges for a 9-year-old and an 18-year-old"(Noel),* noting this as a factor that may have impacted on the information given at the training sessions. Parents made some suggestions and observations based on their perspectives on participation in post-diagnostic parent training. Parents reported enjoying working as part of a group when the group size was small. Others noted that the small group work allowed them to feel more supported and less alone with their concerns in relation to their child's ASD, suggesting that, *"doing the group work you realise you are not alone with your struggles and your concerns"(Q).* However, when the training was delivered in larger groups, some parents perceived it as intimidating, reporting that

> *"the first day I was like, oh wow there is loads! I suppose when you did split into smaller groups you did feel more at ease to kind of speak, otherwise its quite intimidating" (Mary).*

Parents' experiences of the impact of the training were mixed with some parents reporting no changes since their participation. This is in contrast to the quantitative results which found a statistically significant increase in parents' confidence following the post-diagnostic parent training. A number of parents noted that there had been no changes at all for them, and that *"it didn't make me more competent or confident" (Mary).* However, some parents reported a change in their own approach to parenting their child, noting an increase in patience *"I have become a bit more patient…I have realised the extent of how hard it is for her, so I have become more patient" (Ann),* citing an example of a newfound readiness to apologise to her daughter:

> *"she might have noticed I'm a bit more patient and that I apologise if I snap at her. I'm more inclined to say sorry, that wasn't your fault if I miscommunicate" (Ann).*

Other parents remarked upon the practical ways in which attendance at the training has impacted upon them and their child, in terms of implementing strategies learned on the programme:

> *"I got some good advice on helping Colin to express his feelings and I've noticed that he started to do that a little bit more, he spoke about having a red side and a blue side to his brain recently and I thought that was amazing, really profound way of expressing it" (Katie).*

"Now I just encourage her to get up for 5 minutes and just walk around rather than sitting uncomfortably or if she's just reading to let her sit up on the sofa"

Parents made some practical suggestions for how the training could be improved in future, most of which pertained to having more time to access learning and information. Shorter breaks, a longer-term training programme and better timekeeping were all suggested as ways to maximise training time. Additionally, a number of parents suggested an interactive aspect to training which would allow parents more involvement in the topics to be covered:

> *"if we had the chance to email some questions in advance things could have maybe incorporated those into the session" (Ann).*

The suggestions that parents made in relation to the practicalities of attending the post-diagnostic parent training were primarily in relation to gaining opportunities to have their voices heard, whether that be in relation to seeking information, sharing their stories, or maximising their time together amongst their parenting peers.

4.4 Summary of Quantitative Findings

The results of the quantitative analysis suggest that parents' self-reported levels of knowledge and understanding of ASD improved as a result of participating in the post-diagnostic training programme. Furthermore, the findings indicate that parents' self-reported rating of their skills in managing the needs of their child with ASD improved following participation in the post-diagnostic training. Additionally, the results suggest that parents reported an increase in their confidence in both supporting their child with ASD and in parenting their child following participation in the training intervention. Following participation in the post-diagnostic parent training, participants in the current study reported no significant changes in *Frequency of Communication with Other Parents*, *Difficulty Managing Child's Behaviour, Confidence in Understanding Child's Behaviour, Difficulty in Communication with your Child with ASD*, and *Confidence in Meeting Intervention Needs for Your Child with ASD.*

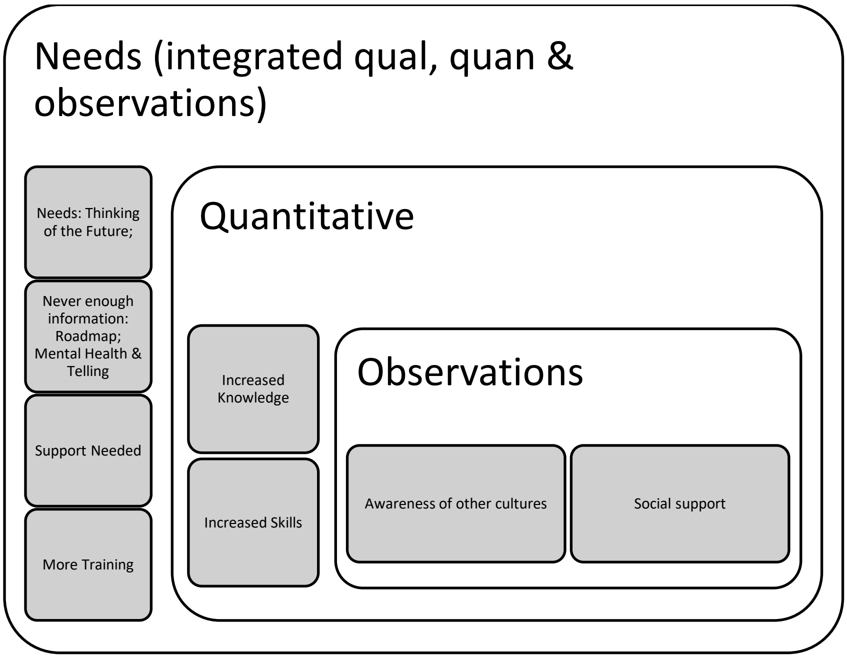
4.5 Observation Results

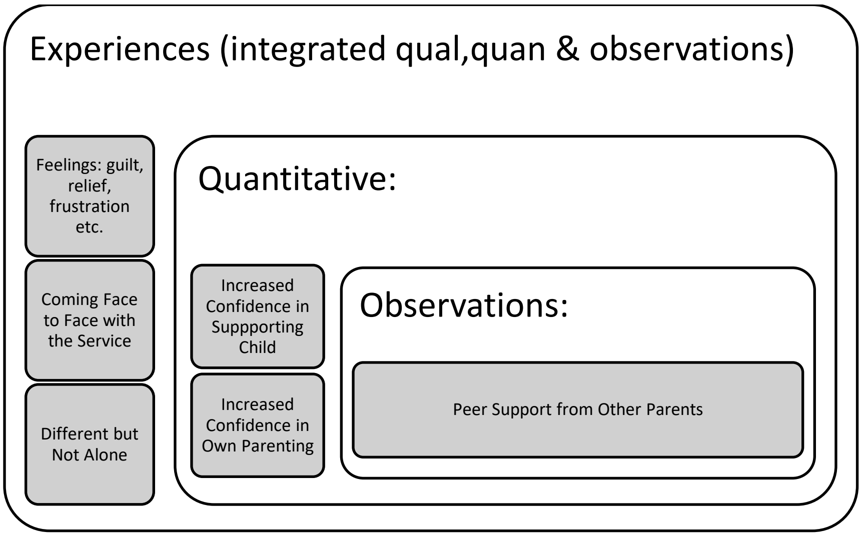
The results of the observation of the training programme were compiled into a booklet (Appendix B), synopsising the information provided to parents by the clinicians. The observation results triangulate with the qualitative findings reported by parents in terms of their information needs and experiences. The findings are presented in Table 6 below.

Table 6. Triangulated Researcher and Parent Reports of Parent Training

Qualitative Finding	Researcher Observation
Parents identified needing information on how to tell their child about the diagnosis of ASD.	Telling your child about the diagnosis of ASD was not covered in the post-diagnostic parent training.
Parents identified a need for information on how to support their child with ASD in terms of their mental health, specifically anxiety, self-harm and, as one parent mentioned, suicidal ideation.	The psychology evening of the parent training programme addressed emotional regulation. However, this information focused primarily on managing emotional outbursts and 'meltdowns', as opposed to anxiety, self-harm or suicidal ideation.
Parents reported a need for interaction with other parents of children with ASD in order to gain a sense of shared identity or belonging.	Clinicians divided participants into small groups for groupwork, and also provided a twenty-minute break in order to allow parents the opportunity to interact with each other.
Parents felt that the training was rushed at times, reporting that they did not have enough time to ask questions.	The clinicians ran out of time for questions on three occasions due to the need to cover vast amounts of information on their particular discipline in one evening. Hence, on these occasions, parents did not get the opportunity to engage in discussion or to ask questions.
Parents reported that some of the information provided on the training programme was overly simple and repetitious at times e.g. the triad.	Each discipline discussed "What is ASD" and "the triad of impairment", but each covered the topic in a discipline-specific manner e.g. psychology focused on executive functioning in their explanation of the triad.

Additional observations that were not mentioned in the data provided by the participants were noted by the researcher. Given that demographic information in relation to ethnicity and cultural considerations was not gathered as part of data collection in the study, the researcher informally noted that of the approximately 60 attendees at the training overall, only three parents were non-Irish with English as a second language. While 2 of these parents (a couple with a son with ASD) had fluent English, the third parent did not. On the second training night she attended with a daughter who helped to translate and explain the content to her. Following this, it was noted that she did not return. This parent had asked for some advice in telling her extended family about the diagnosis of ASD, noting that in her culture disability was seen as something extremely shameful. As the weeks of the training programme progressed, parents began to arrive early, stay later and spend the whole tea-break time chatting, swapping phone numbers and exchanging laughter, information and stories. At one point, a parent was heard to comment that being interrupted by a clinician to ask her to return for the next part of the session was very irritating as she was gaining more from her conversation than from the training. On the whole, parents appeared to be engaged in the training, taking notes, asking questions when possible and nodding along to points they agreed with. This was most notable on the occasion that a parent came to co-host the session and gave her testimony (Session One), the attending parents were totally silent, engrossed in her story, some even shedding tears at parts. The camaraderie and social support reported by parents in the qualitative and quantitative data was evident throughout the parent training programme. It was very clear that the social exposure to other parents of children with ASD and the opportunity to be heard by what had been a faceless service to many, and by parent peers, were the most crucial parts of the parent training programme. It appeared that this aspect of the training programme was meeting some emotional and adaptive need that was not being fulfilled otherwise.


Needs (integrated qual, quan & observations)
Needs: Thinking of the Future;
Never enough information: Roadmap; Mental Health & Telling
Support Needed
More Training
Quantitative
Increased Knowledge
Increased Skills
Observations
Awareness of other cultures
Social support


Experiences (integrated qual,quan & observations)
Feelings: guilt, relief, frustration etc.
Coming Face to Face with the Service
Different but Not Alone
Quantitative:
Increased Confidence in Suppporting Child
Increased Confidence in Own Parenting
Observations:
Peer Support from Other Parents

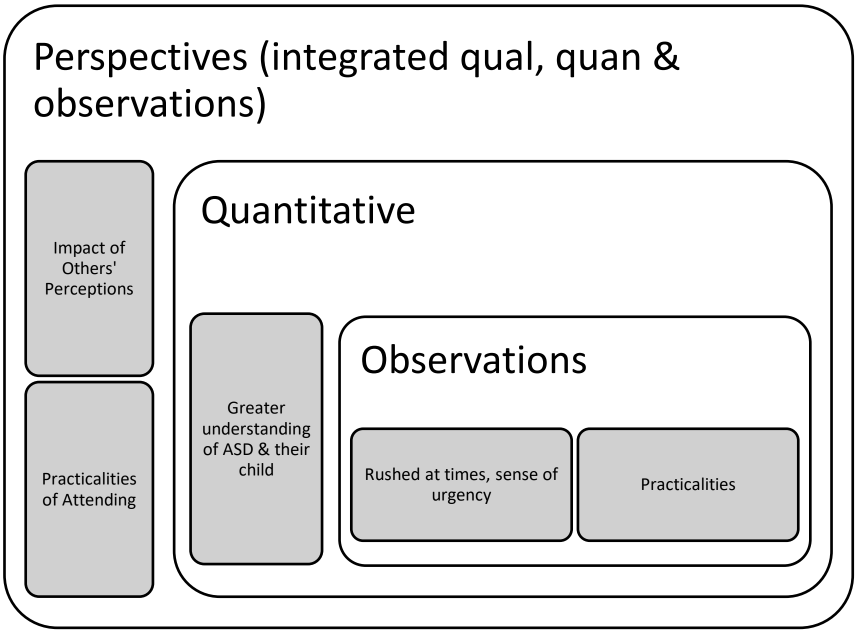

Perspectives (integrated qual, quan & observations)
Impact of Others' Perceptions
Practicalities of Attending
Quantitative
Greater understanding of ASD & their child
Observations
Rushed at times, sense of urgency
Practicalities

Figure. 12: Integrated Results of Current Study: Needs, Experiences & Perspective

4.6 Conclusion

The quantitative results of the current research study suggest that parents' self-rated knowledge of ASD significantly improved from pre-training to post-training ($t\ (31) = 4.597$, $p < .001$). This finding is supported by the qualitative results in part. While parents reported satisfaction with the information and knowledge received in generic ASD information, parents stated a clear desire to receive knowledge on specific areas, mental health, and telling about the diagnosis. Parents identified these as priority information needs which were not addressed. The quantitative and qualitative data both reflect a significant increase in parents' self-reported ratings of their understanding of ASD. Prior to training, understanding emerged as a priority learning need for this cohort of parents, and quantitative results suggest that understanding of ASD significantly increased from before training to when training ended ($t\ (31) = 4.227$, $p < .001$). Qualitative data supports this finding, with parents citing increases in their understanding of ASD, theories behind ASD and ASD in their own child. Parents' self-reported skills in managing their child's needs also increased significantly from pre-training to post-training ($t\ (31) = 2.373$, $p < .001$) , as evidenced in both quantitative and qualitative findings. In the qualitative data, the sharing and use of practical, every-day skills, tips and strategies was noted to be a beneficial aspect of the training, which may have impacted on their perceived skills level. Given parents pre-training desire for a gain in confidence in their parenting of their child with ASD ($t\ (31) = 2.745$, $p < .001$), quantitative and qualitative data both show evidence of gains in the areas of supporting the needs of the child and also, in parenting the child ($t\ (31) = 2.942$, $p< .001$). There were no significant gains made in terms of parents' communication with their child with ASD or in the management or understanding of behaviour, in either the quantitative or qualitative data. The results of this research provide considerable insight into the needs, experiences and perspectives of parents who participated in post-diagnostic training in an ASD service. The results will be discussed in the context of the existing literature in the field in Chapter Five.

Chapter 5: Discussion

5.1 Introduction

The purpose of this chapter is to examine the findings of the current research study in light of existing research in the field. This case study aimed to explore parents' experiences and perspectives of taking part in post-diagnostic parent training in an ASD assessment and intervention service. This chapter discusses and interprets the findings of this study in terms of the literature. Consideration was given to whether the findings are consistent with other studies of parents' post-diagnostic experience, and where this was not the case, further discussion was undertaken to examine why this might be so.

The findings of this study were considered in light of three key categories, **Needs**, **Experiences** and **Perspectives**. Hence, this chapter is presented in this format, with an interpretation of quantitative and qualitative results and careful consideration of the research questions:

- What are parents' **perspectives** of their **training needs** following a diagnosis of ASD for their child?
- What are **parents'** self-reported **experiences** of **post-diagnostic parent training in an ASD service?**
- What are parents' **perspectives on taking part in post-diagnostic parent training**?

The discussion is guided by the research questions and centres on three umbrella categories and nine key themes which emerged from the findings.

5.2 Parents' Needs

Following a diagnosis of ASD for their child, parents report a number of different needs. This study set about examining parents' perspectives of their training needs following a diagnosis of ASD for their child. Parents' needs were elicited and categorised under the following themes, *Thinking of the Future, "There can never be enough information to help us navigate ASD", "We need support from every angle!" and "Please can we have some more (training)?.* Findings in relation to parent needs are discussed and critically analysed here in the context of the relevant literature in the area.

5.2.1 Thinking of the Future.

Following a diagnosis of ASD for their child, parents referred to a need for reassurance and certainty about the future. Parents in the current research study reported a need for information in relation to next steps for the immediate future, but also information in relation to the longer-term implications for their child across the lifespan. This finding is supported by research conducted by Murphy and Tierney (2006), who noted that following a diagnosis of ASD, parents report considering needs in both the short and long term. Information seeking behaviours following an autism diagnosis are linked to a parental desire to regain an element of control over the situation, and further, to assist in planning for the child's future (Gibson et al., 2017; Grant et al., 2015).

Congruent with the findings of the current study, some parents found it difficult to have certainty about what the future may hold for their child (Murphy & Tierney, 2006). Given that the disorder is a lifelong condition, which pervades across the lifespan, parents consider the diagnosis of ASD and the implications for their child's future (Lutz, Patterson & Klein, 2012; Murphy & Tierney, 2006). It is noteworthy that participants in the current study had received a diagnosis of ASD for their child within six months of taking part in the training programme. Hence, the findings of Murphy and Tierney (2006) that parents' seek less information as they become more familiar with their child's ASD profile over time is not applicable to parents at this early stage. Furthermore, some parents in the current research study expressed a need for information on implications of ASD for their child as they approach adolescence and adulthood. In light of research by Gibson et al. (2017) relating to the decreasing availability of information about ASD as children get older, it is possible that this will continue to be an area of need for families. Additionally, research shows that the average age of a diagnosis for autism is 55 months, or when the child enters the school system (Brett et al., 2016; Crane et al., 2016). Thus, many post-diagnostic interventions and information sources focus on early intervention and early school years, rather than on the information needs of those with later diagnoses or the needs of adolescents and young adults, as seen in the current research study (Bearss et al., 2015; Francis, 2005; Ingersoll & Dvortcsak, 2006; Mitchell & Holdt, 2014; Oono et al., 2013; Orinstein et al., 2014; Warren et al., 2011).

Finally, parents in the current research study reported a need for information about the service and the types of support they would possibly receive in the future.

This desire for clarity in the face of service uncertainty is a theme found in the literature, with a sense of uncertainty being reinforced by a perceived lack of support and direction from professional services (Murphy & Tierney, 2006; Mansell & Morris, 2004; Howlin & Moore, 1997). Additionally, parents in the current research study reported awareness of the resource constraints faced by the ASD service and had varied experiences of contact and waiting times with the current service. In this context, and in light of media reports (Baker, 2018; O'Loughlin, 2018) and statements issued by the HSE (Health Service Executive, 2013; Psychological Society of Ireland, 2018), it is unsurprising that parents seek information on the service itself and on what they can expect to receive in terms of intervention for their child in the years ahead.

5.2.2 “There can never be enough information to help us navigate ASD”.

This section addresses the following research question:

What are parents’ **perspectives** of their **training needs** following a diagnosis of ASD for their child?

Parents identified a number of aspects in relation to their information needs following a diagnosis of ASD for their child. The current research identified categories of information need as outlined by parents, *Looking for a Roadmap for ASD, How to tell my child about their diagnosis; and Mental Health and Wellbeing Concerns for Children with ASD. Telling about the Diagnosis* and *Mental Health.*

5.2.2.1 Looking for a Roadmap for ASD.

Parents in the current research project outlined that knowledge, understanding and information about ASD were priority learning needs. This finding is supported by the literature, with information-seeking reported as a key need for parents following a diagnosis of ASD for their child (Banach et al., 2010; Grant et al., 2015; Murphy & Tierney, 2006; Reichow et al., 2012). Additionally, in a finding supported by Murphy and Tierney (2006), prior to training beginning, parents cited knowledge about available supports and services for their child as a priority information need. Furthermore, in line with evidence presented in the literature, parents in this study reported a need for practical tips and strategies which could be implemented in the everyday lives of their families (Murphy & Tierney, 2006).

Following the completion of the training programme, parents in this study reported that their knowledge about ASD had increased significantly from pre- to post-training. This suggests that post-diagnostic parent training can meet parents' need for general information about ASD. This finding supports recent research by McAleese et al. (2014), which found that parents of children with ASD who attended a psychoeducational, therapeutic group following their child's diagnosis experienced a significant increase in their knowledge of how ASD presents and also their knowledge of behavioural strategies to support their child. A systematic review conducted by Oono et al. (2013) also reported that post-diagnostic parent-mediated interventions for children with ASD increased parents' knowledge about the condition. The findings of this study, supported by the aforementioned research, provide a strong evidence base for the benefits of providing post-diagnostic parent training as a means of enhancing parents' knowledge base and meeting their needs for general information on ASD. Furthermore, the provision of good quality, evidence-based information from reputable sources, in this instance, experienced clinicians from the ASD service, can act to protect parents and their children from unsubstantiated, often commercial, interventions sold on the internet (Grant et al., 2015; Matson & Williams, 2015; Matson et al., 2013; Reichow et al., 2012; Stephenson et al., 2012).

5.2.2.2 How to tell my child about their diagnosis.

While many parents reported a need for generic information on ASD, some parents in the current research mentioned specific information needs. A finding of the current research study highlighted that parents relayed a need for information in relation to telling their child about their diagnosis of ASD and how to support them in understanding the diagnosis. While the need for support in telling about the diagnosis has been outlined in previous research studies (Murphy & Tierney, 2006), the current research found that this need remains unmet for many parents. While much research has been conducted on parents' experiences of the autism diagnostic process, there is a lack of research on parents' experiences of telling their child about their diagnosis of ASD (Finnegan, Trimble, & Egan, 2014). The lack of research in this area has led to a paucity of expert guidance on decision-making about what to tell the child about ASD and when to disclose the diagnosis to the child. Consequently, parents report feeling anxiety and concern about the disclosure (Finnegan et al., 2014). Finnegan et al. (2014) suggest that future research in this area address the role of professionals in supporting parents through this process, as well as examining the child's readiness to learn about their ASD diagnosis and their experiences of receiving their diagnosis. In the context of the current research, and in light of the lack of an established body of knowledge on this topic, it is possible that due to the personal, context-specific nature of such a need, a generic, large group training situation is not the most appropriate space for this information need to be met.

The findings of a systematic review of the literature on parental disclosure of an ASD diagnosis to their child highlight the importance of supporting parents in telling the child about the ASD diagnosis. The findings of the current study note that parents sought information on telling their child about the diagnosis, especially in terms of supporting their child in making sense of their own identity, feelings and behaviours. Furthermore, given that parents in the current research study are reporting a need for guidance in telling their child about the diagnosis of ASD, the findings of Smith et al. (2018) are corroborated by the current study. The findings of the current research study emphasise the importance of Smith et al. (2018) call for the development of best-practice guidelines to support parents in telling their child about ASD and also, the call for further research in the area.

5.2.2.3 Mental Health and Wellbeing Concerns for Children with ASD.

A further information need which arose from the current research study centred around providing parents with information on anxiety, emotional regulation and mental health for children with ASD. A number of parents in the current research study spoke about their child's experiences of anxiety, deliberate self-harm, and suicidal ideation, with their journey to a diagnosis of ASD coming through initial contact with the Child and Adolescent Mental Health Services, who then referred their child onwards for an ASD assessment. Hence, for participants in this study, there was a stated desire for the topic of mental health and ASD to be covered in parent training. This finding is in contrast with much literature on parents' post-diagnostic information needs, in that research in this area has tended to emphasise parents' emotional well-being as a priority need rather than that of their child with ASD (Pottie & Ingram, 2008; Woodgate et al., 2008). This is, perhaps, linked to the focus of the current research study, which examined parents' needs, experiences and perspectives of post-diagnostic training, unlike other research which sought to examine parental coping or stressors following a diagnosis of ASD for their child (Baker-Ericzén et al., 2005; Divan et al., 2012; Pain, 1999; Pepperell et al., 2018; Pottie & Ingram, 2008; Vernhet et al., 2018).

A number of other factors may have contributed to this discrepancy in findings. Firstly, the training was attended by a number of parents of girls with ASD. Given that ASD in girls can be manifested through profiles of anxiety, isolation and low affect (Loomes et al., 2017; Salas et al., 2017), it is hypothesised that the presence of so many parents of girls with ASD may have impacted on the results of this study. Secondly, the needs of populations change over time, and in light of the availability of generic ASD information from sources such as online websites (Gibson et al., 2017; Reichow et al., 2012; Stephenson et al., 2012), it is possible that the need for specific information and support in relation to mental health issues and ASD has arisen in recent times.

Research has shown that the relationship between ASD and mental health is complex, and multi-faceted (Psychological Society of Ireland, 2010). It is widely accepted that people with ASD are at a greater risk for anxiety and mood disorders than the general population (Carr, 1999; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000). A study by Simonoff et al. (2008) investigated the prevalence and type of psychiatric disorders amongst a group of 112 ten to 14 year old children with ASD. Within this group, children with ASD, DSM-IV criteria for psychiatric diagnoses of childhood anxiety disorder, depressive disorder, oppositional defiant and conduct disorder, attention deficit hyperactivity disorder, tic disorders, trichotillomania, enuresis and encopresis, were identified. Seventy percent of participants in this study had at least one disorder presenting in addition to their ASD diagnosis; 41% of participants presented with two or more co-morbid disorders (Simonoff et al., 2008).

According to the Psychological Society of Ireland, care must be given at the time of diagnosis to differentiate between mental health difficulties and the challenges presented by autism spectrum disorder (Psychological Society of Ireland, 2010). The diagnostic assessment must consider the presence of mental health difficulties as co-existing with ASD or as a differential diagnosis in order to avoid the risk of under-diagnosis of either ASD or mental health disorders (Psychological Sociey of Ireland, 2010). In light of the prevalence of ASD and co-existing mental health disorders, this study found that parents in the current research study sought additional information on supporting their children with their mental health.

5.2.3 We need Support from Every Angle!

The current study found that parents cited coping and support needs as priority needs prior to their engagement in the post-diagnostic parent training. This is a finding which is echoed across studies of parents post-diagnostic need, with references made to both support from other parents and from services and clinicians (Banach et al., 2010; Barnett et al., 2003; Divan et al., 2012; Hennel et al., 2016; Murphy & Tierney, 2006; Siklos & Kerns, 2006; Symon, 2001). A study by Pottie and Ingram (2008) highlighted that problem-focused coping strategies are not always helpful for parents of children with ASD given the pervasiveness of the challenges faced on a daily basis. This finding contrasted with research by Vernhet et. al (2018), who noted that a problem-based approach to coping lowered parental stress levels and served as a protective factor for parents of children with ASD.

The current research study found that parents reported benefitting from the social support provided by undertaking group training with other parents of children with ASD. The need for support from people who have shared similar experiences in this study is supported by findings from Banach et al. (2010) and Law et al. (2001). Woodgate, Ateah and Secco (2008) noted that parents of children with ASD are at greater risk of social isolation and lack of support than parents of typically developing children. This finding highlights the importance of group training and exposure to other parents with children with ASD, as a protective coping factor. Parents in the current research study reported discovering a new sense of ‘normalcy’ and not being alone in their experiences of parenting a child with ASD. Participation in post-diagnostic group training for parents of children with ASD is associated with increased coping and decreased stress levels (Bitsika & Sharpley, 1999; Mansell & Morris, 2004).

5.2.4 Please can we have some more (training)?

Despite having completed over ten hours of parent training in a four-week period, parents in the current research study identified themselves as having a need for further, more in-depth training. Given that most post-diagnostic parent training programmes are delivered over a six to twelve week period (Bearss et al., 2015; Postorino et al., 2017), it is possible that the shorter time-frame of training in the current post-diagnostic programmed (four weeks) may have been insufficient in terms of meeting parents’ training needs.

The participants in this study also reported a need for training for educators and school staff involved in supporting their child in educational settings. Parents felt that training for school staff provided by clinicians working in an ASD service would be hugely beneficial both for education workers and for children with ASD. This recommendation supports a finding by Guldberg et al. (2011), who indicated that educators of children with ASD should attend training in order to learn about ASD and its characteristics, and also to support the use of evidence-based interventions in education settings. Interestingly, in Ireland, teacher training programmes include specific training on tenets of inclusivity and special educational needs, including ASD. Additionally, groups such as the National Council for Special Education (NCSE) and the Special Education Support Service (SESS) provide opportunities for educators to engage in ongoing continuing professional development in the area of ASD.

While it is noted that there has been significant investment in teacher training and continued professional development in the area of education for children and young people with ASD, parents in the current research study expressed dissatisfaction with their child's experiences of inclusion in the Irish education system. Parents reported a need for teachers to experience the same type of multi-disciplinary, eclectic training programme provided by the ASD service in order to gain insights into the disorder and how it impacts on children and young people at school. This would suggest there is a discrepancy between the inputs available to education staff and the experiences of parents and their children with ASD in the school environment. This finding begs the question, if educational supports and continued professional development courses are available, why are parents feeling frustrated by schools' responses?

5.3 Parents' Experiences

This section explores the experiences of parents attending post-diagnostic parent training, addressing the research question:

- What are **parents'** self-reported **experiences** of **post-diagnostic parent training in an ASD service?**

The discussion is framed by the following themes, *Feelings of Taking Part: Fear, Guilt, Relief, Frustration. Coming Face to Face with the Service* and *Your Family is Different, but You are Not Alone.* Contemporary research findings frame the discussion of experiences in this section.

5.3.1 Feelings of Taking Part: Fear, Guilt, Relief, Frustration.

Parents in the current research study expressed experiencing greater understanding of their child with ASD and their worldview following participation in post-diagnostic parent training. This finding supports other research on post-diagnostic training, in that training of this type is linked to improved understanding of what it is like to have ASD and the challenges that people with ASD can face (Ingersoll & Dvortcsak, 2006; Kuhaneck et al., 2015; Lundahl et al., 2006; Matson et al., 2009; McConachie et al., 2005). Parents in the current research study discussed their role as advocate and support system for their child within their families, schools and the wider world, noting particularly how vital understanding ASD is to this role and how the training programme facilitated the development of this understanding. This is in keeping with other research which found that the importance of understanding ASD and how that may impact upon a child with ASD is especially heightened in the advocacy and support role assumed by parents of children with additional needs (Bearss et al., 2015; Drake et al., 2008; Law et al., 2001; Murphy & Tierney, 2006). The quality of information offered to parents around the time of the ASD diagnosis is known to impact upon parents' level of overall satisfaction with the diagnosis and their subsequent coping skills (Baird et al., 2000).

5.3.2 Coming Face to Face with The Service.

The current research study found that parents' experiences of accessing information on the training programme were mixed. Some parents in this research study reported uncertainty around the structure of the course. Additionally, despite initial negative views of service prior to attending the training programme, some participants reported their experiences of receiving information from professionals as being positive, albeit ad-hoc. Other participants on the post-diagnostic training programme described having discussions with clinicians at break times and after the training, in which they received advice and input not provided on the training programme, which they reported to be very positive. These interactions were unplanned and not available to all participants, hence there was a discrepancy in the support received by parents on the programme. On occasions, the clinicians ran out of time for questions from the participants, which consequently limited the participants' access to information. Both of these types of experiences led to the ad-hoc and unequal distribution of information and/or advice. This finding, in relation to the unplanned and circumstantial interactions with clinicians offering informal and impromptu advice at unstructured times of the training programme, is in keeping with Murphy and Tierney's statement that informational relationships of this kind are often piecemeal and disorganised (2006). This finding is reflective of the challenges faced by parents when accessing information following a diagnosis of ASD for their child (Grant et al., 2015; Mackintosh et al., 2005).

For some parents in the current study, the information received on the training programme was likened to generic information found on online websites. Participants reported that they ‘already knew’ the material presented by the clinicians from their own research in the time following their child’s diagnosis. This finding suggests that parents are increasingly using the internet as a source of information and knowledge about ASD. The findings of the current study support the findings of Hall et al. (2016) and Mackintosh et al. (2005), in noting that increasing numbers of parents cite the internet as a crucial source of information. Furthermore, Jones et al. (2013) and Pagliari et al. (2005) found that the volume of information for parents of children with additional needs has grown exponentially. While the internet is a very useful tool when access to professional support is limited (Hall et al., 2016), the information available online can be of questionable quality (Pagliari et al., 2005). The risk of relying on websites for information is that parents and their children may be exposed to unsafe and unvalidated interventions, without the support and guidance of experienced clinicians (Matson & Williams, 2015; Matson et al., 2013). It is possible that the ease of access to information online has raised the expectations of the standard of information a parent would seek from a clinician, leading to findings such as those of this study, whereby parents express some dissatisfaction with the information presented to them as being “regurgitated” from information already accessed online.

Both pre- and post- intervention, parents in the current research study displayed awareness of the financial and time constraints of the service providing the training. In keeping with the findings of the current study, a lack of resources and the pressures of providing intervention for families were referred to across a number of studies, highlighting the ongoing nature of the resourcing issues for ASD services over the last decade (Murphy & Tierney, 2006). The awareness of shortfalls in resourcing has impacted upon parents expectations of intervention for their child with ASD, with many expressing frustration and disappointment, despite being grateful for any support received from services (Crane et al., 2016; Divan et al., 2012; McAleese et al., 2014; Murphy & Tierney, 2006). The findings of the current research study are in line with research which highlights the dichotomy between being upset with the lack of services provided by the ASD service, while also being appreciative for the little support received (Crane et al., 2016; McAleese et al., 2014). Parents in the current research study reported valuing the opportunity to attend post-diagnostic training and were appreciative of the information received. This may be linked to the sense of relief felt by parents when offered support and good quality information with a solid evidence-base from professionals, rather than having to search through a barrage of information by themselves (Connolly & Gersch, 2013; Murphy & Tierney, 2006; Schopler, 1995). Some parents expressed frustration at the lack of intervention available to them, referring specifically to information from the service listing the supports which would not be provided to their child. For Pain (1999), information on the lack of accessibility of appropriate interventions can lead to feelings of disheartenment and frustration for parents.

The issue of the quality of information presented to parents by clinicians was reported in the current research study. The "basic" level of information was cited as being disappointing. Parents also reported expecting a higher quality of information from having face to face time with clinicians; they stated that this expectation was not met. It is suggested here that an issue may lie with parents' perceptions and expectations of the role of clinicians in post-diagnostic training. Mansell and Morris (2004) and Sullivan (1997) outline the role of the clinicians as one of information provision around support, risk factors, and challenges, as well as to foster positivity and hope and to provide evidence-based information. Additionally, Bearss et al. (2015) highlight the importance of supporting parents in managing their own assumptions and expectations about ASD. Any lack of clarity around expectations of parents in terms of the role of clinicians, the type of intervention on offer and the training programme itself may lead to frustration, disappointment and unfulfilled expectations on behalf of participants.

5.3.3 Your Family is Different, but You Are Not Alone.

Experiences of coping and support of parents in the current research were largely positive. Similar to a finding by Banach et al. (2010), participants reported experiences of gaining knowledge, understanding and acceptance from other parents taking part in post-diagnostic training. Feelings of normalcy and not being alone were reported by many parents, who cited hearing other parents' experiences as key to diminishing their own sense of difference and isolation. Post-diagnostic training groups have been shown to increase parents' sense of belonging (Law et al., 2001), while Bitsika and Sharpley (1999) found improvements in parents' self- reported self-concept and reduced levels of stress in participating parents. The development of a sense of a "new normal" following a diagnosis of ASD was reported in the current study, a finding which was also evident in contemporary post-diagnostic research (DePape & Lindsay, 2015; Koydemir-Ozden & Tosun, 2010).

Parents differentiated between the support provided by other parents of children with ASD and that provided by clinicians and professionals. Parents in the current study placed a greater value upon the information from other parents than that of professionals, a finding which supports that of Mansell and Morris (2004), whose research found that parents rated information from other parents as the most useful of all. Mackintosh et. al (2005) refer to this preference for parental testimonies and support as the "walking in my shoes factor" (p.50).

5.4 Parents' Perspectives

This section presents a discussion on parents' views of attending the training, addressing the research questions:

- What are parents' **perspectives on taking part in the training**?

The discussion is framed by the themes of *Realising the Impact of Other People's Perceptions of ASD: Positives and Negatives* and *Practicalities of Attending Post-Diagnostic Training*.

5.4.1 Realising the Impact of Other People's Perceptions of ASD: Positives and Negatives.

The results of the current research study offered insight into parents' perspectives of sources of coping and support. In common with other research in the area of post-diagnostic training, parents reported that other parents were the best source of support (Banach et al., 2010; Mansell & Morris, 2004). Despite the positive impact of the support of other parents, Murphy and Tierney (2006) highlighted some concerns over the quality of information exchanged between parents, noting that this information would not necessarily be based on best practice evidence.

Other sources of support mentioned in the current research study are that of family members and the school system, both of which were reported to be lacking. Parents reported frustration and disappointment at the perceived lack of understanding of their extended family networks, preferring instead to draw on the support of other parents of children with ASD. This result is supported by studies which suggest that parents prefer to seek social support from those who also have experiences of parenting a child with ASD, citing a lack of understanding from those who have not shared this experience (Mackintosh et al., 2005; Murphy & Tierney, 2006).

As discussed earlier, parents in the current study reported a lack of understanding of ASD from education staff in their child's school, detailing a need for links and training programmes to be established between the ASD service and schools. Parents often find themselves in the role of advocate for their child, especially in relation to schools and other services (Drake et al., 2008). Following participation in post-diagnostic parent groups and training programmes, parents report increased levels of confidence, leading to an enhanced sense of empowerment in their abilities to advocate for their child (Bearss et al., 2015; Law et al., 2001). Parents who took part in this research reported acting in the role of advocate by sharing tips and strategies with their child's school, while still acknowledging that this piecemeal sharing of information is not necessarily as beneficial as teacher training might be. Furthermore, the advocacy role has been shown to increase feelings of stress for parents at times (Altiere & von Kluge, 2009; Myers et al., 2009), which may serve to explain some of the frustration expressed by parents in the current research in relation to the perceived lack of understanding from their child's schools.

5.4.3 Practicalities of Attending Post Diagnostic Training.

Parents shared their perspectives on post-diagnostic training in this study, making practical suggestions in terms of group size, emphasising a preference for smaller groups. Additionally, parents suggested a longer-term training programme be implemented, in line with other research on post-diagnostic training (Bearss et al., 2015; Postorino et al., 2017). Longer training programmes allow for more material to be covered, and also contribute to the consolidation of knowledge and skills. Furthermore, parents suggested a facility to send the clinicians their questions in advance to allow for a more specific and relevant training programme. A measure such as this would allow for the voice of parents to be heard in the training programme, while also offering opportunities for parents of children with ASD to be active consultees in addressing their own learning needs (Guldberg et al., 2011). Participants in the current research study noted a number of factors pertaining to practical elements of the training programme which they experienced. However, other research in this area is not concerned with factors such as session length, group size or the age ranges of the children of parents attending.

Parents’ experiences of the impact of training in this study was mixed, with some parents stating they had not experienced any changes, while others reported changes in their attitudes to their child’s needs and their own use of strategies to support their child. Bearss et al. (2015) and Farmer and Reupert (2013) report increased skills for parents who participated in ASD-specific parent training. A similar finding was reported by parents in this study. Quantitative data shows a significant increase in self-rated skills in managing the child’s needs from pre- to post- parent training, indicating that post-diagnostic parent training programmes can increase parents’ skills level. Furthermore, in agreement with findings by Kuhaneck et al. (2015), quantitative results in this research show significant increases in parents’ confidence in supporting their child and also, confidence in parenting their child with ASD following the parent training intervention.

In contrast to studies by Rivard et al. (2016) and Bearss et al. (2015), the current research study did not find any significant changes for parents self-rated ability to manage their child’s behaviour or to understand their child’s behaviour. There were no significant differences in parents self-reported communication difficulties with their child or in their confidence in meeting their child’s intervention needs. These quantitative findings may be insignificant for a number of reasons. Firstly, the duration of the current programme is shorter than other parent training programmes studied in the literature, which may have had an impact on parents’ consolidation of skills. Secondly, research suggests that the most impactful parent training programmes involve direct work on parent-child interactions with both present, an activity that was not undertaken in the post-diagnostic training programme in this study (Wyatt Kaminski et al., 2008).

5.5 Reflexivity

Although attempts were made to control for the researcher’s impact on the current research study, (including journaling, critical reflection, clarifying the researcher position as separate to the service, displaying impartiality), the issue of researcher positionality and reflexivity are likely to have had some bearing on the outcome of the research study. As noted in Chapter 4, some participants appeared to assume that the researcher was conducting the research on behalf of the disability service. Additionally, maintaining impartiality was difficult at times, particularly given the sensitive and emotional nature of the parent training and the evident upset and vulnerability of some participants both during the training and at the interview stage. Reflective journaling and consultation with the research supervisor helped to maintain focus on the role of the researcher and the importance of an awareness of positionality.

5.6 An Ecological Perspective on Capturing the Voices of Parents in Post-Diagnostic Training in an ASD Service.

Bronfenbrenner’s (1979) ecological model provided an appropriate framework for contextualising, analysing and interpreting parents’ needs, experiences and perspectives of taking part in post-diagnostic training for ASD for the purposes of the current research study. This research study was conceptualised under this framework as taking place at the interface between the parent and the disability service, or in Bronfenbrenner’s ecological model, at the interface between the microsystem and the mesosystem. The participants in this research were parents of children with ASD who were undertaking post-diagnostic parent training provided by a disability service as a means of intervening for their child. The clinicians providing the training used an eclectic, multidisciplinary psychoeducational approach as a means of indirectly working with a large number of recently diagnosed children. Hence, in this conception the child remains at the centre of the ecosystem, with the participant-parents in the microsystem, supported by the disability service and clinicians in the mesosystem. The outcomes for the child with ASD are influenced by the interactions between people and events in their immediate and wider environment (Odom et al., 2004). Interactions and events in the child’s immediate environments are considered to be most impactful, while factors in the wider mesosystem, macrosystem and exosystem are not as influential but remain significant (Bronfenbrenner, 1979).

5.6.1 The microsystem

The participants in this study were all parents of children recently diagnosed with ASD. The demographic information gathered on the participants was limited by ethical and service constraints, hence little is known about the microsystem’s in which each of the participants supported their child. What was common to all participants is that they were each the primary carer of a child diagnosed with ASD within the previous six months, each lived within a particular catchment area, and each had agreed to attend post-diagnostic training as a means to support their child in the context of adapting to the recent diagnosis. The knowledge and skills acquired by the participants over the course of the training programme are intended to be implemented in the microsystem as a form of intervention. Changes in understanding, attitudes and emotionality impact at the microsystemic level.

The clinicians and local disability service are also operational at the microsystemic level for the child with ASD, most particularly around the period of diagnosis and immediately afterwards through assessment and intervention processes. However, in the context of the chronosystem, this placement within the microsystem changes over time, with the service likely to become less important depending on the level of involvement and services provided. At the time of the post-diagnostic training, the clinicians are considered by the researcher to form an important and influential part of the microsystem, given the implications of the recent diagnosis for the child, the impact of the training directly on the child and the intensive assessment period which will have recently drawn to a close.

5.6.2 The mesosystem

This layer of Bronfenbrenner's (1979) ecological model is made up of the interrelationships between the variables in the microsystem; in this instance, the parent-participants and the clinicians providing the training on behalf of the disability service. This research found that the interaction between these two aspects of the child's microsystem impacted upon factors such as parents' knowledge, skills, understanding and feelings about their child's recent diagnosis. The results of the current study also indicate that the mesosystem is crucial for parents coping and adapting to a diagnosis of ASD for their child, with parents discussing the impact of other peoples' perceptions of the condition, such as extended family and school staff.

5.6.3 The exosystem

A number of variables from the exosystem directly impact the child with ASD, the parent-participants and also the clinician's delivering the training programme. Factors such as the financial resourcing provided by the government of Ireland to the disability service, media awareness of the challenges of ASD and the health and education systems impact upon the intervention provided and the potential outcomes for the child. Participants noted the impact of waiting lists and lack of resources on their child and on themselves.

5.6.4 The macrosystem

The macrosystem contains societal attitudes, beliefs and culture. These factors have shaped people’s core beliefs about disability, with participants from different cultural backgrounds highlighting that conceptions of disability often varying across cultures, races and religions. The attitudes of society as a whole to inclusion and to ASD in this research influences legislation, resource allocation and acceptance.

5.6.5 The chronosystem

This conception acknowledges the impact of change over time on an individual. In the current research study it is noted that ASD is a pervasive, lifelong condition which impacts people across the lifespan. It is also stated that the needs of the individual will wax, wane and vary across the lifespan, hence the need for parent training to be developed to meet these needs as the child with ASD develops into an adult with ASD.

5.7 Conclusion

The discussion and critical analysis has indicated that taking part in post-diagnostic parent training results in positive outcomes for participants. Taking that into account, however, it must be acknowledged that there are some gaps between the self-reported needs of the participants following a diagnosis of ASD, and the materials covered by clinicians as part of the training programme. Positive, supportive relationships both with other parents and with clinicians are positive experiences drawn from participating in post-diagnostic training. The ease of accessibility of information about ASD online has left some parents feeling disappointed in the level of knowledge they received. In line with research findings in the field, the findings of the current study indicates that post-diagnostic parent training significantly improves parents’ knowledge, understanding and skills in ASD (Lundahl et al., 2006; McAleese et al., 2014; Wyatt Kaminski et al., 2008).

Chapter 6: Conclusion

6.1 Introduction

This final chapter presents the current research findings in the context of the research questions proposed. Future research directions and implications for practice are presented. The strengths and limitations of the study are outlined. Plans for the dissemination of the research findings are discussed.

6.2 The Research Questions

This research examined the experiences and perspectives of parents participating in post-diagnostic parent training in an ASD-specific service following a diagnosis of ASD for their child. Capturing the voices of parents at the post-diagnostic stage of their ASD journeys was a central aim, which the research addressed through the following questions:

- What are parents' **perspectives** of their **training needs** following a diagnosis of ASD for their child?
- What are **parents'** self-reported **experiences** of **post-diagnostic parent training in an ASD service?**
- What are parents' **perspectives on taking part in post-diagnostic parent training**?

A case study approach was employed, using a mixed methods methodology for data collection. Results of this study were categorised under the following headings, **Needs, Experiences** and **Perspectives.** A critical analysis of the research findings led to the voice of parents in the post-diagnostic stage being elicited in terms of their self-identified needs, experiences and perspectives of participation in post-diagnostic parent training.

6.3 Findings

The current research study examined the needs, experiences and perspectives of parents who participated in post-diagnostic parent training in an ASD service. Following participation in the training programme, parents reported significant increases in knowledge of ASD and understanding of ASD. Additionally, there were significant increases in parents' ratings of their skills in managing their child's needs. Parents reported a significant increase in their confidence in supporting the needs of their child with ASD. Parents also reported a significant increase in their own confidence in parenting a child with ASD. These quantitative findings are borne out in the qualitative results of this study.

It was anticipated that the findings of this study would be congruent with contemporary research in the field, and while this was predominantly the case, some new information regarding parents’ self-reported needs and experiences of participating in training came to light. Amongst these findings was participants’ self-reported need for more information about the links between mental health disorders and ASD. Another finding which did not arise in the literature review in the current study, but which was highlighted by parents was the need for information and support in the process of disclosing the diagnosis of ASD to their child. Participants in the current research study noted a need for greater support and understanding from schools and school staff, and suggested that school staff would benefit from participation in this training programme. A further finding in the current research study was that parents sought greater information from the training programme, as many felt that they had accessed a certain level of information through online sources of information.

6.3.1 Research Question 1: What are parents’ perspectives of their training needs following a diagnosis of ASD for their child?

This study found results which were consistent with the literature in the field. Parents expressed a need for knowledge about ASD, understanding of the condition and how it may impact on their child, as well as a need for support from services and from other parents of children with ASD. Following the post-diagnostic parent training programme, parents’ knowledge, understanding and confidence increased significantly. Parents’ reported benefitting from the parent training programme and being grateful for the opportunity to receive this intervention. Parents also noted that they would benefit from ongoing training of this nature and would like to be offered the opportunity to participate in more in-depth follow up training in the future.

Additionally, parents reported a need for information on mental health for children with ASD, and also information about telling their children about their diagnosis. Parents stated a need for greater knowledge and understanding from school staff in relation to supporting their child with ASD, suggesting a similar type of training would be beneficial for teachers. Parents also cited needs for information about supporting their child with ASD into adolescence and adulthood, particularly in relation to the education system. Parents’ perspectives on taking part in the post-diagnostic parent training programme were that they found the programme to be mostly beneficial, however there was some discrepancy between the training needs reported by parents and the information provided by clinicians.

6.3.2 Research Question 2: What are parents' perspectives on taking part in the training?

Parents in this study were appreciative of the opportunity to attend post-diagnostic parent training. However, some parents reported uncertainty around what to expect. Some parents reported having low expectations of participation due to a perceived lack of contact and support from the service in the past due to resourcing issues and long waiting times for assessment.

Parents displayed awareness of the lack of resources experienced by the service and were pragmatic about the impact this had on clinicians' abilities to provide longer training programmes. That said, parents highlighted the negative impact of service statements, about the interventions and therapies which would not be offered to their child, which were made in advance of training participation. Parents reported that this led them to feel defensive and disappointed in the training before they attended. In terms of the participants' interactions with clinicians themselves, participants reported satisfaction with these interactions, noting that despite huge time and financial constraints, clinicians made great efforts to provide the best quality information and service they could in the limited time allowed.

6.3.3 Research Question 3: What are parents' self-reported experiences of post-diagnostic parent training in an ASD service?

Parents reported an increased sense of belonging and normalcy following participation in the post-diagnostic training programme. The support provided by other parents of children with ASD, and the experiences of hearing other families' stories led to a reduction in feelings of isolation and difference.

Following participation in post-diagnostic training, parents reported increased patience and understanding of their child with ASD. Others cited implementing practical tips and strategies learned on the programme. Parents outlined a desire to make sessions more interactive with time for questions, which they suggested could be shared with clinicians in advance of the training in order to make the sessions more pertinent to their situations. This highlights parents' desire to carve out a space for their voices to be heard in post-diagnostic parent training.

6.4 Limitations of the Current Research

This was a small-scale research study; this factor is associated with a number of limitations. A case study methodology was employed to facilitate the single-researcher aspect, the time constraints and the bounded nature of the training programme. Therefore, the results of this study cannot be generalised across populations of parents of children with ASD who have participated in post-diagnostic parent training.

One of the limitations of this study was the small sample size (N=39), which may not be representative of the broader population of parents of children with ASD. The sample of participants were also drawn from a small, restricted geographical area, a fact which further impacts on the relevance of the findings for a wider demographic. However, it must be acknowledged that the aim of case study research is to gain an in depth understanding of a particular, bounded situation. The aim of this case study research was not to be generalised to a broad population, but rather to garner a thorough understanding and information which can be considered in a very specific context, i.e. a post-diagnostic parent training programme in an ASD service.

Additionally, the sample in this study was self-selecting, in that participants had chosen to accept the invitation to attend post-diagnostic parent training. It is possible that parents in this sample are not representative of the wider population of parents of children with ASD, in that they were motivated to attend training, while it cannot be assumed that other parents would also be. Furthermore, the sample excluded parents who could not attend the programme for whatever reason, nor did it include parents assigned to other services in which parent training is not offered. The sample used in this study could not be said to be a random sample. Furthermore, demographic information or personal data, such as parental age, socioeconomic status, ethnicity, educational status, etc. was not collected so it was not possible to analyse and compare this data across wider population norms.

This study did not employ a control group; therefore, the findings of the study could not be viewed in line with the needs, experiences and perspectives of parents who did not attend or were not offered post-diagnostic parent training. Therefore, factors such as length of time since diagnosis or lack of intervention could not be controlled for.

Data in relation to cultural, religious and home backgrounds, language fluency or initial understanding of ASD was not gathered from participants. A small number of participants did not speak English as a first language and were of an ethnicity which might have different cultural beliefs in relation to conceptions of disability. These factors may have impacted upon their needs, experiences and perspectives.

Very little demographic information or information about the child's ASD was collected, hence important and impactful factors such as cognitive functioning, severity of ASD, co-morbid conditions, additional family members with ASD etc. could not be accounted for in this current study.

The quantitative tool used in the study, the questionnaire pre- and post-intervention, was not normed or standardised. The reliability and validity of the questionnaire was unclear, factor analysis could not be conducted due to the sample size, and while attempts were made to pilot the questionnaire and to gather feedback from experienced clinicians in the field, the quantitative tool used was of questionable quality and in retrospect, better suited to a scoping exercise.

The issue of researcher positionality and reflexivity is likely to have impacted upon the research study. Participants, at times, appeared to associate the researcher with the ASD service, and the researcher had to reiterate her impartiality on a number of occasions. This may have impacted upon participant responses.

A further limitation of the study is that attendance data was not collected as the ASD service providers felt that given the large numbers of attendees and the time constraints in the training sessions, a sign in system would have been unwieldy and untenable. Hence, the information on the effectiveness of the intervention is weakened given that parental attendance and engaged is known to significantly impact on treatment effectiveness.

This study collected data pre- and post- intervention. It would have been beneficial to have a further data collection at a 3-month and/or a 6-month timeframe to gauge any possible longer-term impacts of participation in the post-diagnostic training programme. This would also be useful to decipher whether parents' post-diagnostic needs had changed in this timeframe, or if their perspectives on participation had changed over time.

6.5 Strengths of the Current Research

This research contributes to current literature on the post-diagnostic needs, experiences and perspectives, giving a voice to parents following their child's diagnosis of ASD. Furthermore, this research adds to a body of work on the importance of parent training as a post-diagnostic intervention. This research shows that post-diagnostic parent training increases parents' knowledge, understanding and confidence in supporting and parenting their child with ASD.

The use of a case-study approach allowed for the gathering of information from a variety of sources, such as researcher observation, surveys and semi-structured interviews. This created a rich, consistent picture of the post-diagnostic training received by participants and allowed for the voices of parents to be captured at this stage of the post-diagnostic journey.

This research is unique in an Irish context, and in light of the ongoing changes to how disability services are delivered in the Republic of Ireland, it should be considered as a useful resource for informing the post-diagnostic intervention and communication with parents. Furthermore, post-diagnostic parent training is a timely and cost-effective means of delivering support to a large group of people at once, and so may be considered as an effective means of intervention for ASD services across the country.

The use of a mixed-methods methodology allowed for a variety of types of data to be collected and critically analysed. Furthermore, the congruence between quantitative and qualitative data enhance the reliability of the findings of the study.

6.6 Unique Contribution of this Research

- This research study provides a contemporary insight into the needs, experiences and perspectives of parents in post-diagnostic training in an Irish context. Other research studies on this topic in the Irish context, such as Murphy and Tierney (2006) and McAleese et al., (2014) were conducted in a different setting and in a different disability resourcing climate than the current study. Given that resource shortages and waiting lists in ASD services in Ireland remain at a crisis level, it is vital that researchers continue to study the impact on children and their families in a real-life context.
- This research gives a voice to those parents who are currently involved in the ASD service. This research empowers parents by acknowledging their experiences, fears, suggestions, needs and perspectives.

- This research gathers contemporary data on one solution implemented by clinicians to meet parental demands by an ASD disability service. This research provides insight into what is working well and also identifies gaps in our stretched health service.
- This research highlights concerns around mental health and ASD, telling about the diagnosis and school staff's understanding of ASD. This research has identified a number of previously unidentified training needs for parents of children recently diagnosed with ASD. Previous research did not identify mental health information as a need for parents at post-diagnostic parent training, nor did previous research identify telling the child about the diagnosis as an information need at post-diagnostic parent training. These identified needs are part of this research's unique contribution to the body of evidence on post-diagnostic parent training.
- This research identified a concerning discrepancy between the training and development received by teachers of children with ASD, and the experiences of frustration and disappointment experienced by children and their parents in this study. This research found that parents reported that teachers required further training in the area of ASD, as they felt school staff lacked understanding of ASD and the challenges it presents.

6.7 Implications and Recommendations

6.7.1 Implications for Policy.

The conclusions of this study aim to inform future service provision and policy, in terms of meeting the needs of families as they see them. This will enable services to support parents of children with ASD in understanding, supporting and intervening for their child with ASD into adulthood.

- Parent training as an intervention strategy has a strong evidence-base, which is furthered by the current research. This research could be used to support the development of nation-wide parent training as a strategy to intervene for large numbers of children with ASD and their parents.
- In light of the development of new national policies and guidelines in relation to the assessment and intervention for ASD, the current research allows for the

voices of parents in this journey to be heard and incorporated in the development of future policy.

- Colleges of Education, as well as organisations offering professional development training to school staff, should seek to investigate the apparent discrepancy between parents’ reports of the need for further training for teachers in the area of ASD. Perhaps, the multi-disciplinary nature of the training provided, or the disability-specific experiences of the clinicians providing the training offers a different perspective on ASD that is not always available in training delivered from an education system perspective alone.

6.6.2 Implications for Practice.

- Educational psychologists are trained in consultation skills, and use their communication skills to engage and facilitate group interactions. With this in mind, educational psychologists are well placed to provide the support needed by parents following a diagnosis of ASD for their child.
- Parents requested a more complex level of information on ASD, in light of the information available to them through the internet, books and other media. Staged training programmes could be considered, whereby over the course of a four-week training programme, information begins at an introductory level and progresses to include more advanced theoretical input and strategies such as executive functioning, emotional regulation strategies and sensory processing. To support such an approach, training could be presented in a trans-disciplinary manner, rather than as separate, discipline-specific evenings.
- Parents sought greater interaction with parents and inclusion of their questions into the training programme. A more discursive approach to training, with smaller groups would support more interaction between clinicians and participants. Additionally, parents suggested sending in questions in advance to clinicians in order to have more input in course content and having their information needs addressed.
- Parents requested information that ranged from the generic to the specific. This format may be considered in future programme delivery.
- Parents may benefit from engaging in a longer training programme, six to twelve weeks, in line with the literature, rather than the four-week training offered in the current research project.

6.6.3 Recommendations for Future Research.

- As this study accessed a small sample from a single geographic catchment area, it would be beneficial to extend the study using a larger sample and to include a control group. Furthermore, the inclusion of a larger sample would allow for comparison across regions, demographics and a broader range of ethnicities.
- It would be beneficial to replicate a study of this type across a variety of geographic regions, or using a larger number of participants. Future studies, with a larger sample, could examine any potential sex differences in terms of the child or also in terms of the needs of mothers versus fathers.
- Further studies could also explore the use of a training programme of this nature with teachers and other school staff in order to investigate the needs, experiences and perspectives of school staff who work with children with ASD.
- Additionally, future studies could examine the needs identified this study in terms of mental health needs. To address the issue of the level of information provided in the study, data could be collected in relation to sources of information previously accessed by parents prior to post-diagnostic parent training.
- Given that the current research highlighted a paucity of research in the area of information and support in relation to telling one’s child, future research should address this area, in order to compile evidence-based, best practice guidelines for parents.

6.7 Dissemination of Research

Aspects of this research have been presented at the annual Psychological Society of Ireland conference in 2018. It is envisaged that the results of this study would be presented at the upcoming 2019 conference.

An empirical paper, based on the findings of the current research study, entitled “Capturing the Voices of Parents: The Self-Reported Needs of Parents following a Diagnosis of ASD”, has been compiled (Appendix O). This paper focuses on the needs identified by parents in the current study. This paper will be submitted to the academic journals “Research in Autism Spectrum Disorders” and “Autism”.

6.8 Conclusions

This study has provided an insight into the post-diagnostic needs, experiences and perspectives of parents of children with ASD who participate in parent training programmes. The voices of parents emerged through this study, highlighting unmet information needs, as well as citing valuable and positive aspects of their experiences. The perspectives of parents on participating in post-diagnostic training can offer clinicians and services with an insight into how to design and present programmes and information in a way that can support parents in meeting their self-identified needs.

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Appendices

Appendix A: Assumptions of Paradigms in Research

Post-Positivism	**Transformative**	**Pragmatism**	**Constructivism**
Causes most likely determine effects. Social world can be studied in much the same way as the natural world through empirical observation and measurement. Knowledge is conjectural; there is no absolute truth. Researchers in this paradigm do not set out to prove a hypothesis, but rather indicate a failure to reject the hypothesis (null hypothesis). Objectivity is important; measures of bias, validity and reliability are essential in this research. (J.W. Creswell, 2014; D. M. Mertens, 2015).	Multiple realities, contextualised by differing political, social or cultural experiences. One reality is privileged and another disempowered in some way. Engaged with politics and must drive a political change agenda to confront social injustices. Importance is placed on the lives and experiences of diverse and marginalised groups, especially in terms of how they have experienced oppression Collaborative. Linked to action and change (Bryman, 2015; Cohen et al., 2007; J.W. Creswell, 2014; Merriam, 2009; D. M. Mertens, 2015).	Focus on the research problem and its resolution through whatever means and approaches available and practicable. Choose methods, techniques and procedures which best meet their research needs. Methods are matched to particular research questions. Emphasis placed on the pursuit of knowledge and understanding above rigid methodological stances. Social, historical, cultural and political contexts impact upon research (Bryman, 2015; J.W. Creswell, 2014; D. M. Mertens, 2015; Patton, 1990).	Reality and knowledge are socially constructed in the research process. Attempt to understand experiences from the perspective of those who live it. Designed to describe, understand and interpret phenomena. Constructs a rich picture of what is happening and posit theories as to why this may be the case. Multiple realities, depending on context, experiences and perspectives. Multiple participants can experience different realities or meanings. Interactive relationship between researcher and participant through which meaning is made. (Bryman, 2015; Cohen et al., 2007; J.W. Creswell, 2014; Merriam, 2009; D. M. Mertens, 2015).

Appendix B: Detailed Summary of Material Covered in Post-Diagnostic Parent Training Programme.

This is a summary of the information provided by SERVICE. This information has been gathered from the information disseminated to parents by Multi-Disciplinary Professionals over four evenings. This document is a summary of information and strategies provided during this training.

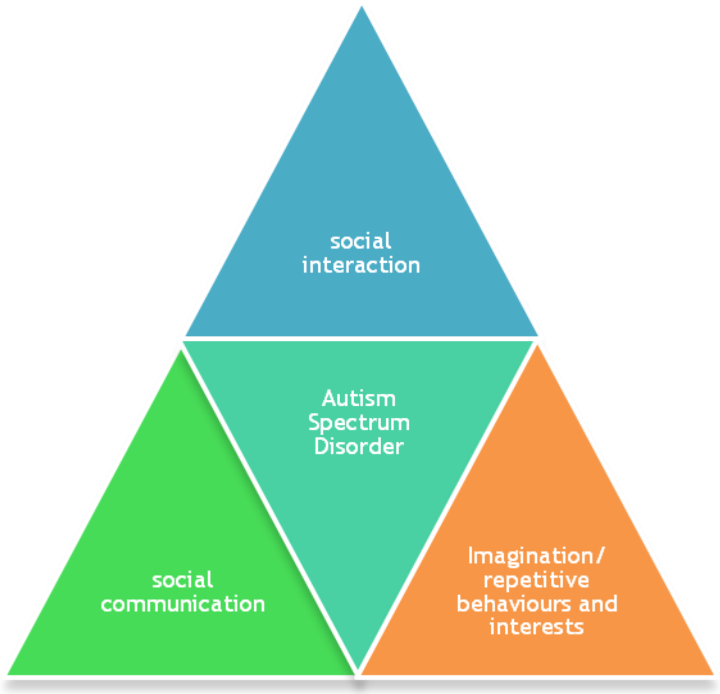
Who provides a service to children with ASD in my area?

If your child receives a diagnosis of an Autism Spectrum Disorder (ASD), he or she will receive services from the Autism Services. Depending on your child's needs you may be eligible for support from the following disciplines; speech and language therapists, psychologists, social workers, occupational therapists, home support workers and preschool therapists.

Currently, due to limited resources intervention for newly diagnosed children within the Autism Services is limited to a social work follow up visit, parents post diagnostic group, parent information sessions and parent drop in groups.

What is an Autism Spectrum Disorder?

Children with Autism Spectrum Disorders (ASD) are individuals whose condition tells us they share difficulties in three key areas: social communication, social interaction and social imagination. They may have emotional regulation difficulties, sensory issues, gross and fine motor difficulties, difficulty with attention and concentration, and they may present with repetitive, routine and stereotypical behaviours. Some of these challenges may lead to anxiety for some children.



An Autism Spectrum Disorder is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It is a spectrum condition, which means that, while all people with autism share certain traits/characteristics. Some people may have accompanying learning difficulties or intellectual disability.

There are two main “systems” of classifying autism spectrum disorders. The two systems are DSM V and ICD-10.

Children with Autism Spectrum Disorder (ASD) will not all present with the exact same characteristics, but will have key differences/difficulties in the following three areas:

Social Interaction differences/challenges may include:

Making friends

Turn taking

Eye contact

Sharing

Understanding “hidden rules”- e.g. personal space

Understanding what others are thinking and feeling – Theory of Mind

Social Communication differences/challenges may include:

Language Difficulties

Tone of voice

Volume

Body language – including gestures

Eye contact

Facial expressions

Conversation skills- e.g. starting, staying on topic, asking and commenting on what you said, finishing the conversation

Social Imagination differences/challenges may include:

Black and white thinking

Perseverance to complete a task

Focussed attention on minute details

Very interested in particular topics

Perfectionistic

Insistence on adhering to the same routines

Difficulty coping with transitions (e.g. to new places or new people etc.)

Difficulty coping with change in their environments (e.g. new clothes, new teacher, new furniture, new car etc.)

Repetitive behaviours

Repetitive play – playing with toys in the exact same way every day.

Speech & Language Therapy

Speech & Language Therapists (SLT) work with all aspects of a child's communication, including:

Understanding of language, sign language or pictures/symbols

Expression of language, sign language or pictures/symbols

Speech sounds

Feeding, Eating, Drinking and Swallowing (FEDS) difficulties

SLT also works on supporting the individual's social communication, social interaction and inflexibility of thinking. This includes:

When to talk & how to know whose turn it is to talk (Social Communication)

Taking turns/sharing/making friends/understanding 'hidden' rules (Social Interaction)

What other people are thinking and feeling (Social Imagination & Flexibility)

Effective communication happens when we have a means, a reason & an opportunity to communicate. Individuals with Autism Spectrum Disorders (ASD) can have difficulties in any of these areas & SLTs aim to help you and your child maximise their potential to communicate.

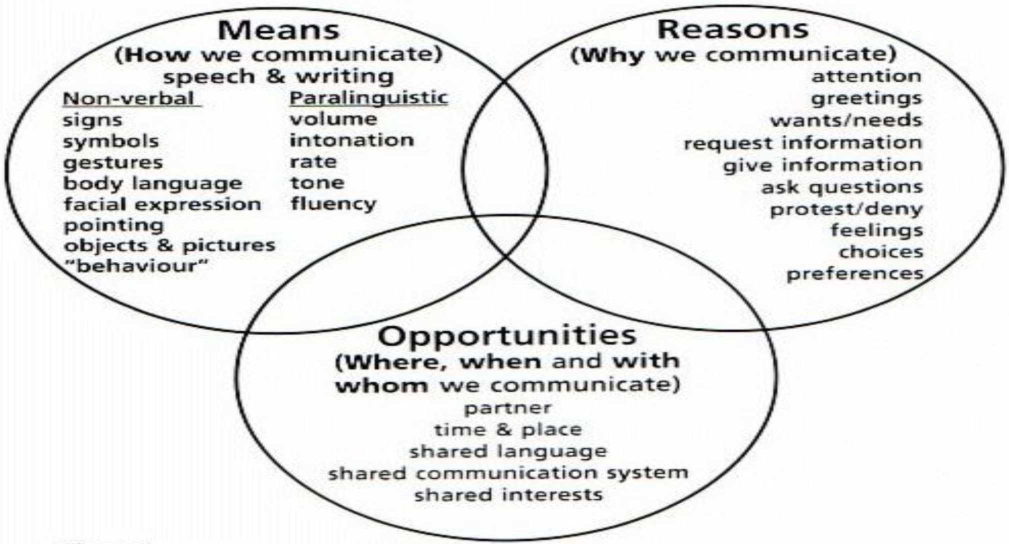


Figure 1
Means, Reasons and Opportunities: The original model

The SLTs in Autism Services promote the philosophy of the early communication experts, The Hanen Centre. Some communication strategies include:

Say Less: fewer words, shorter sentences

Stress: exaggerate facial expressions, gestures and actions. Repeat

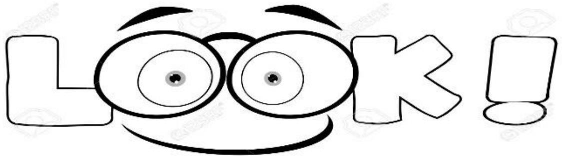
Go Slow: slow down your speech and actions; keep your expression on your face longer

Show: point, action songs, pictures, gestures, facial expressions

ALSO, the "tuning in" approach, which talks about the stages children go through when learning how to become more aware of other people's thoughts and feelings.

We also promote the Elklan philosophy for further language development. These are key strategies to support communication and interaction. (See attached 'Elklan Traffic Light Poster')

Visuals are pictures, photos, symbols, written text, real objects, etc. They can be ANYTHING to help an individual understand & become independent!



Visuals can be used to:

Make choices

Understand what is happening today (first/then; part day schedule; calendar

Learn a skill (like make a sandwich, or brush their own teeth)

Prepare for a change or new situation

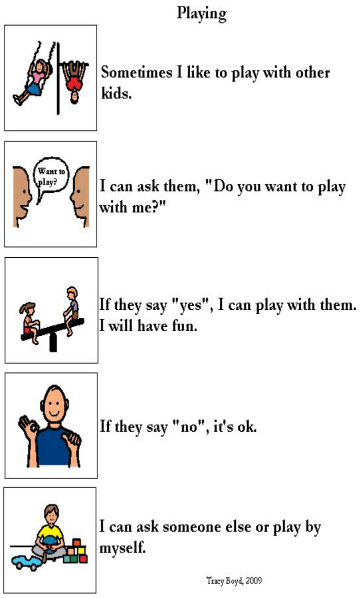
Some children need other types of communication systems that will help reduce their frustration, promote their independence and speech development.

Lámh is a simplified sign language which is used with speech to help young or non-verbal individuals to understand and request

PECS (Picture Exchange Communication System) is a picture system which children can use to request what they want

Social Stories & Comic Strip Conversations are extremely useful strategies to help children understand social situations.

Social Stories/Social Articles are used to explain social behaviours or situations which are sometimes difficult for children/teenagers with ASD to understand, as they don't know what to do. Social Stories can help them understand what might happen, or review something which did happen.



Playing

Sometimes I like to play with other kids.

I can ask them, "Do you want to play with me?"

If they say "yes", I can play with them. I will have fun.

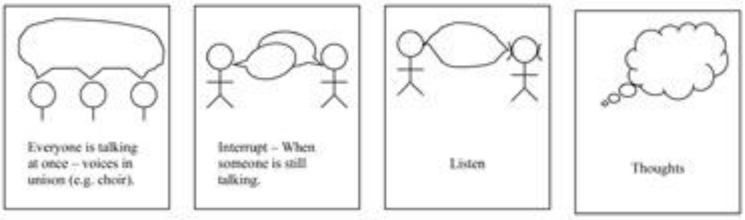
If they say "no", it's ok.

I can ask someone else or play by myself.

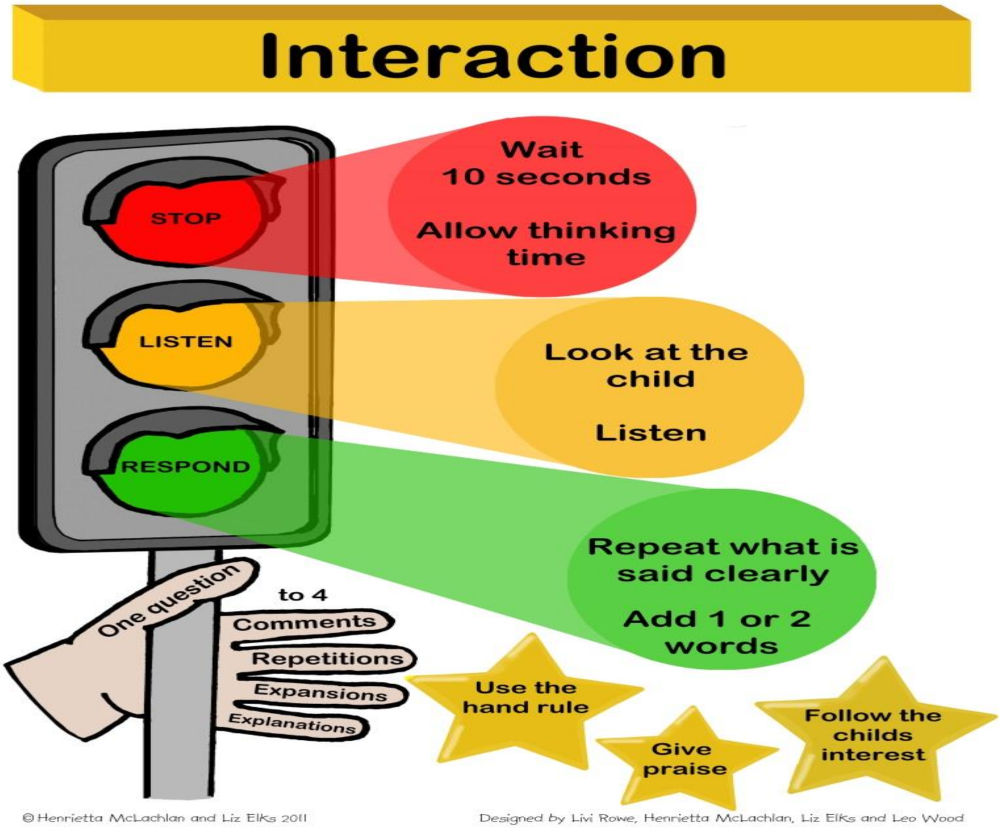
Tracy Boyd, 2009

Social Articles are more appropriate for older students.

Comic Strip Conversations are used to explain visually a specific, recent situation in terms of what people are thinking and saying in a particular incident.



One of the main intervention modes for speech and Language Therapy is through parent groups, where parents are enabled to support their children's communication and social interaction skills. This follows international best practice recommendations for language and communication in a natural setting. The Hanen parent courses: More Than Words and/or TalkAbility are recommended parents training groups.



The hand rule is: Don’t just ask questions; <u>for every question you ask, you need to</u>:

Comment on what your child says or

Interpret and repeat what your child says or

Expand what your child says or

Explain

For example: …If you asked, “What did you eat at Nana’s?” You may get a 1-word answer, “Pizza”

(Old way: next question: then what did you do?, often followed by question after question!)

New Way:

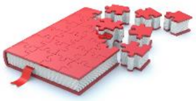
Repetition: You ate pizza, oh, that's nice….……….   and WAIT... or

Comment: Oh, that's my favourite….……..   and WAIT… or

Expansion: You ate pizza, but I bet Granda didn't!.……. and WAIT… or

Explanation: Nana makes really good pizza because she's Italian…… and WAIT!!!

References & Useful Resources



Elklan: www.elklan.co.uk

Hanen: www.hanen.org

Lamh: www.lamh.org

Picture Exchange Communication System: www.pecs.co.uk

Social Stories and Comic Strip Conversations:

www.carolgraysocialstories.com

Occupational Therapy

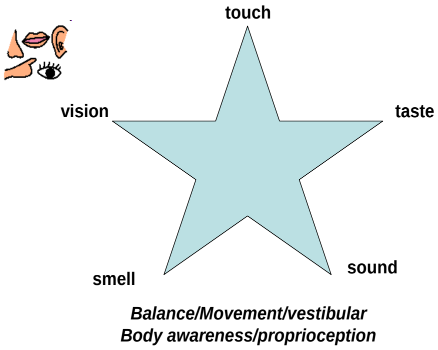
Occupational Therapy is an intervention approach that helps children do what they need to do in their day to day activities (independence skills, academic skills and play skills) at home, school etc.

What is Sensory Processing?

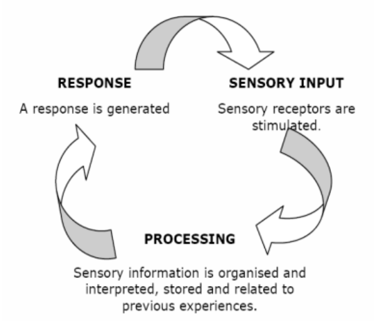
Sensory processing is the continuous flow of information through sensory systems to the brain. Sensory information is filtered, sorted and prioritised to inform us about our body and environment.

We all process information differently, some of us are more sensitive to certain type of sensory input and some of us crave certain type of sensory input. This is normal! It is only a problem if it prevents us or impairs our ability to take part in activities we need to do every day, then sensory processing difficulties or dysfunction occurs!!

Our Senses



Sensory Integration/Processing



Proprioception: This is the body awareness sense; it provides input to the muscles and joints. Some children seek out proprioceptive input and love crashing and banging into furniture and chewing on non-food items. Children who have difficulty in processing this type of sensory input may also have difficulty gauging how much force to apply when kicking or throwing a ball or interacting with other functional objects like how much pressure to place on a pencil.

Vestibular: This is the sensory system that responds to changes in head and body movement through space and that coordinates movements of the eyes, head, and body. Receptor site is in the inner ear. Vestibular sensory processing has a big part to play in keeping your balance and carrying out movement. Children who seek out this type of sensory input may enjoy twirling around excessively and need much more movement than their peers to feel regulated.

Some sensory systems may need lots of sensory input. (Sensory Seeking)

Some sensory systems can only tolerate a small amount of sensory input. (Sensory Sensitivity)

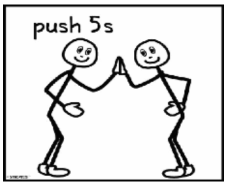
Reminder of Some Useful Strategies

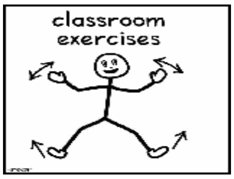
Consider what behaviours you see???

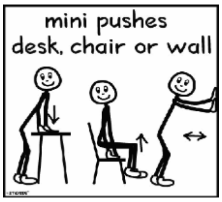
Are you removing sensory input from a specific sensory system?

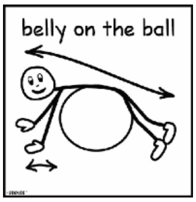
Or

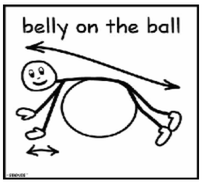
Are you adding sensory input to a particular sensory system?

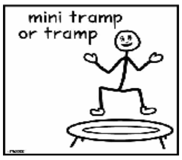












Independence Skills

Visual schedules can support the structuring and sequencing of tasks by breaking down desired tasks into discrete steps (task analysis), reducing the pressure on an individual to remember each step and allowing them focus their attention and ability on completion of steps rather than the sequence. They also provide a visual prompt or guide as how to complete specific steps in a task (e.g. dressing, toileting, showering teth brushing etc or helping a child/teenager to be more organised).

Visuals should be located in the areas where they will be used, e.g. visual for teeth brushing should be in the bathroom, visuals for dressing should be in the bedroom etc. Checklist for school attached to a child's school bag.

Visuals should be concise and to the point.

Visuals may be pictures, photos of the child completing the steps, stick images, words & images or just words.

See below example of visuals that can be used to help increase Independence

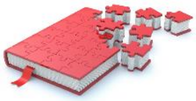
<u>School Organisation can be supported by:</u>

Colour code books and copies according to subjects by firstly deciding on a colour system for each subject and then placing a sticker or strip of this colour on the spine and front of all books and copies for this subject.

Using plastic folders where all the books and copies associated with a subject are in one folder, again of a specific colour.

Create a checklist that can be laminated, and a key ring attached that the child/teenager can attach to the outside of their school bag to highlight items he/she needs to bring to school or bring home from school.

References & Useful Resources



Equipment

www.thinkingtoys.ie

www.sensationalkids.ie

www.disabilityaids.ie

Books

Building Bridges through Sensory Integration, Second Edition [Ellen Yack, Paula Aquilla, Shirley Sutton]

The Out-of-Sync Child [Carol Kranowitz, Lucy Jane Miller]

Sensational Kids: Hope and Help for Children With Sensory Processing Disorder (SPD) by Lucy Jane Miller

Can't Eat, Won't Eat: Dietary Difficulties and Autistic Spectrum Disorders by Brenda Legge

Websites

www.southleeasd.wordpress.com

http://www.spdfoundation.net

See tips on support children who are picky eaters here

http://www.sensory-processing-disorder.com/

http://www.sensoryintegration.org.uk/parents-corner

www.ncse.ie

Psychology

Psychology addresses the child’s emotional, behavioural and developmental difficulties in the variety of environments that they participate in.

Emotional awareness – is your child able to communicate about the emotion that they are experiencing?

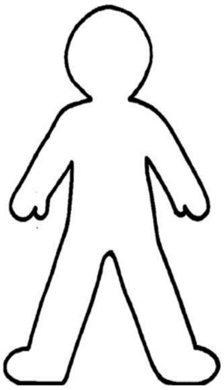
Some practical strategies for developing emotional awareness include:

Modelling emotions for your child e.g. modelling and naming facial expressions

Using a mirror to identify or name emotions

Visual supports and specific programmes can be used e.g. body outlines, Zones of Regulation.

When helping your child to develop emotional awareness it is important to validate what they are feeling. Remind your child that it is okay to be angry or upset, that everyone feels this way. What is important is how you act when you are experiencing these emotions.



The ZONES of Regulation®

BLUE ZONE	GREEN ZONE	YELLOW ZONE	RED ZONE
Sad Sick Tired Bored Moving Slowly	Happy Calm Feeling Okay Focused Ready to Learn	Frustrated Worried Silly/Wiggly Excited Loss of Some Control	Mad/Angry Mean Terrified Yelling/Hitting Out of Control

Emotional regulation – is your child able to regulate their emotions and manage distress in an age-appropriate way?

Some practical strategies for helping your child to manage their emotions:

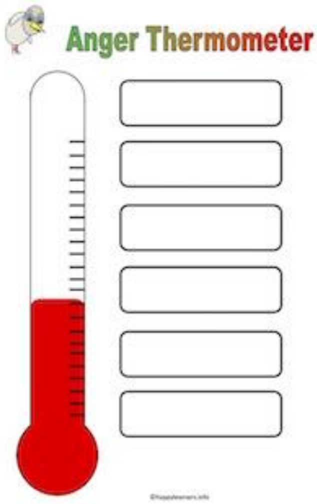
Every child is unique and strategies that work for one will not necessarily work for another. Try to find out what helps your child to calm down and relax.

Encourage your child to contribute to and agree to a plan in order to help them regulate their emotions.

Visual aids such as body outlines, anger thermometers and the ‘Incredible Five Point Scale’ can be used. These can help your child to identify when they need to take action.

Use reward or praise when your child chooses a positive or appropriate action when distressed, for example, when they go to their room when feeling overwhelmed.

It can be important to plan for times of distress in advance. Have visual aids and strategies prepared for your child to use if needed.



Pre-emptive strategies

There are a number of strategies that you can use regularly in order to prevent or reduce the chances of difficult to manage behaviour developing:

Communication – Use clear verbal communication with your child. Reduce language during times of distress. Use visuals to support communication. Social Stories$^{\text{TM}}$ and Comic Strip conversations can help your child understand difficult social situations or see things from the perspectives of others.

Structure and boundaries – Try to establish clear boundaries for your child. Reduce uncertainty using a visual schedule or giving your child a written copy of the plan. Younger children will benefit from using ‘First’ and ‘Then’. If you have promised that you will do something try to follow through on that promise.

Choice – Where possible, give your child a choice. This will provide them with a sense of control in difficult to manage situations. Try to limit choices if you can, for example, encourage your child to choose between A or B rather than make an open-ended choice. For children who struggle to make choices, encourage them to practice between choosing between something that they really want and something that they do not.

Praise and reward - Encourage positive and appropriate behaviours through the use of praise and reward. Be specific in your praise e.g. “Good listening”, “I liked the way you said thank you to your teacher”. If using rewards make sure that your child knows exactly what they have to do in order to get the reward.

Encourage positive behaviour – Tell your child what to do, not what not to do. An example of this is saying “Quiet hands” instead of “Stop hitting the table”.

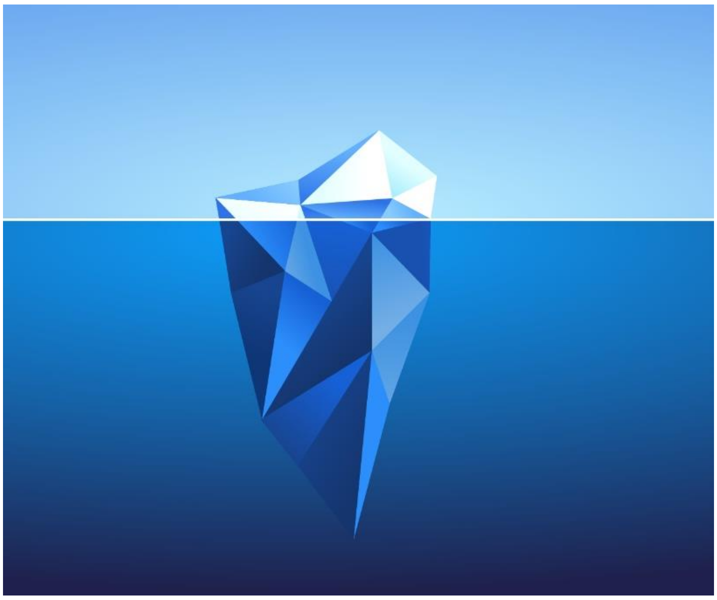
Behaviour

Behaviour does not occur in a vacuum

All behaviour is FUNCTIONAL. It occurs for a reason or a purpose

When a person with ASD behaves in a way that challenges others, it is very important to try and understand WHY

The Iceberg Method can be a useful way of analysing your child’s behaviour.



← What is the behaviour?

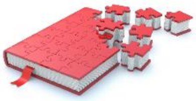
← Why is it happening?

Some tips

When you are trying to define what the behaviour is, be as specific and as detailed as possible.

When considering why the behaviour might be happening, remember to refer to the Triad of impairments. Think of situations and challenges that children with a diagnosis of ASD may find difficult.

Don’t forget to consider other factors such as tiredness or medical issues.



References & Useful Resources

The National Autistic Society (NAS) website

www.autism.org.uk

Excellent website with lots of information around ASD including explanation of diagnosis and strategies for intervention as well as advocacy

Middletown Autism Website

https://www.middletownautism.com/

Information on Free Training Courses for Parents and Professionals

Do2Learn Website

https://www.do2learn.com/

Educational printable resources, e.g. picture schedules, songs and games

The Zones of Regulation – Leah M. Kuypers

www.zonesofregulation.com

Emotional awareness and regulation curriculum

The Incredible 5-Point Scale – Kari Dunn Buron

www.5pointscale.com

Strategy for identifying and regulating emotions

Social Work

Social work offers practical and emotional support to families during their journey with ASD.

When a child receives a diagnosis of Autistic Spectrum Disorder it can be an emotional and uncertain time for his or her parents. The Social Work role is to support you and your family, to explain Autism and the impact on family members including siblings, to listen to concerns expressed and to offer information regarding community, social and educational supports. The social worker will also provide information on what you may be entitled to.

Parental Entitlements

You may be entitled to some of the following:

Domiciliary Care Allowance

Domiciliary Care Allowance is a monthly payment for a severely disabled child who is under age 16 and needs full-time care and attention far beyond what is normally required by a child of the same ages. The payment is not based on the type of disability but on the resulting physical or mental impairment which means that your child needs more care and attention than a child of the same age.

Carer’s Allowance

Carer's Allowance is a means-tested payment for carers who look after certain people in need of full-time care and attention on a full-time basis. If you are in receipt of another social welfare payment and you are providing someone with full time care and attention you may qualify for a reduced rate of carer’s allowance in addition to your original payment.

Carers Benefit

Carer's Benefit is a payment for people who have made social insurance contributions and who have recently left the workforce or have reduced their hours of work to 15 hours per week or less and are looking after somebody in need of full-time care and attention. You can get Carer’s Benefit for a total of 2 years for each person being cared for. You may be eligible for carer’s leave.

Carer’s Support Grant

The Carer’s Support Grant is an annual payment for full-time carers who look after certain people in need of full-time care and attention. The payment is made regardless of the carer's means but is subject to certain conditions

Disability Allowance

Disability Allowance is a weekly allowance for people with a disability aged between 16 and 66. Your disability must be expected to last for at least one year. You must pass a medical exam, a means test and be habitually resident in Ireland to get the allowance.

Incapacitated Child Tax Credit

The tax credit can be claimed where a claimant proves that he or she has living with them, at any time during the tax year, any child who is permanently incapacitated either physically or mentally from maintaining himself/herself.

Medical Expenses rebate

Med 1 Form.

Home Tuition Grant

Home tuition is intended to provide education for children with a clear diagnosis of Autistic Spectrum Disorder who have a significant special educational need and who are awaiting the provision of an appropriate school based educational service. The form can be downloaded from www.education.ie.

Details and qualifications of teacher must be included in the application form. This may be submitted with the home tuition application or directly to the Home Tuition Section, Special Education, indicating the name of the child to whom he/she will be delivering home tuition. Sanction of Home Tuition will only be given when full details of the proposed teacher are provided to the Department of Education and Science and the application has been fully completed.

Copies of recent professional reports should be attached.

Home Tuition is sanctioned on a term basis only/or until a school placement has been sourced (arrangements should not be entered into with teachers in anticipation of funding beyond the sanction date unless Department of Education & Science sanction has been received). Retrospective Grant Claim Forms will not be processed.

July Provision

This scheme provides funding for an extended school year for children with a severe or profound general learning disability or children with an Autism Spectrum Disorder (ASD). The extended year is more commonly known as July Provision or the July Education Programme. Where school-based provision is not feasible, home based provision may be granted.

Children on the Autism Spectrum are eligible for a maximum of 40 hours tuition (or 10 hours per week over 4 weeks) in the month of July.

The school year of participating schools is extended by four weeks for eligible pupils and pupils with an ASD in mainstream classes in receipt of resource support are also eligible for home-based July

References & Useful Resources

Websites

www.revenue.ie

www.welfare.ie

http://www.citizensinformationboard.ie/en/

www.education.ie

Appendix C: Example Clinician Description of Training Programme

Role/Discipline: Psychology

Number of training sessions to be given: 2 (one for under 9 cohort; one for over 9)

Topics to be covered (Please list):

- Psychoeducation around ASD
- Developing understanding of emotions
- Strategies to promote emotional regulation
- Iceberg analogy for understanding behaviour

Structure of sessions (e.g. Opening activity, group work etc. and how much time spent on each part):

- Information sharing around the aforementioned topics – hour
- Groupwork around iceberg analogy – 30 minutes
- Group discussion – 30 minutes

Materials/Resources:

- Positive Parenting Strategies E.g. Incredible Years, Parents Plus
- The Zones of Regulation – Leah M. Kuypers
  www.zonesofregulation.com
- The Incredible 5-Point Scale – Kari Dunn Buron
  www.5pointscale.com
- The National Autistic Society (NAS) website
  www.autism.org.uk
- ASD evidence-based strategies e.g. visuals, clear communication
- SCERTS by Barry Prizant

Evidence/Research Base for information provided to parents:

- Carol Gray
- SCERTS
- Incredible Years
- Parents Plus

Clinician:		**Discipline:**	**Educational Psychologist**
Clinician:		**Discipline:**	**Senior Educational Psychologist**
Clinician:		**Discipline:**	**Clinical Psychologist**

Item 1: Name	***Please provide a brief name or phrase that describes the intervention:*** **Parents Post-Diagnostic Group**
Item 2: Why?	*Please describe any rationale, theory or goal of the elements essential to this intervention.* **We know from the research that equipping parents with the appropriate knowledge during the first-year post diagnostic is crucial to the acceptance of the diagnosis and positive outcomes for the young person.**
Item 3: What (materials)?	*Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery. Please provide information on where the materials can be accessed (if possible).* **See resources emailed. A booklet was made available (seek from coordinator of group); resources recommended; flipchart paper; iceberg sheets.**
Item 4: What (procedures)?	*Describe each of the procedures, activities and/or processes used in the intervention.* **The procedures included a combination of information giving through psychoeducation and group work.** **We analysed ‘behaviour’ or dysregulation through the iceberg analogy using group work.** **The coffee break facilitates conversation among parents who have recently experienced a similar thing.**
Item 5: Who provided?	*For each category of intervention provider, please describe their expertise, background and any specific training given.* **2X Educational Psychologists** **1x Clinical Psychologist** **All working in ASD / ID.**
Item 6: How?	*Describe the modes of delivery e.g. face to face, individually vs. group?* **Face to face group presentation.**

Item 1: Name	***Please provide a brief name or phrase that describes the intervention:*** **Parents Post-Diagnostic Group**
Item 7: Where?	*Describe the type of location where the intervention occurred, including any necessary infrastructure or relevant features.* **Family resource centre.**
Item 8: When and How much?	*Describe the frequency of the intervention and over what period, including the number of session, and their duration.* **5 nights in total. 1X 2 hour from psychology.**
Item 9: Tailoring	*If the intervention was planned to be personalised or tailored for the needs of participants, please describe what, when, and how.* **By the age of the children (grouped as under and over 9s)** **By recency of the diagnosis.** **All parents** **By behavioural issues that arose.**
Item 10: Modifications	*If the intervention was modified during the training, describe the changes (what, when, why, and how).* **n/a**
Item 11: How well (planned)?	*If any strategies to maintain or improve fidelity are used, please describe them.* **Reflective practice** **Evaluation sheets**
Item 12: How well (actual)?	*Describe the extent to which the intervention was delivered as planned.* **It was delivered as planned although time was a challenge.**

Appendix D: Pre-Training Questionnaire

Question	**Descriptor**						
How would you rate your knowledge of Autism Spectrum Disorder (ASD)?	0 None	1 Very Little	2 I know a little	3 Not sure	4 Good	5 Very Good	6 Excellent
How well do you feel you understand what ASD is?	0 None	1 Very Little	2 I know a little	3 Not sure	4 Good	5 Very Good	6 Excellent
How would you rate your skills in managing your child's needs?	0 None	1 Very Little	2 I know a little	3 Not sure	4 Good	5 Very Good	6 Excellent
How confident do you feel in supporting your child with ASD?	0 Not at all	1 A little	2 Some	3 Moderate	4 Fairly	5 Very	6 Extremely
How often do you communicate with other parents of children with autism?	0 Not at all	1 Rarely	2 Sometimes	3 Every few months	4 Monthly	5 Weekly	6 Daily
How difficult do you find it personally to manage your child's challenging behaviours?	0 Not at all	1 A little	2 Some	3 Moderately	4 Fairly	5 Very	6 Extremely

Question	**Descriptor**						
How confident are you in dealing with your child's behaviour?	0 Not at all	1 A little	2 Some	3 Moderately	4 Fairly	5 Very	6 Extremely
To what extent do you feel in control of parenting your child with ASD?	0 Not at all	1 A little	2 Some	3 Moderately	4 Fairly	5 Very	6 Extremely
Do you find it difficult to communicate with your child with ASD?	0 Not at all	1 A little	2 Some	3 Moderately	4 Fairly	5 Very	6 Extremely
How confident do you feel in meeting your child's intervention needs?	0 Not at all	1 A little	2 Some	3 Moderately	4 Fairly	5 Very	6 Extremely

What are your expectations of this training course?

____

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____

__________________Please list your three top priorities for this training:

1. ____
____

2. ____
____

3. ____
____

Appendix E: Post-Training Questionnaire

Question	Descriptor						
How would you rate your knowledge of Autism Spectrum Disorder (ASD)?	0 None	1 Very Little	2 I know a little	3 Not sure	4 Good	5 Very Good	6 Excellent
How well do you feel you understand what ASD is?	0 None	1 Very Little	2 I know a little	3 Not sure	4 Good	5 Very Good	6 Excellent
How would you rate your skills in managing your child's needs?	0 None	1 Very Little	2 I know a little	3 Not sure	4 Good	5 Very Good	6 Excellent
How confident do you feel in supporting your child with ASD?	0 Not at all	1 A little	2 Some	3 Moderate	4 Fairly	5 Very	6 Extremely
How often do you communicate with other parents of children with autism?	0 Not at all	1 Rarely	2 Sometimes	3 Every few months	4 Monthly	5 Weekly	6 Daily
How difficult do you find it personally to manage your child's challenging behaviours?	0 Not at all	1 A little	2 Some	3 Moderately	4 Fairly	5 Very	6 Extremely

Question	Descriptor						
How confident are you in dealing with your child’s challenging behaviours?	0 Not at all	1 A little	2 Some	3 Moderately	4 Fairly	5 Very	6 Extremely
To what extent do you feel in control of parenting your child with ASD?	0 Not at all	1 A little	2 Some	3 Moderately	4 Fairly	5 Very	6 Extremely
How difficult do you find it to communicate with your child with ASD?	0 Not at all	1 A little	2 Some	3 Moderately	4 Fairly	5 Very	6 Extremely
How confident do you feel in meeting your child’s intervention needs?	0 Not at all	1 A little	2 Some	3 Moderately	4 Fairly	5 Very	6 Extremely

What parts of the training programme (if any) did you find the most useful?

____

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Why?

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What parts of the training programme did you find the least useful?

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Why?____

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What changes (if any) would you like to see?

____

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How satisfied were you with the training programme overall?

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How “easy to understand” was the information?

____

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____

What changes would you like to see to future post-diagnostic parent training?

____

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____

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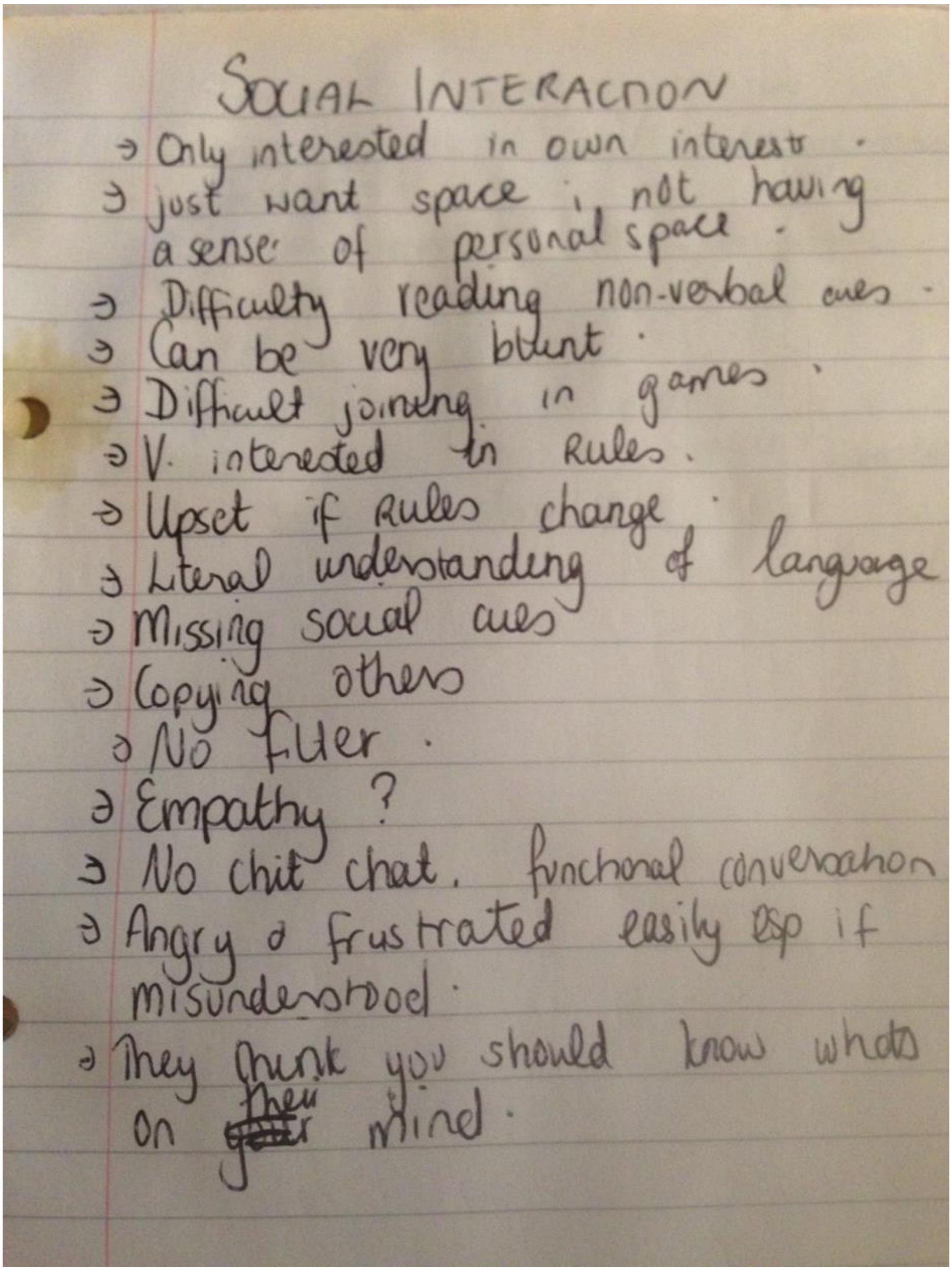
Appendix F: Semi-Structured Interview Prompt Questions

Interview Prompt Questions

1. Can you tell me about how you felt on the first night of training?
2. What were your expectations of the training?
3. Can you tell me about your child?
4. What are your priority learning needs?
5. Has anything changed for you since taking part?
6. Were there any positives to taking part in the training?
7. Were there any negatives to taking part?
8. What would you change about the training?
9. Did anything about the training surprise you?

Appendix G: Sample of Researcher Observations



SOCIAL INTERACTION

- → Only interested in own interests.
- → just want space, not having a sense of personal space.
- → Difficulty reading non-verbal cues.
- → Can be very blunt.
- → Difficult joining in games.
- → V. interested in Rules.
- → Upset if Rules change.
- → Literal understanding of language
- → Missing social cues
- → Copying others
- → No filter.
- → Empathy ?
- → No chit chat. functional conversation
- → Angry & frustrated easily esp if misunderstood.
- → They think you should know whats on ~~your~~ their mind.

Appendix H: Overview of Training from Clinicians' Descriptions

Discipline	Topics Covered	Strategies/ Methodology
Social Work 2 hours 30 min	Welcome to training Explanation of format Explanation of service structure and current resourcing situation Overview of ASD Parent Testimony	Whole group Lecture Style Small group work to brainstorm "What autism looks like in my child"; everyone returned to large group to feedback. Break Parent of two children with autism, spoke to group for 1 hour & 15 min with time for Q & A; covered her diagnostic experiences, taking part in training; her family's experience of education system and accessing services.
Occupational Therapy 2 hours 30 min	What is autism? What is Occupational Therapy? Sensory Processing & practical strategies Sensory regulation Motor Coordination and planning Backward Chaining and Task Analysis Practical strategies for home	Grouped into Over 9 years for one session & Under 9 years for one session Large group presentation; opportunities to ask questions throughout Practical activities: demonstration of vestibular and proprioceptive senses (parents active); demonstration of "blue breaks"/movement breaks for children (parents active) Demonstration of equipment e.g. move'n'sit cushion, fidgets, theraputty, theraband
Speech and Language Therapy 2 hours 30 min	What is Speech and Language Therapy? Effective Communication Communication Strategies & Communication Systems Social Stories Comic Strip Conversations Social interaction strategies	Grouped into Over 9 years for one session & Under 9 years for one session Large group presentation No opportunity for questions No group work

Discipline	Topics Covered	Strategies/ Methodology
Psychology (Clinical Psychologist and Educational Psychologist) 2 hours 30 min	What is autism? Triad of Impairments Explanation of Spectrum Theory of Mind Executive Function Emotional Regulation Sensory Processing and Behaviour Behaviour as Communication (Antecedent, Behaviour, Consequences) Problem Solving for Behaviour Positives of autism	Grouped into Over 9 years for one session & Under 9 years for one session Large group presentation; Group work to brainstorm “My Child and the Triad” Group work to brainstorm behaviour using Iceberg Method Some Q&A but ran out of time

Appendix I: Participant Consent Form

Informed Consent Form

(Please tick boxes to indicate that you agree)

- I have read and understood the Participant Information Sheet. ☐
- I understand what the research is about. ☐
- I know that my participation is voluntary and that I can withdraw from the project at any stage without giving any reason and without consequence. ☐
- I am aware that my results will be kept confidential. ☐
- I have read this form completely and am happy to take part in this study. ☐

Signed: ___________________________________ Date: ____________________

Appendix J: Thematic Analysis Procedure

Six Phases of Thematic Analysis (Braun & Clarke, 2006)
Phase One *Familiarisation with the data*: is common to all forms of qualitative analysis – the researcher must immerse themselves in, and become intimately familiar with, their data; reading and re-reading the data (and listening to audio-recorded data at least once, if relevant) and noting any initial analytic observations. **Phase Two *Coding:*** This involves generating pithy labels for important features of the data of relevance to the (broad) research question guiding the analysis. Coding is not simply a method of data reduction, it is also an analytic process, so codes capture both a semantic and conceptual reading of the data. The researcher codes every data item and ends this phase by collating all their codes and relevant data extracts. **Phase Three *Searching for Themes:*** : A theme is a coherent and meaningful pattern in the data relevant to the research question. This ‘searching’ is an active process; themes are not hidden in the data waiting to be discovered, rather the researcher constructs themes. The researcher ends this phase by collating all the coded data relevant to each theme. **Phase Four *Reviewing Themes:*** Involves checking that the themes ‘work’ in relation to both the coded extracts and the full data-set. The researcher should reflect on whether the themes tell a convincing and compelling story about the data, and begin to define the nature of each individual theme, and the relationship between the themes. **Phase Five *Defining and Naming Themes:*** Requires the researcher to conduct and write a detailed analysis of each theme, identifying the ‘essence’ of each theme and constructing a concise, punchy and informative name for each theme. **Phase Six *Writing Up:*** Weaving together the analytic narrative and data extracts to tell the reader a coherent and persuasive story about the data, and contextualising it in relation to existing literature.

Appendix K: Sample of Coded Transcript

Thematic Analysis of Open-Ended Questions:

Pre-Training Questionnaire:

What are your expectations of this training course?

To gain confidence and better understanding of my child's needs. To help me focus on this child alone, away from the distractions of family life. (5)

More understanding in how my son thinks and looks at the world. (7.5)

Just some guidance-I feel lost and as if the weight of the world on my shoulders (4.5)

Hoping to learn some things I can do to support my son now; also, what public and private supports are out there; meet and learn from other parents, particularly those further along in journey (7)

Meet parents in a similar situation; learn more; get help/tips etc. (7)

To gain some knowledge and understand potential hurdles and difficulties that may lie ahead (3)

I hope to learn techniques to help my daughter (6)

To hear about autism and how to manage my child's needs while dealing with everyday life when viewed through his eyes (7)

Commented [EMC1]: Confidence

Commented [EMC2]: Understanding

Commented [EMC3]: Child's needs

Commented [EMC4]: Child's needs

Commented [EMC5]: Child's world view

Commented [EMC6]: Need for guidance/support

Commented [EMC7]: Feelings of parent

Commented [EMC8]: Child's needs

Commented [EMC9]: Available supports/Services

Commented [EMC10]: Other Parents

Commented [EMC11]: Other parents

Commented [EMC12]: Knowledge/information

Commented [EMC13]: Practical tips

Commented [EMC14]: Knowledge/information

Commented [EMC15]: Future

Commented [EMC16]: Practical tips

Commented [EMC17]: knowledge

Commented [EMC18]: child's needs

Commented [EMC19]: child's worldview

Aid me in giving better help and guidance to my child; help me to develop some of the tools I have; better understanding of autism; (4)

Provide more knowledge about autism; provide guidance on how to assist my child; to provide information on assistance providers (3)

I have completed a lot of the Middletown training so I expect this to be fairly similar, I just hope that I can pick up some practical tips (6)

Not sure (7)

More general information on autism (10)

More understanding of autism (8)

I don't have any (6)

Getting more information; hearing other parents' different situations (8)

To gain an understanding of my son's needs and behaviour (4)

Better understanding of the issues my daughter is encountering (6)

To access information to enable me to deal with my child's difficulties; facilitate my learning; meet people that can give me support going forward (6)

Gain deeper understanding of autism spectrum and get skills and knowledge to support my daughter; understand how I can help to maximise her potential and guide her into adulthood (14)

Commented [EMC20]: guidance/support

Commented [EMC21]: knowledge/information

Commented [EMC22]: understanding

Commented [EMC23]: knowledge/information

Commented [EMC24]: guidance/support

Commented [EMC25]: available supports/services

Commented [EMC26]: practical tips

Commented [EMC27]: knowledge/information

Commented [EMC28]: understanding

Commented [EMC29]: knowledge/info

Commented [EMC30]: learning from other parents

Commented [EMC31]: child's needs

Commented [EMC32]: knowledge/info

Commented [EMC33]: child's needs

Commented [EMC34]: information

Commented [EMC35]: guidance/support

Commented [EMC36]: understanding

Commented [EMC37]: information

Commented [EMC38]: future

To learn more about her needs and how to help her progress to the best of her ability; keeping her wellbeing at the forefront and also to help me to understand her better (14)

To find out ways to help the situation more positive and learn coping skills and strategies to help her move forward at a good pace and feel good about herself and learn ways to tell her that she has the diagnosis (11)

Understanding of “normal”; meet other parents (17)

No expectations (10)

I hope to understand my child’s needs a bit better to be able to see the world from his perspective; making contacts with parents of a child the same age as mine; sharing of ideas and strategies to cope (17)

To learn more from professionals; also, to learn from other parents (10)

More knowledge; meeting new people (10)

Knowledge on how to calm my son when he is having a meltdown; to help him accept that he has autism and not think of it as a negative; to teach his siblings how to detach themselves when he is getting awkward and not to take it so personally (9)

None (12)

Commented [EMC39]: child’s needs

Commented [EMC40]: wellbeing/mental health

Commented [EMC41]: understanding

Commented [EMC42]: coping

Commented [EMC43]: practical tips

Commented [EMC44]: wellbeing/mental health

Commented [EMC45]: telling about the diagnosis

Commented [EMC46]: understanding

Commented [EMC47]: other parents

Commented [EMC48]: child’s needs

Commented [EMC49]: child’s worldview

Commented [EMC50]: other parents

Commented [EMC51]: coping

Commented [EMC52]: knowledge/information

Commented [EMC53]: learning from other parents

Commented [EMC54]: knowledge/info

Commented [EMC55]: other parents

Commented [EMC56]: anger/meltdown/behaviour

Commented [EMC57]: telling about the diagnosis

Commented [EMC58]: family

I would like to learn how to help my daughter more with school work; mainly it is socially that she has problems so I would like to be able to help her with that too (13)

That I will have an understanding of what goes on in my son's head and how I can support him and make his life less stressful (18)

To understand my child and to learn how to deal with him and his needs (11)

To broaden my knowledge of how best to understand and assist in the development of my son (9)

To gain some insight from the professionals from the ASD service to help my child manage and better understanding of what they can offer (11)

Learn about what is available in terms of support to both child and parents; learn about what to expect in the years ahead; learn about what the service do as so far for us its just been waiting lists (9)

Learning to cope with and understand difficulties that may arise as our daughter navigates her teenage years (13)

Meet others in similar situation and hear about personal stories (7)

Commented [EMC59]: child's needs

Commented [EMC60]: child's worldview

Commented [EMC61]: child's needs

Commented [EMC62]: well being

Commented [EMC63]: understanding

Commented [EMC64]: knowledge/information

Commented [EMC65]: supports available

Commented [EMC66]: child's needs

Commented [EMC67]: supports available

Commented [EMC68]: supports available

Commented [EMC69]: future

Commented [EMC70]: supports available

Commented [EMC71]: coping

Commented [EMC72]: other parents

Appendix L: Application to MIC Ethics Committee

Doctorate in Educational and Child Psychology
Research Ethics Committee

DECPSY Ethics Application Form

Instructions:

1. *Complete all relevant sections of this form. The information provided must be comprehendible to non-experts.*
2. ***Attach a copy of all relevant documentation to the application.** Failure to provide the necessary documentation will delay the processing of the application.*
3. *Your research supervisor must sign Section 4 of this form.*

1a	**Title of Research Project**
Parent/Guardian Perspectives on Post-Diagnostic Parent/Guardian Training in an Autism Spectrum Disorder Diagnostic and Intervention Service: A Case Study.	
1b	**Brief Outline (50-75 words)**
The purpose of this study is to explore parental perspectives and experiences of a Post-Diagnostic Parent/Guardian training programme within an Autism Spectrum Disorder service. The study will identify parental expectations, needs, experiences, knowledge, skills and challenges. Connolly and Gersch (2013) found that parents/guardians often described the process of receiving an autism spectrum disorder (ASD) diagnosis as a "journey". This research aims to uncover the role post-diagnostic training plays in that journey using a mixed-methods, exploratory, case-study methodology.	

2	**Proposed Start Date**	**Month**	April	**Year**	2018
	Anticipated Completion Date	**Month**	September	**Year**	2020

3	**Applicant**		
3a	**Applicant Details**		
Name:	Elaine McCarthy	**Student ID:**	0540471
E-mail:	00540471@micstudent.mic.ul.ie	**Phone:**	0860885783

3b Ethical Guidelines / Ethical Clearance from Another Source				
Are there Ethical Guidelines to which you must adhere in your field of study? If yes, please specify below:	**Yes**	**X**	**No**	
This research will also be guided by the Brothers of Charity Ethical Guidelines (Appendix A) and by the Psychological Society of Ireland (PSI) Code of Ethics (2010), as well as the Data Protection Bill (2018). Mary Immaculate College and DECPsy ethical and research guidelines will be adhered to throughout this research project.				

Do you require Ethical Clearance from another source? If yes, please specify below:	**Yes**	**X**	**No**	

I require ethical clearance from the Brothers of Charity Southern Services, who are the overarching body for the Autism Spectrum Disorder service in which I intend to conduct my research. A copy of this form can be found in Appendix A. This Ethics application will be made once ethical approval has been received from the DECPsy Panel and will be completed based on the information contained in my approved application.

4 Supervisor

To be completed by the research supervisor.

I hereby authorise the applicant named above to conduct this research project in accordance with the requirements of DECPSY REC 2 FORM* and I have informed the applicant of their responsibility to adhere to the recommendations and guidelines in DECPSY REC 2 Form

**The DECPSY REC 2 will outline the decision of the ethics committee and may contain a number of recommendations pertaining to the study. This form will be emailed to both the trainee and supervisor.*

Name	**Contact Details**	**Date**	**Signature**
Dr. Stella Long	Stella.long@mic.ul.ie	24/04/18	Stella Long

5 Study Descriptors

Please mark the terms that apply to this research project with a ✓

Healthy Adults	X	Vulnerable Adults	
Children (< 18 yrs)		Vulnerable Children (<18yrs)	
Physical Measurement		Psychological Measurement	
Video Recording/Photography		Voice recording	X
Questionnaire/Interview	*X*	Observational	
Physical Activity		Record Based	
Project is Off-Campus	X	'Other' descriptor(s) not named here	
Please specify 'Other' descriptor(s)			

6 Project Design and Methodology

6a Rationale, Purpose and Benefits of Research Project

This project will investigate parents'/guardians' perspectives and experiences of post-diagnostic training following their child's ASD diagnosis. Experience is conceptualised as concrete events of which one is cognisant, where one may gather knowledge, opinions, and skills, while perspective is conceptualised as one's outlook on or consideration of events and experiences (Thinés, 2015; Varela, Thompson & Rosch, 2017). These terms will be explained to parents/guardians through the research information sheets.

The purpose of this study is to explore parental perspectives and experiences of the Post-Diagnostic Parent training programme within the ASD specific service to identify parental expectations, values, needs, experiences, knowledge, skills and challenges.

For families, receiving a diagnosis of autism spectrum disorder for a child is a significant experience (Banach et al., 2010; Boullier, Drake, & Banach, 2008). Research has found that the reactions of families to an ASD diagnosis can range from relief to grief to anger, shock, surprise or self-blame (A. Fleischmann, 2004; Hutton & Caron, 2005). Regardless of the range of emotions experienced by families, many studies have found that families reported not receiving the help and support they needed following the diagnostic process (Boullier et al., 2008; K. Midence & O'Neill, 1999). Banach et al. (2010), McAleese, Lavery and Dyer (2014) report that effective post-diagnostic support can impact upon the acceptance of the diagnosis, while also providing skills in dealing with behaviour, parental self-care and advocacy.

Research into support for parents following a diagnosis of a developmental disorder shows that group involvement with families of a child with a disability has significant positive impact (M. Law, King, Stewart, & King, 2001), while parents ranked post-diagnostic information delivered by professionals as both highly desirable (Twoy, Connolly, & Novak, 2008) and highly useful (Mansell & Morris, 2004). According to Panerai, Ferrante and Zingale (2002a), incorporating the parenting role with the role of co-therapist has shown some promising results. Intervention in the form of parent training in psychoeducational theoretical approaches has been shown to be an effective means of enhancing knowledge and confidence (McConachie, Randal, Hammal, & Couteur, 2005), and to support generalisation and maintenance (B. Ingersoll & A. Dvortcsak, 2006).

The rationale for this research is that a non-standardised, eclectic post-diagnostic training is offered as indirect intervention for children with ASD through the medium of parents/guardians, as an alternative to direct contact-time with clinicians (Matson, Mahan & Matson, 2009; Scahill et al., 2016; Stadnick, Stahmer & Brookman-Frazee, 2015). Clinicians train parents/guardians to enhance their knowledge of ASD and communication and behaviour management. Thus, the training provided by the service in this case study must be evaluated from the perspectives of the participants expected to use this knowledge and skillset to support their children with ASD, i.e. parents/guardians.

This project proposes these questions:

1. What are parents' experiences of post-diagnostic parent training in an ASD service?
2. What do parents perceive as their skills level in supporting their child with ASD? (e.g. communication, behaviour management, managing sensory needs etc.)
3. What are parents/guardians' priority needs prior to training?
4. Are these parent-identified training needs met by post-diagnostic parent training?
5. What, if any, is the impact of post-diagnostic parent training on
    - parents' perspectives (parents/guardians views and opinions about ASD and post-diagnostic parent training)
    - experiences (of parenting a child with ASD, of taking part in a group training intervention

- self-efficacy (belief in one's own abilities and competencies in supporting a child with ASD)?

This research will have implications for educational psychology, as it will establish an evidence-base for the experiences and perspectives of parents/guardians on post-diagnostic training in an ASD service. Such a study has not been conducted in this context.

This research could inform future practice in post-diagnostic intervention, support parents/guardians in a meaningful way, allow psychologists to "give their psychology away" (Birch et al., 2015; Miller, 1969) and to maximise the use of their time through group training (Banach et al., 2010; McAleese et al., 2014; Wright & Williams, 2007). The evidence can be used to enhance experience quality for parents/guardians who attend training of this type in the future.

6b (i) Research Methodology

An exploratory, mixed-methods, case study methodology will be applied. This approach has been selected as appropriate to explore what Yin deems "a contemporary phenomenon within its real-life context" (2003, p.13). This methodology allows for an extensive, in-depth description of social phenomena and experiences (Robson, 2011; Yin, 2009). This methodology is suitable given that the researcher in this study will not be designing the training provided to parents/guardians and thus has little control over the events and experiences of the participants (Yin, 2009). A case study protocol will be designed and adhered to rigorously to support and enhance the reliability, validity and theoretical generalisability of the research (Robson, 2011; Yin, 2009).

This research subscribes to the pragmatic paradigm.

The questionnaires (Appendices B & C) have been designed by the researcher and are, as yet, unvalidated. To enhance the credibility and validity of the questionnaires I will ask a panel of five psychologists with experience in ASD to assess the questionnaires and to provide critique. Questionnaires may then be revised considering the suggestions of this panel of psychologists working in the field. I will pilot the questionnaire with a group of three parents/guardians of children with an ASD diagnosis, known to me, to ascertain feedback on validity and usability, and also to gain an accurate insight into the length of time the questionnaire will take to complete.

Questionnaires will include a section for age and gender of child, relationship to child, length of time since diagnosis, co-morbid difficulties, other interventions undertaken, siblings with ASD or not. This information will be analysed and presented as descriptive statistics, with categorical data being analysed using a Chi-Square test. Pre- and post- training questionnaires will later be analysed using an independent samples t-test to compare differences. The closed questions in the questionnaires take the form of five-point Likert scales which can be rated by participants. Five-point Likert scales were chosen above the use of a seven-point scale as research has found that the use of a five-point scale increases response rate and response quality, while reducing respondent frustrations (Babakus & Mangold, 1992). Furthermore, five-point Likert scales have been found to be more easily comprehensible than scales with greater points (Revilla, Saris & Krosnick, 2013). The questionnaires also contain open-ended questions to allow for broader information to be provided by participants. Participants will be asked to provide the last four digits of their mobile phone numbers on the pre- and post-questionnaires. This is to allow the questionnaire responses to be matched, tracked and analysed from before the training commences to afterwards. The information from the questionnaires will be stored securely, coded and pseudonyms used where necessary throughout so that research participants cannot be identified by anybody other than the researcher and those named in this form with access to the data. The use of Likert Scales in the questionnaires, along with the revision of some questions and the option to take part in semi-structured interviews (Phase Two), will address any discrepancies in parental literacy levels in accessing the study. Furthermore, the researcher will be present to relay information orally and to answer any questions participants may have about the contents of the questionnaire and other written materials. The questionnaire part of the research project will be known as Phase One, while the semi-structured interviews will form Phase Two of the study.

Quantitative data from the questionnaires will be analysed via a paired samples t-test in order to compare pre and post training ratings. Qualitative data from the questionnaires (Phase One, Appendices B, C & D) and semi-structured interviews (Phase Two, Appendices E & F) will be coded and thematic analysis will be used. SPSS and NVivo software will be used in the data analysis process. It is envisaged that Phase One will firstly establish a baseline for knowledge, skills and experiences before participating in post-diagnostic parent/guardian training and will be used to establish any differences following participation in the training. It is hoped that this phase will facilitate the gathering of information from a large group of people, while Phase Two (semi-structured interviews) which will take place later will allow for a more in-depth discussion with a small number of participants. The researcher selected the semi-structured interview methodology as a time-efficient means of gathering rich qualitative data from a small group of people who undertook a shared training opportunity. Semi-structured interviews (Phase Two) will be used as a qualitative approach which creates opportunities for a narrative to unfold, while including questions informed by theory and by information garnered in the questionnaires (Galletta, 2013). This method offers insight into individual experiences and perceptions and is designed to yield a more complete story than quantitative means alone (Galletta, 2013). Furthermore, a semi-structured interview method allows participants to express their views (Bryman, 2015; Mertens, 2005). Interview questions can be identified in advance, along with general topics for discussion (Bryman, 2015; Gill et al., 2008). This approach also allows for additional questions and probes to be used throughout the interview in a flexible manner (Bryman, 2015; Gill et al., 2008; Howitt, 2013).

6b(ii) Research / Data Collection Techniques

The training is an eclectic, clinician-designed programme, planned by the multi-disciplinary team and based on evidence-based best practice. The clinicians will be asked to document the training programme on a researcher-designed template, noting resources used, evidence-base and delivery (Appendix G). Additionally, clinicians will be asked to use the Template for Intervention Description and Replication (TIDieR) (Hoffman et al., 2014). The TIDieR (Appendix H) was designed by an international group of experts and stakeholders to improve the completeness of reporting and replicability of interventions (Hoffman et al., 2004). Clinicians are asked to complete the TIDieR as it is important that the training can be described accurately and replicated, especially in light of the fact that it is not a manualised programme. Completion of the TIDieR (Appendix H) along with researcher observations (Appendix I) and the training description form (Appendix G) will lead to an accumulation of triangulated information from numerous sources (i.e. the researcher and various clinicians), which will in turn enhance the validity, reliability and replicability of the training intervention programme. This will lend itself to the corroboration and validity of the research findings and will also aim to widen the audience to whom this research is relevant. The researcher will attend each training session to record the training material and delivery (Appendix I), to experience the training as delivered and to record any deviations from the clinicians’ training plan. This data, along with course documentation, will provide a detailed, rich description of the training in line with case study methodology (Eisenhardt, K. M., 1989; Yin, 2009). This data will be analysed thematically, with the researcher using quantitative techniques to identify themes within the training information provided, allowing for the organisation of training materials into categories. To further ensure the fidelity of the training programme, the researcher will apply a conceptual framework for implementation fidelity in line with best practices outlined by the National Institute of Health Behaviour Change Consortium (Bellg et al., 2004). This framework makes recommendations for strategies to monitor the delivery of training, the receipt of training and the enactment of treatment skills, while also accounting for monitoring the design of the training. The aim of this research is not to carry out an evaluation of the training programme, rather to uncover the experiences of the participants within that programme. That said, by documenting and monitoring the training provided through the use of the TIDieR, the researcher designed template, the observation schedule and the conceptual framework for implementation fidelity, the researcher can draw themes and conclusions, and can comprehensively describe the training programme, despite the lack of a manual. The rationale of this approach is that although the training is not manualised, it is being offered to parents as a form of intervention and thus their perspectives and experiences must be researched.

At the beginning of the first training session, the researcher will speak to the parents/guardians about the research project, outlining the topic, aims, procedure etc. This information will also be provided on written information sheets (See Appendices D, F & J). The parents/guardians will also be given informed consent sheets for participation in Phase One (questionnaire) of the project. The prospective participants will be afforded time (approximately ten to fifteen minutes) to read the sheets and to ask questions of the researcher in relation to the project. Training time will not be impacted by the administration of questionnaires, as the time will be accounted for when timetabling the training session. There is no alternative activity available for non-participants. At this point, the training session will begin. After the mid-way break in training, parents/guardians will be asked to complete the consent forms and the questionnaire if they wish to take part. The researcher will then ask that all completed questionnaires and consent forms be placed in a box at the top of the room. This is to avoid placing social pressures on the parents/guardians and to remove any onus on them to participate. Participants will also be asked to complete a post-training questionnaire (Appendix C) at the last training session. The training takes place over five sessions, at a rate of one per week in the evenings. The questionnaires will provide both quantitative and qualitative data to provide firstly a baseline and any change in data at the post-intervention stage (Robson, 2011). The participants will be given an information sheet and informed consent for Phase Two, the semi-structured interview, on the final night. Participants will be invited to provide contact information on the informed consent form if they are willing to take part in an interview.

6-8 participants will be chosen by random selection and invited to participate in an individual semi-structured interview to explore parental perceptions and experiences of the training. Informed consent will be sought from participants in Phase Two (semi-structured interviews). Interview questions will be developed from information garnered from the pre-training and post-training questionnaires (see hypothetical examples in Appendix E), in line with the pragmatic paradigm (Galletta, 2013; Mertens, 2015). By incorporating qualitative measures, in this instance a semi-structured interview process, it allows for a sample population of participants to express their in a less restricted manner than in quantitative research alone (Bryman, 2015; Gill et al., 2008; Howitt, 2013; Kitzinger, 2005; Krueger & Casey, 2014). The interviews will be audio-recorded to facilitate the transcription and analysis of the data. Participants will be informed of this recording orally, in the information sheets, the interview consent form and again, in person on the day of the interview. If a participant decides that they do not wish to be recorded, they will not be interviewed. If a participant changes their mind about the recording once it has begun, they will not be able to remove their utterances but will be free to leave/discontinue their participation at any point. Participants will be made aware of this prior to the interview.

6c Steps taken to Minimise Risk

All participants (parents/guardians) and the clinicians giving the training will be provided with information sheets and informed consent forms prior to taking part in the research (separate information and consent forms for the questionnaire phase and the interview phase; see Appendices D, F, J, K, L & M). Additionally, copies of all documentation (information sheets, consent forms, questionnaires, interview questions, training templates) will be provided to the Brothers of Charity Research

Committee (See Appendices B-M). The information sheets and consent forms will be presented in an accessible and appropriate manner to ensure that it is understood by all relevant parties (Rice & Broome, 2004; Rice, Bunker, Kang, Howell, & Weaver, 2007).

It will be made clear to all participants that their participation in the research is voluntary and that they have the right to withdraw from the research at any stage, without any repercussions to themselves from the researcher, the clinicians, clinical manager (where relevant), and Brothers of Charity (where relevant). Participation or non-participation will have no bearing upon the services that children will receive. Furthermore, it will be emphasised that the researcher is not an employee of the service, as this could potentially impact upon the power imbalance as parents/guardians may feel under pressure to participate.

Contact details of the researcher, their supervisor, and the DECPsy course leader will be provided to all participants in case they have any queries or concerns relating to the research. Additionally, a key person will be appointed within the service so that participants or the clinicians providing the training can raise any concerns they may have relating to the research which they may not feel comfortable addressing with the researcher directly. This key person, a psychologist, will not have access to the written data and will be bound by the PSI Code of Professional Ethics. They will liaise with the researcher in terms of ensuring the ethicality and safety of the research according to the Brothers of Charity research guidelines.

The interviews (Phase Two) will take place in XXX, as this is a setting which is familiar to all participants. Furthermore, the location is insured for public indemnity and has appropriate furniture and meeting facilities for this kind of activity. The researcher, with the approval of the clinical manager of the setting, will require that clinicians do not come to the building (one of 3 on the site) where the interviews are taking place. This restriction is with a view to preserving the comfort of participants, ensuring that they can respond freely without the presence and pressure of a clinician listening to their comments on the training.

The participants will be assured that the researcher will not be disclosing anything that they have said unless there are disclosures regarding child protection issues, harm to themselves or others, or intent to commit a crime. This will be made clear to the participants in their informed consent forms, and again at the beginning of the interviews (F. Gibson, 2007; Psychological Society of Ireland, 2011). The participants will be given the option of withdrawing from the study again at this stage, without any consequences. If they have any concerns or questions once the interview is completed they can contact the researcher, her supervisor or the service itself.

If a participant becomes upset during the interview, they will be given the option of stopping or taking a break. The researcher will have access to the service's liaison person and may use her clinical judgement to decide whether the support of that clinician is required in assisting the upset participant. The researcher reserves the right to check in with all participants following the interview to see if they have been affected by any of the issues discussed either in the training programme or the subsequent interview. Furthermore, all participants will be provided with contact information for relevant support groups and helplines before the interview and will be reminded of these when leaving. If necessary, the researcher can meet with any upset participant following the interview to discuss any issues. Also, the service will allow for access to a social worker follow-up visit following the post-diagnostic training. The researcher can contact the social worker with any concerns regarding the welfare and/or well-being of participants arising from the interviews.

To summarise:

Participation in all aspects of the study is voluntary.

Information will be provided to participants both orally and in written format, allowing for informed consent to be given.

The research will be conducted in safe, well-lit, comfortable environments to ensure the physical well-being of the researcher and participants.

Details of counselling services and ASD support services will be made available to participants at training sessions and at the subsequent focus group.

Data will be stored in a secure and responsible manner, for no longer than required by the research guidelines of Mary Immaculate College, (2018).

6d Location(s) of Project

XXXXX

6e Questionnaires and Interviews

Please find attached a questionnaire which will be used to gather data from the participants pre-and post- training (Appendices B & C).

Interview questions will be designed following the analysis of the questionnaire data. As this is an exploratory study which draws upon the principles of the pragmatic paradigm, there is some flexibility in terms of the themes which will arise for discussion over the course of the research. Hypothetical/Draft questions are attached in Appendix E.

7 Participants

7a How will potential research participants be identified and selected?

Parents/guardians of children recently diagnosed with ASD will be invited to attend Post Diagnostic Parent/Guardian Training evenings as part of their child's intervention by the staff of the ASD service, as per their usual administrative protocol (waiting list operated for children diagnosed with ASD; training takes place up to three times per year). The training takes place once a week over the course of five weeks. On the first evening, I will invite the parents/guardians attending the training to participate in the research study. I will verbally explain the study, as well as providing a written information sheet. Pre- training data will be gathered at this stage through the pre-training questionnaire (Appendix B). Post- training data will be collected through a questionnaire on the final evening (Appendix C).

Parents will be informed about Phase Two (semi-structured interview) of the research on the final night. They will be provided with an information sheet about the interviews. Participants for the semi-structured interviews will be recruited from the pool of parents/guardians who register their interest and contact details on the informed consent form for the interviews, giving permission to the researcher to contact them up to two weeks after the training programme. Participants will be randomly selected from this pool. It is envisaged that 6 to 8 parents will be interviewed, or less if the data becomes saturated in advance of this (Galletta, 2013).

7b How many participants will be recruited?

For the questionnaire part of the study (Phase One), approximately 40 to 50 participants would be expected to be recruited. This is the estimated number of participants who will attend the training. This figure is based upon the reports of clinicians, along with my own attendance at previous Post-Diagnostic Parent/Guardian Training with this service, where approximately 60 parents/guardians participated.

It is envisaged that 6 to 8 parents will be interviewed, or less if the data becomes saturated in advance of this (Galletta, 2013).

7c	**Will participants be reimbursed for taking part in this research project?** **If YES, please attach the details to this application.**	**Yes**		**No**	**X**
7d	**Will incentives / inducements be provided to participants for taking part in this research project?** **If YES, please attach the details to this application.**	**Yes**		**No**	**X**
7e	**Will Recruitment Letters/Advertisements/e-mails, etc. be used to recruit participants?** **If YES, please attach the details to this application.**	**Yes**		**No**	**X**

8 Confidentiality of collected data and completed forms (e.g. informed consent)

8a What measures will be taken to ensure confidentiality of collected data?

Data will be anonymised, and the identities of participants will be protected in line with ethical guidelines (PSI, 2010; Mary Immaculate College, 2018) and data protection law (2018). Once the questionnaires have been coded and the responses recorded, the paper questionnaires with the participants contact details will be destroyed by the researcher.

Data will only be stored for the duration stipulated by the Mary Immaculate College research guidelines (2018). Data will be destroyed in line with these guidelines.

8b Where and how will the data be stored / retrieved?

Hard copy data e.g. paper questionnaires will be stored in a locked filing cabinet in the researcher's office until all data has been coded and recorded. Following this, the paper questionnaires with the contact details on them will be destroyed by the researcher. Only the researcher will have access to this filing cabinet.

Soft data will be stored in password protected files in a password protected laptop, with an additional copy saved on an encrypted external hard drive.

Contact details for participants in the semi-structured interviews will be stored both in a hard and soft format in the manners outlined above. All data storage will follow Irish Data Protection Law.

8c Who will have custody of, and access to, the data?

Elaine McCarthy (researcher and custodian of data)
Dr Stella Long (supervisor with access to data)
Dr Therese Brophy and Siobhan O'Sullivan (DECPsy research co-ordinators with possible access to data)
XXX Research committee
Mary Immaculate College research support staff may have access to anonymised data in the event of supporting the researcher with data analysis.

8d For how long will the data from the research project be stored? *(Please justify)*

Data will be held for the duration of the research project, plus three years in line with the document retention schedule outlined by Mary Immaculate College (2018).

9 Information Documents

Indicate which of the following information documents are applicable to your Research Project by ticking either Yes or No in the checklist below. Attach a copy of each applicable information document to the application.

	Applicable Please ✓	
Documents	***Yes***	***No***
Participant Information Sheet	**X**	
Parent/Responsible Other Information Sheet		**X**
Participant Informed Consent Form/Assent Form	**X**	
Parent/Responsible Other Informed Consent Form		**X**
Questionnaires	**X**	
Semi Structured Interview Questions	**X**	
Training Description Template	**X**	
Training Observation Template	**X**	
Template for Intervention Description and Replication (TIDieR)	**X**	
External Agency Ethics Protocol	**X**	

10 Declaration

The information in this application form is accurate to the best of my knowledge and belief, and I take full responsibility for it. I undertake to abide by the ethical principles outlined in the DECPsy Research Ethics Guidelines. **If the research project is approved, I undertake to adhere to the study protocol without unagreed deviation, and to comply with any conditions sent out in the letter sent by the DECPsy REC Committee notifying me of this. I undertake to inform the DECPsy REC of any changes in the protocol.** I accept without reservation that it is my responsibility to ensure the implementation of the guidance as outlined in DECPsy REC 2 Form

Name (Print) Elaine McCarthy **Signature** Elaine Mc Carthy

Date 24/04/2018

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Appendix M: Information Sheet for Participants

Participant Information Sheet for Research Study

What is the project about? This study will explore the parental perspective and experience of taking part in Post-Diagnostic Parent/Guardian Training, following a diagnosis of Autism Spectrum Disorder (ASD). This research wants to find out about your experiences of taking part in Post-Diagnostic Parent Training and your perceptions (thoughts and feelings) about it. This study aims to find out what parents/guardians expect from post-diagnostic training, what they would like to learn, and whether the training meets the needs identified by parents/guardians. Also, this research will examine how parents/guardians feel about their own knowledge, skills and self-efficacy (belief in one's own abilities and competencies in supporting a child with ASD) in relation to Autism Spectrum Disorder before and after the post-diagnostic training.

Who is undertaking it? My name is Elaine McCarthy and I am a Trainee Educational Psychologist in Mary Immaculate College, Limerick. I am interested in the support provided to parents/guardians whose child has recently received a diagnosis of ASD. I am conducting this research under the supervision of Dr Stella Long, Mary Immaculate College, Limerick.

Why is it being undertaken? The objective of the study is to obtain the perspectives of parents/guardians on the usefulness of post-diagnostic parent training as a form of intervention and support. I want to find out if the post-diagnostic training meets the needs of parents, as identified by themselves, and, what parent's experiences of the post-diagnostic training are.

What are the benefits of this research? It is hoped that the data gathered will be used to inform future training for parents/guardians of children with ASD for the benefit of the clients, families and ASD services.

Exactly what is involved for the participant? This study will comprise of two questionnaires, one before training commences, and one to be completed at the end of the final training session. The questionnaires in the study will take approximately 10 minutes to complete. The purpose of the first questionnaire is to provide the researcher with an overview of parents' views of their current skill levels and their expectations of the post-diagnostic training before the training begins. At the end of the training programme, the final questionnaire will ask parents to rate their skill level again and to comment on whether their expectations for the programme were met following participation in training. Both questionnaires take the format of scales, as well as open-ended questions.

The questionnaires ask you to enter the last four digits of your phone number. This is to facilitate the tracking of responses from before and after the training. All data will be protected and stored in line with Irish Data Protection Laws.

Do I have to take part? Participation in this study is voluntary. Partaking or not partaking in this study will not have any impact on any future services your child will receive from this or any other service. You are free to withdraw from the study at any point.

How will the information be used / disseminated? The data from these questionnaires will be combined with that of the other participants in this study. The data from the questionnaires will be used to find out about the experiences and perceptions (thoughts and feelings) of parents/guardians of the Post-Diagnostic Parent/Guardian Training. The data from questionnaires (Phase One) will be used to inform the topics of discussion in the interviews (Phase Two). Summary data only will be used, individual participant data will not be shown. The information in this study will form part of a Doctorate in Educational and Child Psychology thesis and anonymized results may be printed in psychology journals and presented at conferences.

How will confidentiality be kept?

All information gathered will remain confidential. The following people will have access to the data: Elaine McCarthy (researcher and custodian of data); Dr Stella Long (supervisor with access to data); Dr Therese Brophy and Siobhan O'Sullivan (DECPsy research co-ordinators with possible access to data); Brothers of Charity Research committee; Mary Immaculate College research support staff may have access to anonymised data in the event of supporting the researcher with data analysis.

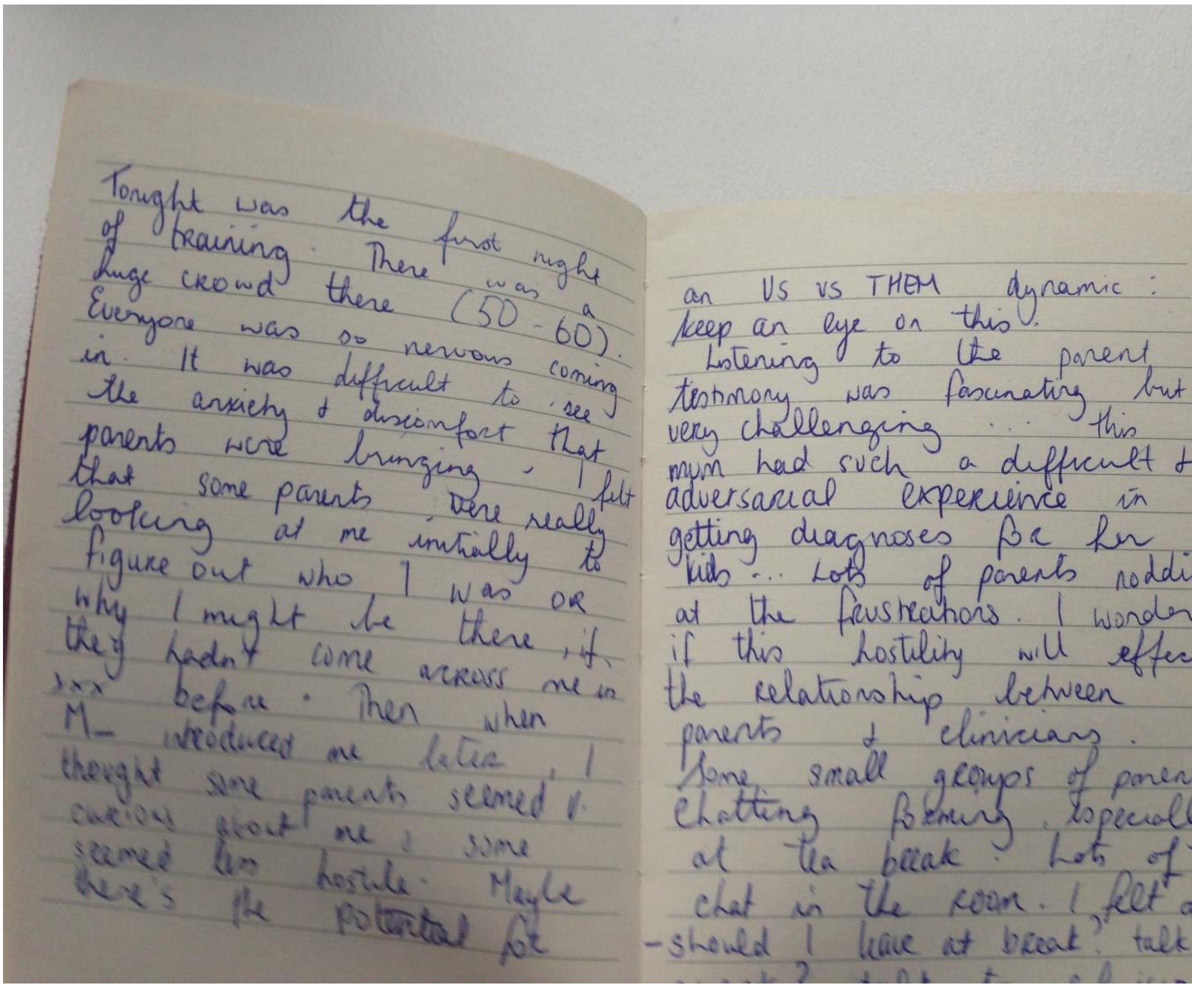
What will happen to the data after research has been completed? In accordance with data protection all research data will be stored for the duration of the project plus three years, which is in line with Mary Immaculate College Data Retention Schedule.

Next Steps? If you are willing to participate in this study, please sign the Informed Consent form and complete the short questionnaire. Once completed, these can be returned at the end of this session.

Further Information and Contact details

If you have any questions or queries in relation to this research, please contact:

Appendix N: Excerpt from Reflective Journal



Tonight was the first night
of training. There was a
huge crowd there (50-60).
Everyone was so nervous coming
in. It was difficult to see
the anxiety & discomfort that
parents were bringing. I felt
that some parents were really
looking at me initially to
figure out who I was or
why I might be there, if
they hadn't come across me in
xxx before. Then when
M_ introduced me later, I
thought some parents seemed v.
curious about me; some
seemed less hostile. Maybe
there's the potential for

an US vs THEM dynamic:
keep an eye on this.
Listening to the parent
testimony was fascinating but
very challenging ... this
mum had such a difficult &
adversarial experience in
getting diagnoses for her
kids ... Lots of parents noddi
at the frustrations. I wonder
if this hostility will effec
the relationship between
parents & clinicians.
Some small groups of paren
chatting, forming, especiall
at tea break. Lots of
chat in the room. I felt a
- should I leave at break? talk

Appendix O: Empirical Paper for Dissemination

Doctorate in Educational and Child Psychology

Empirical Paper

Capturing the Voices of Parents: The Self-Reported Needs of Parents following a Diagnosis of Autism

Elaine McCarthy

Supervised by Dr Stella Long

Abstract:

Internationally, the prevalence of autism diagnoses is increasing. In Ireland, the prevalence rate is estimated to be 1 in 65, in line with international trends. There is a growing demand for autism services, with large waiting lists for diagnostic assessments and reduced resources to provide intervention. Consequently, some autism services offer post-diagnostic parent training as intervention for parents of children recently diagnosed with autism. This research explores the self-reported needs of parents who participate in post-diagnostic parent training in Ireland.

Aims: This research aims to capture the voices of parents in post-diagnostic parent training by investigating parents' needs . Furthermore, parents' perceptions of their skills and priority needs were sought prior to training, to determine if these parent-identified needs were met following participation.

Method: A mixed-methods, exploratory, case-study methodology was employed to examine the transition from diagnosis to post-diagnosis for parents undertaking post-diagnostic training as intervention.

The needs of parents were accessed via pre- and post-training questionnaires. Semi-structured interviews were utilised to gain insight into parents' perspectives on post-diagnostic training and their participation as a form of intervention. Documentary analysis and ethnographic observations were also used to capture and describe the intervention delivered. Thematic analysis was used to analyse the quantitative data, while paired sample t-tests were used to analyse the pre- and post-intervention questionnaires.

Results and Conclusions. The post-diagnostic needs of parents and guardians were discussed in the context of future training, intervention and service delivery based on the voices of parents captured at this stage of the post-diagnostic transition process. This research builds an evidence-base for post-diagnostic parent training in an Irish context.

Introduction

Autism Spectrum Disorder (ASD), or autism, is a pervasive neurodevelopmental condition characterised by impairments in social interaction, social communication and behavioural inflexibility (Baron-Cohen et al., 2009; Carr, 1999; Cline & Frederickson, 2009; Volkmar et al., 2004). Autism is characterised by what is described as the “triad of impairments” (Cline & Frederickson, 2009; Frith, 1989; King et al., 2008; Rajendran & Mitchell, 2007; Volkmar et al., 2004), in the areas of social imagination, social communication and social interaction. Autism is also frequently accompanied by distinct sensory sensitivities or preferences and repetitive, stereotyped movements or actions (Y.-H. Chen et al., 2009; Frith, 1989).

Autism is viewed along a continuum ranging from severe social, communication, behavioural and cognitive impairments to average or above average IQ with mild impairments in socialising, communication and behaviour (Woolfson, 2011). The concept of the spectrum is key to working with individuals with autism (Silberman, 2015). Deficits manifest across a spectrum in the areas of social communication, social interaction and social imagination (Eyal, 2010; Frith, 2003; Morgan, 2016; Ring et al., 2018; Volkmar et al., 2004). Communication difficulties can include issues with echolalia, pre-verbal/lack of speech, formal use of language, deficits in social interaction skills can manifest as lack of imaginative play, difficulty making and keeping friends and lack of awareness of social norms, while social imagination difficulties can present as repetitive and/or restrictive interests, inflexibility in routines and rigidity (Carr, 1999; Cline & Frederickson, 2009; Frederickson & Cline, 2002). Profiles of people with autism can be quite diverse in terms of their strengths and needs. Additionally, people with autism can have additional sensory needs and motor skills deficits (Frederickson & Cline, 2002; King et al., 2008; Nicholas et al., 2008).

Parents of Children with Autism following a Diagnosis

The process of diagnosing autism in children and young people can be lengthy and onerous, with Connolly and Gersch (2013) reporting that parents/ guardians often describe the process of receiving a diagnosis as a “journey”. Receiving a diagnosis of autism is a significant life event which can frequently elicit strong emotional reactions from the parents/guardians of the diagnosed child (Banach et al., 2010), with many describing receipt of the diagnosis as a life-changing experience (Amos Fleischmann, 2004). Parents describe the role of the professional in the diagnostic process as that of a guide who would show the route, and note that for the family of a child with autism, the journey will take a "slightly different path" (Connolly & Gersch, 2013).

Rationale:

Having taught across a range of roles and types of schools in the Irish primary system over the course of eight years, I have worked with many children with autism and their families. While teaching in a special class for children with autism, I completed a Higher Diploma in Psychology. I subsequently left this position to undertake a three-year, full time Doctorate in Educational and Child Psychology. Over the course of my studies, I have had the opportunity to embark on professional placements across a range of settings and services, including an autism diagnostic and intervention service. This placement opportunity allowed me to gain an insight into the world of autism from the perspectives and experiences of parents, rather than through the lens of school. The service offered post-diagnostic parent training following a diagnosis of autism. Having attended each session, I became interested in the needs of parents receiving this eclectic training

Research has highlighted the potential benefits of group training for parents of children with autism as an intervention following diagnosis (Brookman-Frazee et al., 2006; Brooke Ingersoll & Anna Dvortcsak, 2006; Lundahl et al., 2006; M. L. Matson et al., 2009; Wyatt Kaminski et al., 2008). Not only can training potentially benefit parents in terms of support (Divan et al., 2012; Francis, 2005; Lutz et al., 2012; Pottie & Ingram, 2008; Ring et al., 2018; Vernhet et al., 2018), but it can also help to meet parents self-reported information needs following a diagnosis of autism for their child (Murphy & Tierney, 2006). Furthermore, the process of seeking information following a diagnosis is associated with positive psychological wellbeing and adjustment (Farrugia, 2009; Pain, 1999; Salas et al., 2017). Murphy and Tierney (2006) note that service provision for families tends to be predicated on what clinicians and professionals deem to be the needs of parents following diagnosis, a finding which is supported by Pain (1999). The current research study sought to address this issue by capturing the voices of parents, specifically relating to their self-reported needs following a diagnosis of autism for their child.

Needs:

Thinking of the Future.

Murphy and Tierney (2006) conducted focus groups in an Irish context to investigate the information needs of parents, noting that when parents receive an ASD diagnosis, they begin to think about the long-term impact. Given that the difference is a lifelong condition, which pervades across the lifespan, parents consider the diagnosis of ASD and the implications for their child's future (Murphy & Tierney, 2006). Given that for many parents their knowledge of ASD was limited to the film *Rainman* (1988), some participants reported having difficulty in envisaging what the future may hold for their child (Murphy & Tierney, 2006). This uncertainty is compounded by limited supports and direction from professionals (Murphy & Tierney, 2006; Mansell & Morris, 2004; Howlin & Moore, 1997). Thus, the post-diagnostic period can often be a time of information-seeking, searching for supports and swinging between hope and disappointment while adapting to the diagnosis (Mansell & Morris, 2004).

Information Needs.

Families identified the need for follow-up supports in terms of information and services following a diagnosis of ASD as a means of addressing their feelings of uncertainty and the inadequacy of support (Banach, Iudice, Conway and Couse, 2010). Case study research found that parents identified a need for support and information in terms of self-advocacy to schools and other services (Drake et al., 2008).

Whether a parent experiences shock, sadness, anger, relief or surprise at their child's diagnosis, parents tend to seek information on how ASD could impact on theirs and their child's lives. In the period following a diagnosis of ASD, information seeking on the difference is a key activity undertaken by parents (N. Grant et al., 2015; Murphy & Tierney, 2006; Pain, 1999; Reichow et al., 2012). A survey of parents' information needs reported a perceived lack of support from professionals and clinicians, with the responsibility to seek information falling primarily on the parents (Murphy & Tierney, 2006). It is hypothesised that information seeking serves as a coping mechanism following a life-changing diagnosis, while also building connections with local, national and international communities of support (Barnett et al., 2003; Divan et al., 2012; Lutz et al., 2012; Murphy & Tierney, 2006; Pain, 1999; Siegel, 1997; Stoner & Angell, 2006; Vernhet et al., 2018).

Research suggests that information seeking behaviour is associated with positive psychological well-being, with numerous reasons attributed to information seeking, such as coming to terms with a diagnosis, adjusting to the disability, behaviour management and accepting the impact upon the wider family (Farrugia, 2009; Pain, 1999; Salas et al., 2017). While research undertaken in the Irish context supported the international research, it did however identify additional purposes to information seeking, namely, to find answers to specific and immediate questions, to gather information on services and entitlements, to aid decision-making in relation to treatment and intervention, to help to plan for the future and to generally gain a greater sense of control of outcomes for the child and their family (Murphy & Tierney, 2006). Key areas of need emerged from the data: information relating to diagnosis, services, intervention/practical strategies, educational issues, concerns, informing the child and others, resources and future concerns. Further findings include the timeframe in which parents search for information; prior to and following diagnosis were the times when parents searched most urgently for information, including attendance at conferences, trainings and seminars. Following this timeframe, searching became less of a focus with parents reporting seeking information at critical junctures in development or transition (Murphy & Tierney, 2006). A study on the intervention decision-making process and information preferences of parents of children with ASD by N. Grant et al. (2015) found that parents report seeking information on ASD interventions from a number of sources and applying a trial and error approach to choosing and evaluating these interventions. This finding is supported by Murphy and Tierney (2006), whereby participants reported that over time they sought less information as they became more familiar with their child’s profile of strengths and needs within the difference. However, further to this point, A. N. Gibson et al. (2017) note that the availability of information sources for parents decreases as their children get older, with fewer resources for adolescents and adults with ASD.

Pain (1999) stated that information seeking is a vital step in gaining an understanding of the practicalities and realities of the disability. This research was supported in more recent years by that of Salas et al (2017). Both Pain and Salas et al agreed that information seeking behaviours facilitated parental adjustment to the diagnosis. When trying to plan for how to best support their child and meet his/her needs following a diagnosis of ASD, parents can be overwhelmed by the sheer volume of information available outside of clinical sources, in terms of new treatments, diets, medications, behavioural strategies and educational interventions (Murphy & Tierney, 2006). Schopler (1995) discusses how merely searching through the barrage of information can be daunting, with some parents expressing feelings of hopelessness when faced with trying to keep up with each latest advancement, a finding which was later supported by Connolly and Gersch (2013). For Mackintosh, Myers and Goin-Kochel (2005), parents desire knowledge and information, but can feel overcome with the process of finding information which is of good quality and relevant to their own situation. Findings from Pain's research (1999) state that information seeking can be of mixed benefit for the parents of children with disabilities, in that it can provide strategies, knowledge and can aid in emotional adjustment and behaviour management, but can also be disheartening and can increase anxiety, especially if the information outlines a grim outlook for the future or focuses on services which are not available in the region. A. N. Gibson et al. (2017) highlight the changing and different information needs of people with ASD and their families in terms of medical, educational and social supports across the lifespan.

Group Support:

Given that parents of children with ASD are at risk of social isolation and lack of understanding (Woodgate et al., 2008), group support can offer an opportunity for parents to meet other parents of children with ASD and to gain knowledge, understanding and acceptance (Banach et al., 2010). One of the greatest needs for families of children with ASD is thought to be acceptance and support from other people (Banach et al., 2010; Woodgate et al., 2008). Parents taking part in a support group for parents of children with disabilities reported an increased sense of belonging, with an enhanced sense of empowerment in their ability to come together to advocate for and support their children at a broader community and societal level (Mary Law et al., 2001). Additionally, participants reported an increased sense of knowledge and competence in managing behavioural issues and other daily concerns (Mary Law et al., 2001). Mansell and Morris (2004) report that a post-diagnostic parent support group was ranked as the most useful of all post-diagnostic information, while a study by Bitsika and Sharpley (1999) highlights the reported increase in self-concept and decrease in stress levels following participation in a parent support group for parents of children with ASD.

Training for Parents.

Following a diagnosis of ASD, the role of clinicians is to provide evidence-based information about ASD, supports, risk factors, to be open to the parents' emotional responses, to show understanding of parental reactions and to acknowledge challenges while also fostering positivity in relation to interventions and strategies that may help their child (Sullivan, 1997; Mansell & Morris, 2004). In the UK and Ireland, the eclectic approach is widely implemented, whereby clinicians and educators adopt a wide range of interventions and strategies to meet individuals' needs (Guldberg et al., 2011). In a review of international evidence-based best practice, Guldberg et al. (2011) note that parent training should be made available to educators and parents/guardians of children with ASD, both to provide knowledge on ASD and its characteristics and to provide information about the range of evidence-based interventions which are available. Parent training, as a term, has been used to describe a wide range of interventions including psychoeducation, social and/or behavioural strategies, language, care or maladaptive behaviours (Bearss et al., 2015). Given that following a diagnosis many parents seek out information (Banach et al., 2010; Crane et al., 2016; N. Grant et al., 2015; Mansell & Morris, 2004), parent training programmes can be useful in providing quality, evidence-based information. Effective programmes can support parents in adjusting to the diagnosis and to manage their own assumptions and expectations about ASD and the prognosis for their own child (Bearss et al., 2015). Programmes tend to be structured over a short term, generally 6 to 12 weeks, and occur in groups or with individuals. Group interventions provide the added benefit of promoting social support within groups of parents of children with ASD (Farmer & Reupert, 2013). Some research has highlighted the need to evaluate parent training programmes in order to gain a measure of their impact on practice and on outcomes for individuals with ASD (Guldberg et al., 2011). A further recommendation from this study is that persons with ASD must be offered opportunities to develop their own knowledge about the spectrum and to be active consultees in relation to addressing their own identified needs.

While there is a vast array of parent training programmes available, both with manuals and without, the most effective parent training programmes have key features in common. Following a meta-analysis of parent training programmes, a number of key components of effective programmes have been identified (Wyatt Kaminski et al., 2008). Firstly, in line with other research on parent training (Lundahl et al., 2006; Maughan et al., 2005; Reyno & McGrath, 2006), there was an overall positive impact of parent training, supporting the implementation of parent training for a range of challenging behaviours (Wyatt Kaminski et al., 2008). Programmes that included training in fostering positive parent-child interactions and which allowed the parent to practice their skills with their own child during sessions yielded significant positive results, while programmes with lesser levels of parent activity or active involvement (for example, homework, role playing) were not predictive of positive programme outcomes (Wyatt Kaminski et al., 2008). Secondly, programmes teaching skills of emotional communication and disciplinary consistency were also likely to produce significant positive results. Interestingly, the use of a standardised or manualised programme did not appear to impact on the outcomes of parent training. Westen et al. (2004) hypothesise that the manualisation of a programme or not is less important than ensuring the programme achieves positive outcomes. Programmes containing the four elements of working with one’s own child, skills relating to emotional communication, teaching positive interactions with children and disciplinary consistency have greater impact and positive outcomes that parent training programmes which do not (Wyatt Kaminski et al., 2008).

Method

Research Setting:

This research took place in a government-funded diagnostic and intervention service for children with ASD aged between six and eighteen years of age. The service is a multi-disciplinary agency, which is operated by a voluntary body in Ireland. Clinicians in this service provide a non-standardised, psycho-educational, eclectic post-diagnostic training to parents following receipt of a diagnosis of ASD for their child. This training is offered as an indirect intervention for children with ASD through the medium of parents/guardians as an alternative to direct contact-time with clinicians (Bearss et al., 2015; M. L. Matson et al., 2009; Postorino et al., 2017; Stadnick et al., 2015).

This research examined post-diagnostic parent training provided by as ASD Diagnostic and Intervention service in Ireland. The training is devised from a combination of evidence-based practice and practice-based evidence. Evidence-based practice in psychology is a long-established tradition, enshrined in the training and education programs in third-level education around the world (M. Barkham et al., 2010; Goodheart et al., 2006). Evidence-based practice is described as the integration of best research evidence with clinical expertise and patient values (Sackett, Rosenberg, Gray, Haynes & Richardson, 1996). Evidence-based practice supports public health and enhances psychological practice through the application of empirically sound, evidence-based practices of psychological assessment, case formulation, therapeutic alliances and appropriate interventions (Goodheart et al., 2006). According to Fineout-Overholt et al. (2005), evidence-based practice comprises of a problem solving approach to practice, which systematically seeks out and evaluates the most relevant evidence to answer a question which arises from clinical practice. For Goodheart et al. (2006), psychologists who have been trained in the skills and practices of evidence-based clinical work have a vital role to play in the continuing development of the paradigm, becoming producers, evaluators and consumers of research and allowing research to inform their practice, and practice to inform their research, with the benefit of the client or patient at the centre of the practice.

Practice-based evidence focuses primarily on what works in a real-world context, taking the emphasis away from randomised-control trials and theoretically orientated constructs of what works, and moving towards clinicians' accounts of what is effective in practice (M. Barkham et al., 2010; Michael Barkham & Mellor-Clark, 2013). This approach supports a move beyond experimental designs, towards field settings and the implementation of interventions in naturalistic settings (Michael Barkham & Mellor-Clark, 2013). Practice-based evidence fits well within a pragmatic, case-study methodology (Barkham et al., 2010). This builds a significant and robust evidence base of effective professional practice in psychology (Barkham et al., 2010; Barkham & Mellor-Clark, 2013; Margison et al., 2000).

Training Description:

The clinicians designing and providing the training work in the autism assessment and diagnostic service, as part of multi-disciplinary teams. The clinicians were from a variety of backgrounds. Two social workers co-ordinated and organised the logistics of the training, two speech and language therapists provided training on the communicative aspects of ASD, two educational psychologists and one clinical psychologist provided psychoeducational input on ASD and two occupational therapists trained parents in supporting functional, sensory and movement needs frequently associated with autism. Each discipline provides a night of training. The training took place across four sessions, once a week for four weeks. Each session lasted approximately three hours, with a social break for refreshments for 20 minutes at the mid-point. The training was conducted in a community centre rather than in the service building itself; this was in order to accommodate large numbers of attendees. All parents of children within the service catchment area who were diagnosed with autism in the previous six months were invited to attend parent training from the service provider.

On the first week of training, all parents received the same input. For the subsequent weeks, parents are divided into two separate groups on the basis of their child's age in order to receive input with parents of similar-age children. Training was provided by clinicians within the service from the disciplines of Social Work, Speech and Language Therapy, Occupational Therapy and Psychology.

Mixed Methods Approach:

Mixed methods research is a methodological approach which includes both qualitative and quantitative features in the research design, data collection and data analysis (Teddlie & Tashakkori, 2009). Mixed methods research is an approach, which allows the researcher to use the most appropriate techniques and methods to gather data to best answer their question (D. Mertens, 2011; Teddlie & Tashakkori, 2009). In mixed methods research , neither qualitative nor quantitative methods are favoured above the other, instead the research uses the methods sequentially at various stages of the study, with each stage informing the subsequent one (J.W. Creswell, 2013; John W. Creswell & Plano Clark, 2011). Mixed methods research can be used to combine positivist objective measurement with subjective, descriptive experiences (Timmins, 2015). A key advantage of a mixed methods approach is that using both qualitative and quantitative approaches in conjunction supports a more comprehensive understanding of research problems than either approach alone (John W. Creswell & Plano Clark, 2011; D. Mertens, 2011). Qualitative research has been defined as the study of processes or behaviours in their natural settings, through which the researcher attempts to understand and make sense of phenomena and the meanings that people attribute to them in their lives (Shank, 2006). Qualitative research provides a methodology through which to explores the experiences of individuals and to develop an understanding of social phenomena (Tong et al., 2009). It can used to gain a rich understanding of phenomena which cannot be measured in numbers or figures easily, while also giving a voice to participants, allowing them to be experts in their own life stories (O'Day & Killeen, 2002). For Morse (1992), qualitative research can be used to develop theory, to assess the conceptual bases of theoretical propositions and to develop a richer understanding of the theory. Quantitative research places an emphasis upon precise measurement of phenomena in order to identify causal relationships between variables and to develop predictive models, while also attempting to isolate individual variables as explanatory factors (S. J. Jones & Forshaw, 2012). An emphasis on quantifying information using mathematical and statistical measures is a key aspect of quantitative research (D. M. Mertens, 2015; Polit & Beck, 2010; Teddlie & Tashakkori, 2009)

There are a number of different types of mixed methods designs which can be used in conducting research, namely, the triangulation design, the embedded design, the explanatory design and the exploratory design (John W. Creswell & Plano Clark, 2011; Klingner & Boardman, 2011). Following consideration of the most appropriate approach for the current research study, an embedded mixed methods design was selected, where quantitative methods are embedded in the overall qualitative research design, providing a supportive, supplementary role within the research (John W. Creswell & Plano Clark, 2011; Odom et al., 2005).

In the current research study, participants were asked to complete a questionnaire pre- and post- parent training intervention (Appendix A & Appendix B). These questionnaires contain a mixture of scaled (quantitative) and open-ended (qualitative) questions. Following completion of the parent training, parents were asked to participate in a semi-structured interview (Appendix C) with the researcher. This information was qualitative in nature and was analysed in a qualitative manner. Furthermore, observations of the parent training were recorded by the researcher; this information was also qualitative in nature (Appendix D). A visual representation of the mixed methods research design is visible in Figure 7 below.

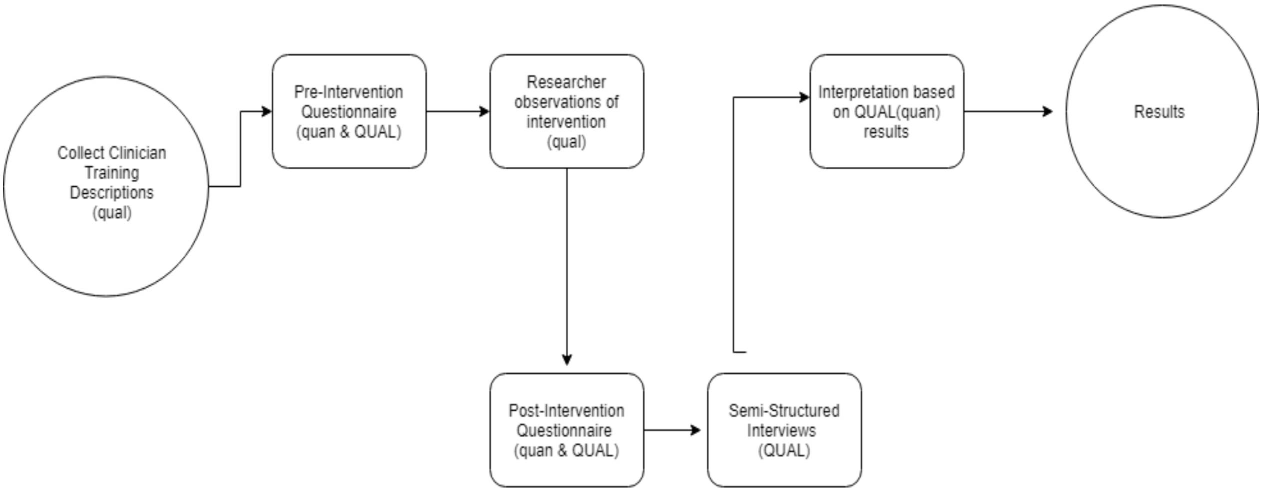


Figure 7. Embedded Mixed Methods Research Design.

Data Collection Procedures

As depicted in Figure 6 above (Data Contributing to Case Study), data was collected in numerous ways in order to capture the needs, experiences and perspectives of parents. Approaches to data collection included gathering clinician descriptions of the parent training (Appendix E), administering pre- and post- training questionnaires to participants, researcher observation of the training and semi-structured interviews with parents following completion of the parent training program.

Figure 8: Data collection procedure

Clinicians' Descriptions

Clinicians were asked to provide information detailing the intervention provided to parents. As each discipline planned and delivered their training on separate nights, the information was provided separately and was later compiled into a descriptive template to provide an outline of the training programme experienced by attending parents (see Appendix F).

Questionnaires:

Questionnaires are frequently used in research and are a useful instrument for gathering survey information, and providing structured, often numerical data, on a topic, while also being relatively straightforward to analyse (Cohen et al., 2007). Surveys can be used to gather the views and opinions of large groups of people (Timmons, 2015). Moule and Goodman (2014) state that questionnaires are used to measure knowledge and should contribute to answering the research question. When developing a questionnaire, one must consider the target population for the tool. Furthermore, the tool must be validated or piloted to ensure that it measures what it intends to measure (Pink et al., 2009).

The questionnaires used in this research study have been designed by the researcher (see Appendix A & Appendix B). In devising the questionnaires, the researcher drew on readings of the EarlyBird programmes devised by the National Autistic Society (1999), as well as a study on the self-efficacy of mothers of children with ASD (Kuhn & Carter, 2006).

This research uses pre- and post- intervention questionnaires, which were administered prior to the parent training beginning and directly following the final parent training session. Given the relatively small number of research participants, the questionnaires in this research study are a mixture of structured, semi-structured and unstructured questions , operating on the hypothesis that the smaller the size of the sample, the less structured, more open and word-based the questionnaire can be (Cohen et al., 2007). Furthermore, this research was bounded to a site-specific case study, therefore a more qualitative and open-ended style of questionnaire was preferred, in order to capture the nuances and specificities of the responses (Cohen et al., 2007)

The closed questions in the questionnaires use five-point Likert scales, which were rated by participants. A Likert scale is a scale used in research to represent people's attitudes to a topic (Brooke, 1996; Matell & Jacoby, 1971). Five-point Likert scales were chosen above the use of a seven-point scale as research has found that the use of a five-point scale increases response rate and response quality, while reducing respondent frustrations (Babakus & Mangold, 1992). Furthermore, five-point Likert scales have been found to be more easily comprehensible than scales with greater points (Revilla, Saris & Krosnick, 2013). The questionnaires also contain open-ended questions to allow for broader information to be provided by participants (Cohen et al., 2007; J.W. Creswell, 2014; D. M. Mertens, 2015). These open-ended questions were analysed using thematic analysis (V. Braun & Clarke, 2013).

Piloting of Questionnaires:

Piloting of questionnaires is recommended in order to check for issues of clarity, usability, validity, operationalisation of the constructs, readability and usefulness of questions asked (Cohen et al., 2007; Oppenheim, 1992; Rattray & Jones, 2007).

To enhance the credibility and validity of the questionnaires, three psychologists with experience in ASD assessed the questionnaires and provided critiques. Additionally, the questionnaires were piloted with a group of parents of children with ASD, as well as by consultants with ASD advocacy organisation, AsIAm. Questionnaires were revised to reflect the considerations arising from the piloting process.

Researcher Observations:

An observational case study is one in which the majority of data gathered arises from participant observation (J.W. Creswell, 2014; Hamilton & Corbett-Whittier, 2012; Merriam, 2009). While to categorise this research as an observational case study would be to overstate the case, there are aspects of the observational case study which this research employs. This research entailed observation of each training session; I attended each training session and conducted narrative observations and note-taking. I used observation skills to document aspects of the training which may not have been documented by the clinicians and interactions with participants which could not be documented in advance. Furthermore, it was crucial to attend and observe the training in order to inform later semi-structured interviews with participants and for the later analysis of raw data.

Semi-Structured Interviews:

Using interviews as a form of data collection allows for very rich data and a deeper level of understanding than other forms of data collection (Hamilton & Corbett-Whittier, 2012). Semi-structured interviews allow for a more in-depth discussion with a small number of participants (V. Braun & Clarke, 2013; Hamilton & Corbett-Whittier, 2012). Semi-structured interviews were selected as a time-efficient means of gathering rich qualitative data from a small group of people who undertook a shared training opportunity. Semi-structured interviews create opportunities for a narrative to unfold, while including questions informed by theory and by information garnered in the questionnaires (Galletta, 2013). This method offers insight into individual experiences and perceptions and is designed to yield a more complete story than quantitative means alone (Galletta, 2013). Furthermore, a semi-structured interview method allows participants to express their views (Bryman, 2015; Mertens, 2005). Interview questions can be identified in advance, along with general topics for discussion (Bryman, 2015; Gill et al., 2008). This approach also allows for additional questions and probes to be used throughout the interview in a flexible manner (Bryman, 2015; Gill et al., 2008; Howitt, 2013). By incorporating qualitative measures, in this instance a semi-structured interview process, it allows for a sample population of participants to express their in a less restricted manner than in quantitative research alone (Bryman, 2015; Gill et al., 2008; Howitt, 2013; Kitzinger, 2005; Krueger & Casey, 2014). The final phase of the current research study was semi-structured interviews. Participants were asked to indicate their interest in taking part in a semi-structured interviews on the Participant Consent Form (see Appendix G). Following the conclusion of the post-diagnostic parent training programme, I contacted the consenting participants. Seven parents agreed to be interviewed, however two of these withdrew from the study at a later stage, and thus, five participants agreed to be interviewed for the final stage of the study.

Data Analysis:

Data analysis in mixed methods research studies involves analysing quantitative data using quantitative means, and qualitative data using qualitative means in order to discover useful information, address research questions, inform conclusions and support decision-making (John W. Creswell & Plano Clark, 2011). The process of data analysis allows sense to be made of the raw data gleaned from data collection methods (S. J. Jones & Forshaw, 2012).

Quantitative analysis:

Quantitative approaches to data analysis emphasise the measurement and quantification of human behaviour (S. J. Jones & Forshaw, 2012). Quantitative approaches rely on mathematical and statistical procedures to understand a phenomenon (D. M. Mertens, 2015). In the current research study, the quantitative data obtained via the questionnaires was analysed using the Statistical Package for the Social Sciences (SPSS v25: IBM) to identify statistically significant differences in the participant group from Time 1 (pre-training) and Time 2 (post-training). The data was analysed to compare the participants' views of their knowledge, understanding, skills and confidence pre- and post- intervention, to identify any changes in their views that had occurred in this time period. Quantitative data from the questionnaires was analysed via a paired samples t-test in order to compare pre and post training ratings. This data was used to inform the development of the qualitative aspects of the interview schedule semi-structured interviews to obtain qualitative data.

Qualitative data analysis:

Qualitative data analysis is a process which is ongoing and emergent; it is an activity which occurs throughout the data collection process (Merriam, 2009; D. M. Mertens, 2015). The process is recursive and dynamic, and tends to become more intensive as the study proceeds (Virginia Braun & Clarke, 2006; V. Braun & Clarke, 2013; Merriam, 2009).

Qualitative data from the questionnaires and semi-structured interviews were coded and analysed thematically. Thematic analysis is an analytic strategy which seeks to systematically identify patterns within and across data and to interrogate and interpret the patterns identified (V. Braun & Clarke, 2013).

This data will be analysed thematically, with the researcher using quantitative techniques to identify themes within the training information provided, allowing for the organisation of training materials into categories. Thematic analysis allows for the data to speak for itself and to build upon a rich and thick description of what is happening in a specific situation (V. Braun & Clarke, 2013; Merriam, 2009; D. M. Mertens, 2015). Once all of the data, including open-ended questions and interviews, had been collected and transcribed, the raw data was analysed using thematic analysis (Virginia Braun & Clarke, 2006; V. Braun & Clarke, 2013). A data-driven method was followed, whereby emergent themes develop, and patterns of meaning are discovered following close readings of the data set. This approach was selected as it allows for the emergence of patterns across the data and is a flexible form of analysis that fits within a mixed method design (Braun & Clarke, 2006). Six key phases of data analysis were followed (Braun & Clarke, 2006) as presented in Figure 8 below.

Six Phases of Thematic Analysis (Braun & Clarke, 2006)

Phase One *Familiarisation with the data*: is common to all forms of qualitative analysis – the researcher must immerse themselves in, and become intimately familiar with, their data; reading and re-reading the data (and listening to audio-recorded data at least once, if relevant) and noting any initial analytic observations.

Phase Two *Coding:* This involves generating pithy labels for important features of the data of relevance to the (broad) research question guiding the analysis. Coding is not simply a method of data reduction, it is also an analytic process, so codes capture both a semantic and conceptual reading of the data. The researcher codes every data item and ends this phase by collating all their codes and relevant data extracts.

Phase Three *Searching for Themes:* : A theme is a coherent and meaningful pattern in the data relevant to the research question. This ‘searching’ is an active process; themes are not hidden in the data waiting to be discovered, rather the researcher constructs themes. The researcher ends this phase by collating all the coded data relevant to each theme.

Phase Four *Reviewing Themes:* : Involves checking that the themes ‘work’ in relation to both the coded extracts and the full data-set. The researcher should reflect on whether the themes tell a convincing and compelling story about the data, and begin to define the nature of each individual theme, and the relationship between the themes.

Phase Five *Defining and Naming Themes:* Requires the researcher to conduct and write a detailed analysis of each theme, identifying the ‘essence’ of each theme and constructing a concise, punchy and informative name for each theme.

Phase Six *Writing Up:* Weaving together the analytic narrative and data extracts to tell the reader a coherent and persuasive story about the data, and contextualising it in relation to existing literature.

Figure 8 Thematic Analysis Procedure

Information from clinicians was used to devise an outline of the training programme, while researcher observations were conducted to support this training description. Documentary data and observation data were used to build a picture of the training experienced by parents and guardians attending post-diagnostic parent training. An overview of the training programme is provided below (Figure 9). A comprehensive summary and description of the material covered in the training is provided in Appendix F). Each evening included a tea break of approximately 25-30 minutes to facilitate parents talking to each other and to the clinicians in a less structured manner.

Discipline	Topics Covered	Strategies/ Methodology
Social Work 2 hours 30min	Welcome to training Explanation of format Explanation of service structure and current resourcing situation Overview of ASD Parent Testimony	Whole group Lecture Style Small group work to brainstorm "What autism looks like in my child"; everyone returned to large group to feedback. Break Parent of two children with autism, spoke to group for 1 hour & 15 min with time for Q & A; covered her diagnostic experiences, taking part in training; her family's experience of education system and accessing services.
Occupational Therapy 2 hours 30 min	What is autism? What is Occupational Therapy? Sensory Processing & practical strategies Sensory regulation Motor Coordination and planning Backward Chaining and Task Analysis Practical strategies for home	Grouped into Over 9 years for one session & Under 9 years for one session Large group presentation; opportunities to ask questions throughout Practical activities: demonstration of vestibular and proprioceptive senses (parents active); demonstration of "blue breaks"/movement breaks for children (parents active) Demonstration of equipment e.g. move'n'sit cushion, fidgets, theraputty, theraband
Speech and Language Therapy 2 hours 30 min	What is Speech and Language Therapy? Effective Communication Communication Strategies & Communication Systems Social Stories Comic Strip Conversations	Grouped into Over 9 years for one session & Under 9 years for one session Large group presentation No opportunity for questions No group work

	Social interaction strategies	
Psychology (Clinical Psychologist and Educational Psychologist) 2 hours 30 min	What is autism? Triad of Impairments Explanation of Spectrum Theory of Mind Executive Function Emotional Regulation Sensory Processing and Behaviour Behaviour as Communication (Antecedent, Behaviour, Consequences) Problem Solving for Behaviour Positives of autism	Grouped into Over 9 years for one session & Under 9 years for one session Large group presentation; Group work to brainstorm “My Child and the Triad” Group work to brainstorm behaviour using Iceberg Method Some Q&A but ran out of time

Figure 9 Training Programme Overview

Participants:

The participants in this research study are parents and guardians of children recently diagnosed with ASD. 57 parents attended the post diagnostic training. 39 parents agreed to participate in the research study. 25 were mothers of children with autism, while 14 fathers participated.

Sampling:

Sampling in case study research involves decisions that the researchers make regarding sampling strategies, the number of case studies, and the definition of the unit of analysis. It is central to theory-building and -testing through case study research. In qualitative research, research studies typically use a small sample of people, studied in depth in their particular context (V. Braun & Clarke, 2013; Merriam, 2009; Miles et al., 2014; Patton, 1990). The current research study used convenience sampling.

Convenience sampling occurs when the participants in the study were chosen due to their overall availability rather than for purposes of generalisability (Cohen et al., 2007; D. M. Mertens, 2015). This can be seen as a limitation, but given that generalisability is not an aim of case study or qualitative research generally speaking, this was not considered to be a significant issue in this research (Merriam, 2009; D. M. Mertens, 2015).

This type of sampling was selected on the basis that the participants were drawn from a specific population, i.e. parents in a specific region whose children were recently diagnosed with ASD by this particular ASD Assessment and Intervention Service who have been invited to and have agreed to attend post-diagnostic parent training. The ASD Service organised the training and were responsible for inviting attendees, therefore purposive sampling was not possible in this study.

Results

Quantitative Data Results

This study obtained quantitative data from pre- and post-training questionnaires administered to a group of 39 parents attending post-diagnostic parent training following a diagnosis of autism for their child. All participants completed the questionnaires at Time 1 (the start of the intervention), however 8 participants did not complete the post-training questionnaire at Time 2 (the end of the intervention, four weeks later). In instances where a full pre- and post- data set was not available, cases with missing values were excluded from analysis.

The analysis below examined scores for each measure, before and after the training. The overall changes to scores across the training period are presented. A paired samples t-test was conducted to evaluate the impact of post-diagnostic parent training on parents' self-reported scores on a number of measures. The results of the paired samples t-test were as follows:

There was a significant increase in scores on "*Knowledge of Autism*" from Time 1(M = 3.16, SD = 1.18) to Time 2 (M = 4.16, SD = .68), t (31) = 4.597, p < .001 (two-tailed). The mean increase in scores was 1.00, with a 95% confidence interval ranging from -1.44 to -.55. The eta squared statistic (.41) indicated a large effect size.

There was a significant increase in scores on “*Understanding of Autism*” from Time 1 ($M = 3.29$, $SD = 1.24$) to Time 2 ($M = 4.16$, $SD = .68$), $t (31) = 4.227$, $p < .001$ (two-tailed). The mean increase in scores was .87, with a 95% confidence interval ranging from -1.29 to -.45. The eta squared statistic (.37) indicated a large effect size.

There was a significant increase in scores on “*Skills in Managing Child’s Needs*” from Time 1 ($M = 3.16$, $SD = .96$) to Time 2 ($M = 3.70$, $SD = .86$), $t (31) = 2.373$, $p < .001$ (two-tailed). The mean increase in scores was .548, with a 95% confidence interval ranging from -1.02 to -.07. The eta squared statistic (.15) indicated a large effect size.

There was a significantly significant increase in scores on “*Confidence in supporting Your Child with Autism*” from Time 1 ($M = 3.06$, $SD = 1.23$) to Time 2 ($M = 3.80$, $SD = 1.04$), $t (31) = 2.745$, $p < .001$ (two-tailed). The mean increase in scores was .74, with a 95% confidence interval ranging from -1.29 to -.189. The eta squared statistic (.2) indicated a large effect size.

There was a significantly significant increase in scores on “*Confidence in Parenting Your Child with Autism*” from Time 1 ($M = 2.87$, $SD = 1.17$) to Time 2 ($M = 3.74$, $SD = 1.26$), $t (31) = 2.942$, $p < .001$ (two-tailed). The mean increase in scores was .87, with a 95% confidence interval ranging from -1.47 to -.26. The eta squared statistic (.22) indicated a large effect size.

Items “*Frequency of Communication with Other Parents”, “Difficulty Managing Childs’ Behaviour”, “Confidence in Understanding Your Childs’ Behaviour”, “Difficulty in Communication with Your Child with Autism”* and *“Confidence in Meeting Interventions Needs for Your Child with Autism”* were also analysed. There were no significant differences between Time 1 and Time 2, pre- and post- training. The results are presented in the table below (Figure 10).

Item	**Pre-Mean**	**Post-Mean**	**Eta Squared (effect size)**	**p. value**
Knowledge of Autism	3.16	4.16	0.41 (large)	.000
Understanding of Autism	3.29	4.16	0.37 (large)	.000
Skills in Managing Child's Needs	3.16	3.70	0.15 (large)	.024
Confidence in supporting Child with Autism	3.06	3.80	0.2 (large)	.010
Frequency of Communication with Other Parents	1.83	1.74	0.003 (small)	.751
Difficulty Managing Child's Behaviour	2.83	2.87	0.000 (small)	.909
Confidence in Understanding Child's Behaviour	3.16	3.32	0.008 (small)	.616
Confidence in Parenting your Child with Autism	2.87	3.74	0.22 (large)	.006
Difficulty in Communication with your Child with Autism	2.32	2.29	0.00 (small)	.917

Confidence in Meeting Intervention Needs for Your Child with Autism	2.58	2.87	0.02 (small)	.354

Figure 10 Results of Paired Samples t-Test.

Summary of Quantitative Findings:

The results of the quantitative analysis suggest that parents' self-reported levels of knowledge and understanding of autism improved as a result of participating in the post-diagnostic training programme. Furthermore, the findings indicate that parents' self-reported rating of their skills in managing the needs of their child with autism improved following participation in the post-diagnostic training. Additionally, the results suggest that parents reported an increase in their confidence in both supporting their child with autism and in parenting their child following participation in the training intervention. Following participation in the post-diagnostic parent training, participants in the current study reported no significant changes in *Frequency of Communication with Other Parents*, *Difficulty Managing Child's Behaviour, Confidence in Understanding Child's Behaviour, Difficulty in Communication with your Child with Autism*, and *Confidence in Meeting Intervention Needs for Your Child with Autism*.

Qualitative Results

Results of qualitative data analysis are presented in this section. Qualitative data was analysed using thematic analysis procedures. The pre- and post- diagnostic surveys contained both closed and open-ended questions. I analysed the data from the open-ended questions using thematic analysis. The data from the questionnaires did not contain identifying information and therefore, qualitative data from the questionnaires will be identified in the upcoming results sections using the letter Q. The interviews and the open-ended questions in the Pre and Post Surveys provided the qualitative data. It will be presented and discussed thematically.

Needs.

Parents discussed their needs following their child's diagnosis of autism. Their needs were further categorised into subthemes: Thinking of the Future, Information Needs, Coping and Support, and Training.

Thinking of the Future

For many parents, the time following diagnosis is one of uncertainty; once attaining an autism diagnosis, the next steps are less certain. Prior to the commencement of the parent training programmed, parents expressed feelings of uncertainty regarding appropriate next steps. One parent commented that:

> *"Right now, I have my diagnosis, where do I go? I just wonder where do I go now? And I just feel like now I have the diagnosis, what do I do?" (Q).*

Despite participation in the post-diagnostic training programme, it appears that these feelings of uncertainty and lack of direction persist. Participation in the post-diagnostic training did not alleviate this feeling of uncertainty. One parent stated:

"I have my diagnosis now and I understand more about the condition now, but what next? Where do I go or what do I do?" (Patricia).

Parents reported further concerns about the medium- and longer-term future, in terms of education and adulthood. Parents identified a pre-training desire to gain an understanding of what challenges they may face in the future, in generic terms such as, *"what to expect down the line" (Q),* but also, more specifically in terms of how to support their child in post-primary education, and further along, into adulthood. Following attendance at the post-diagnostic parent training, parents' uncertainty around the future was not assuaged, with parents reporting persistent need to *"Address the older child; preparation for adulthood"(Q).*

Information Needs

Parents reported information and knowledge as a primary need for them. However, the type of information they report needing ranges from the general to the more specific. Parents in this study reported needing "*Information*", as well as specific information on "*Mental Health/Well Being*" and "*Telling about the Diagnosis*".

Information:

At the beginning of the training programme, parents reported a need to understand autism as a condition and as a spectrum, in order to better manage in their every-day lives. Prior to the training programme, one parent stated that she wished to "*Gain deeper understanding of the autism spectrum"(Q)*, while another parent sought a "*better understanding of theories"* in order to be "*able to apply knowledge to day to day living"(Q)*

Parents were interested in learning about the autism service, and in the role that they might play in helping their child.

Many parents reported needing practical strategies and tips to use in supporting their child with autism. Value was placed on practicable, relevant and realistic skills in terms of type of knowledge parents reported needing, with one parent seeking to gain *"knowledge on how to calm my son when he has a meltdown, I just hope I can pick up some practical tips"(Q)* and another stating a need for the *"sharing of ideas and strategies to cope"(Q).*

Following post-diagnostic parent training, some parents reported satisfaction with the information that they received. A parent reported that following post-diagnostic training that she has gained *" strategies for dealing with behaviour, communication and our child's sensory issues" (Q).* Other parents referred to the specific needs of their own child, seeking information and strategies on supporting their child, rather than generic information. One parent reported disappointment that the topics covered fell short of her expectations, stating a preference for more in-depth information that would be directly applicable to her child:

"I would have liked in more depth something on emotional regulation, because Colin's biggest issue is emotional regulation" (Katie).

Telling about the Diagnosis

For parents, it can be difficult to talk to their child about autism, with different families adopting different approaches. Nonetheless, prior to post-diagnostic training beginning, parents reported needing information from clinicians on how to *"learn ways to tell her (child) she has the diagnosis" (Q),* and further how to support them in adapting to the diagnosis. Parents reported needing information on how to support their child in accepting the autism diagnosis and ensure the child "*not think of it as a negative" (Q).*

Following participation in the training programme some parents had spoken to their child about autism and about having a diagnosis of autism and saw it as an important and impactful need for their child. One parent remarked:

"She was telling me there was something wrong with her before we knew there was something up with her, she knows about her diagnosis now and she's excited now." (Ann).

Some parents reported that their children responded well to knowledge of the diagnosis, expressing relief and pride, with the diagnosis "*like a weight lifted off her shoulders" (Mary).*

Parents reported that knowledge of a diagnosis was important for their child as "*there's reasons for this and explanations" (Mary)*, and also acknowledge the supportive feeling of not being the only one with a diagnosis and removing the uncertainty about why they might feel different to other children. One parent stated:

"it's important for Colin to know because like the parents, he knows that then he's not alone, that there are other people like him and also that there's a reason for why he thinks the way he does and why he is the way he is" (Katie).

Some parents expressed surprise at the fact that the topic of informing your child of the diagnosis hadn't arisen in the parent training programme:

"They didn't really (speak about talking to your child about autism) which might have been beneficial for maybe the younger group, but the older people are newly diagnosed as well, so maybe it would have been beneficial for them too" (Mary).

However, some parents did express reluctance to share the diagnosis of autism with their child or with other people, and acknowledged that telling about the diagnosis is a *"very personal thing"* which can be influenced by child factors, as well as other external or family factors.

Mental Health

Many parents spoke about the anxiety experienced by their child with autism, and how this can impact upon their lives. Prior to the parent training programme, some parents reported that they would like input and knowledge *"to deal with my child's* *anxieties-social and school phobia" (Q).* After training had finished, some parents expressed surprised that anxiety and mental health had not been covered as a topic in the training programme. This parent was surprised that given it was a topic parents were seeking to understand and discuss, it was not covered by the training programme:

"One thing that I noticed from talking other parents was that anxiety came up a lot. I was a bit surprised that that wasn't covered more in the sessions" (Ann)

Parents expressed that mental health, and anxiety more specifically, is a gap in their knowledge that they would like to have had input on, as they are seeing these as needs for their child:

"I would know nothing about the mental health aspects of autism so it would be great to find out a bit more; and it's not something that's spoken about in general… The more subtle things like mental health and anxiety if those were talked about more then maybe we would have seen more of it in her" (Mary).

Parents reported anxiety, mental health and self-harming behaviours as aspects of their everyday lives with their children with autism, so the absence of any input in relation to these topics was disappointing.

Coping and Support.

Coping and support needs were cited by many parents as priority needs prior to the commencement of the parent training programme. The need for support from other parents with autism, and from clinicians was mentioned by parents. One parent reported a need for support in terms of the emotional impact following a diagnosis of autism for their child, stating a need for "*some guidance- I feel lost and as if the weight of the world is on my shoulders"(Q).*

Parents reported needing to learn about available supports from public and private professionals, both in terms of the service providing the training and the wider supports available, "*what public and private supports are out there" (Q).* Parents cited a perceived prior lack of support from the autism services and framed the need to gain their support as *"a battle" (Q)*. Despite prior negative experiences, parents were hopeful that the training would provide them with support from the service and clinicians.

The need for support from other parents with similar or shared experiences was reported by many parents. Prior to the beginning of the training programme parents outlined the need to *"meet parents in a similar position"(Q)* and to *"meet and share advice with other parents on the course"(Q).* Furthermore, parents anticipated the perceived benefits that meeting other parents of children with autism could provide to them in terms of adapting and adjusting to a diagnosis of autism and the emotional impact, with parents hoping to *"gain a sense of being ok" (Q)* and to *"be more confident and assure ourselves that we as parents are doing a good job" (Q).*

Training

For many parents, having completed the post-diagnostic parent training, the need for more training was to the forefront. Despite having completed over ten hours of parent training in a short four-week period, parents felt that training remained a priority need for them following their child's diagnosis. Some parents commented that they would appreciate *"more in-depth training"* and also the need for "*more access to intervention"(Q).*

Additionally, having experienced the post-diagnostic training themselves, some parents felt that the schools and teachers of their children with autism would benefit from exposure to similar training from the autism service. Parents remarked that they had personally benefitted from participating and noted that their children would also should this type of training be made available to their teachers as "*they (teachers) would just understand so much better where he's coming from" (Q).* Parents stated that *"training for teachers would be fantastic for our kids"(Q.*

One parent, when commenting on her child's experiences of attending a mainstream school, felt that teacher training would make a big difference to her child's school experience. She expressed frustration with what she perceived as a lack of knowledge and awareness of behalf of school staff, which she believed could be improved upon by participation in the service's training programme:

"If they had the time to have a team like that go out to school and do things like this training with teachers... like how can you have teachers teaching that are not actually aware of autism?" (Katie).

Furthermore, this parent remarked on the impact that a child's experiences of school can have on their home life. It was felt that teacher training in autism from the autism service would improve school staff's understanding of autism and have a positive impact on the child's school day: *"If there was something done linking the* *team to the school because its half the child's day and whatever happens at school has a huge impact at home and he can get so upset" (Katie)* and *"It should be mandatory for teachers to have to do autism training… so imagine how much understanding that the teachers could bring away from that" (Q).*

Discussion

Needs:

Following a diagnosis of autism for their child, parents report a number of different needs. This study set about examining parents' perspectives of their training needs following a diagnosis of autism for their child. Parents' needs were elicited and categorised under the following subthemes, *Thinking of the Future, Information Needs, Coping and Support,* and *Training.* Findings in relation to parent needs are discussed and critically analysed here in the context of the relevant literature in the area.

Thinking of the Future.

Following a diagnosis of autism for their child parents referred to a need for reassurance and certainty about the future. Parents in the current research study reported a need for information in relation to next steps for the immediate future, but also information in relation to the longer-term implications for their child across the lifespan. This finding is supported by research conducted by Murphy and Tierney (2006), who noted that following a diagnosis of autism, parents report considering needs in both the short and long term.

Congruent with the findings of the current study, some parents found it difficult to have certainty about what the future may hold for their child (Murphy & Tierney, 2006). Given that the difference is a lifelong condition, which pervades across the lifespan, parents consider the diagnosis of ASD and the implications for their child's future (Murphy & Tierney, 2006). It is noteworthy that participants in the current study had received a diagnosis of autism for their child within six months of taking part in the training programme, hence, the findings of Murphy and Tierney (2006) that parents' seek less information as they become more familiar with their child's autism profile over time is not applicable to parents at this early stage. Furthermore, some parents in the current research study expressed a need for information on implications of autism for their child as they approach adolescence and adulthood. In light of research by A. N.

Gibson et al. (2017) relating to the decreasing availability of information about autism as children get older, it is likely that this will continue to be an area of need for families.

Finally, parents in the current research study reported a need for information about the service and the types of support they would possibly receive. This desire for clarity in the face of service uncertainty in a theme found in the literature, with a sense of uncertainty being reinforced by a perceived lack of support and direction from professional services (Murphy & Tierney, 2006; Mansell & Morris, 2004; Howlin & Moore, 1997).

Information Needs.

Parents identified a number of aspects in relation to their information needs following a diagnosis of autism for their child. The current research identified categories of information need as outlined by parents, *Information, Telling about the Diagnosis* and *Mental Health.*

Information.

Parents in the current research project outlined that knowledge, understanding and information about autism were priority learning needs. This finding is supported by the literature, with information-seeking reported as a key need for parents following a diagnosis of autism for their child (Banach et al., 2010; N. Grant et al., 2015; Murphy & Tierney, 2006; Reichow et al., 2012). Additionally, in a finding which supported by Murphy and Tierney (2006), prior to training beginning parents cited knowledge about available supports and services for their child as a priority information need. Furthermore, in line with evidence presented in the literature, parents in this study reported a need for practical tips and strategies which could be implemented in the everyday lives of their families (Murphy & Tierney, 2006).

Following the completion of the training programme, parents in this study reported that their knowledge about autism had increased significantly from pre- to post-training. This suggests that post-diagnostic parent training can meet parents’ need for general information about autism. This finding supports recent research by McAleese et al. (2014), which found that parents of children with autism who attended a psychoeducational, therapeutic group following their child’s diagnosis experienced a significant increase in their knowledge of how autism presents and also their knowledge of behavioural strategies to support their child. A systematic review conducted by Oono et al. (2013) also reported that post-diagnostic parent-mediated interventions for children with autism increased parents’ knowledge about the condition. The findings of this study, supported by the aforementioned research, provide a strong evidence base for the benefits of providing post-diagnostic parent training as a means of enhancing parents’ knowledge base and meeting their needs for general information on autism.

Telling about the Diagnosis.

While many parents reported a need for generic information on autism, some parents in the current research mentioned specific information needs. Parents relayed a need for information in relation to telling their child about their diagnosis of autism and how to support them in understanding the diagnosis. While the need for support in telling about the diagnosis has been outlined in previous research studies (Murphy & Tierney, 2006), the current research found that this need remains unmet for many parents. It is possible that due to the personal, context-specific nature of such a need, a generic, large group training situation is not the most appropriate space for this information need to be met.

Mental Health.

A further information need which arose from the current research study centred around providing parents with information on anxiety, emotional regulation and mental health for children with autism. This finding is in contrast with much literature on parents’ post-diagnostic information needs, in that research in this area has tended to emphasise parents’ emotional well-being as a priority need rather than that of their child with autism (Pottie & Ingram, 2008; Woodgate et al., 2008). A number of factors may have contributed to this discrepancy in findings. Firstly, the training was attended by a number of parents of girls with autism. Given that autism in girls can be manifested through profiles of anxiety, isolation and low affect (Loomes et al., 2017; Salas et al., 2017), it is hypothesised that the presence of so many parents of girls with autism may have impacted on the results of this study. Secondly, the needs of populations change over time, and in light of the availability of generic autism information from sources such as online websites (A. N. Gibson et al., 2017; Reichow et al., 2012; Stephenson et al., 2012), it is possible that the need for specific information and support in relation to mental health issues and autism has arisen in recent times.

Coping and Support.

The current study found that parents cited coping and support needs as priority needs prior to their engagement in the post-diagnostic parent training. This is a finding which is echoed across studies of parents post-diagnostic need, with references made to both support from other parents and from services and clinicians (Banach et al., 2010; Barnett et al., 2003; Divan et al., 2012; Hennel et al., 2016; Murphy & Tierney, 2006; Siklos & Kerns, 2006; Symon, 2001). The need for support from people who have shared similar experiences in this study is supported by findings from Banach et al. (2010) and Mary Law et al. (2001).

Training.

Despite having completed over ten hours of parent training in a four-week period, parents in the current research study identified themselves as having a need for further, more in-depth training. Given that most post-diagnostic parent training programmes are delivered over a six to twelve week period (Bearss et al., 2015; Postorino et al., 2017), it is possible that the shorter time-frame of training in the current post-diagnostic programmed (four weeks) may have been insufficient in terms of meeting parents' training needs.

The participants in this study also reported a need for training for educators and school staff involved in supporting their child in educational settings. Parents felt that a training for school staff provided by clinicians working in an autism service would be hugely beneficial both for education workers and for children with autism. This recommendation supports a finding by Guldberg et al. (2011), who indicated that educators of children with autism should attend training in order to learn about autism and its characteristics, and also to support the use of evidence-based interventions in education settings.

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